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**Understanding Recovery from Schizophrenia in
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Deborah Salem

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**UNDERSTANDING RECOVERY FROM SCHIZOPHRENIA IN A MUTUAL-HELP
SETTING**

VOLUME I

By

Katie Weaver Randall

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ABSTRACT

UNDERSTANDING RECOVERY FROM SCHIZOPHRENIA IN A MUTUAL-HELP SETTING

By

Katie Weaver Randall

This study explores recovery from schizophrenia within a mutual-help organization, Schizophrenics Anonymous. A phenomenological interview approach was used in order to elicit first-person accounts and descriptions of actual experience. Forty-six participants were purposively selected to reflect aspects of participation in a mutual-help group that may influence participants' experience. A cross-case analysis was used to identify recovery themes and a within-case analysis was used to address how members of Schizophrenics Anonymous experience the process of recovery over time. Data was analyzed using an inductive content analysis. Four phases of recovery were identified: (1) grief and mourning, (2) awareness and recognition, (3) redefinition and transformation, and (4) enhanced well-being and quality of life. Characteristics of the recovery process were also identified: (1) it is a continuous and on-going process with no identifiable endpoint, (2) movement through the phases of the recovery process is iterative involving back and forth movement, and (3) it encompasses all aspects of a person's life meaning a person may be simultaneously involved in different phases of the recovery process for different aspects of their life.

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TABLE OF CONTENTS

LIST OF TABLES.....	vii
INTRODUCTION.....	1-2
BACKGROUND.....	2-8
OVERVIEW OF LITERATURE REVIEW.....	8-9
LITERATURE REVIEW.....	9-35
Impact of Schizophrenia on Society and Individuals.....	9-14
Conceptualizations of Schizophrenia: How They Came to be and Their Impact on Recovery.....	14-19
Changing Conceptualizations of Schizophrenia to Include Recovery.....	20-24
Recovery.....	24-32
Consumer Understandings of Recovery.....	24-28
Empirical Studies of Consumer Experiences and Understanding of Recovery.....	28-32
Role of Mutual-Help Groups in Recovery.....	32-35
Summary of the Role of Mutual-Help Settings in Recovery.....	35
CONTRIBUTIONS OF THE STUDY.....	36-38
Research Questions.....	37-38
METHODS.....	38-61
Study Design.....	38-46
Theoretical Framework.....	38-42
Use of Qualitative Methods.....	42-44
Setting Description.....	44-46
Project Description and Procedures.....	46-61

Group Consent Procedures.....	48-49
Group Sample.....	49
Semi-Structured Interviews Consent Procedures.....	49-50
Interview Sample.....	50-53
Semi Structured In-Depth Interview.....	53-55
Exploration of Written Materials.....	55
Interpretation and Analysis.....	55-61
Data Reduction.....	56-57
Cross Case Level Analysis.....	57-58
Within Case Level Analysis.....	58-61
RESULTS AND DISCUSSION.....	61-154
Description of Participants.....	62-73
Results and Discussion of the Cross-Case Analysis.....	74-144
Phase 1: Mourning and Grief.....	78-84
Phase 2: Awareness and Recognition.....	84-99
Phase 3: Redefinition and Transformation.....	99-131
Phase 4: Enhanced Well-Being and Quality of Life.....	131-144
Summary of the Cross-Case Analysis Summary.....	144-146
Results and Discussion of the Within-Case Analysis.....	146-154
Recovery is Ongoing or Continuous with No Clear or Identifiable End Point.....	147-151
Movement Between 4 Phases is Iterative.....	151-153
Recovery Encompasses the Whole Person	153
Summary of the Within-Case Summary.....	154
MEETING THE CRITERIA OF TRUSTWORTHINESS.....	154-158
IMPLICATIONS AND CONCLUSIONS.....	158-174
Changing Attitudes and Beliefs about Schizophrenia and Recovery.....	158-161
Changing the Way we Conceptualize Contexts to Promote Recovery.....	161-168
Optimism and Hope.....	162-163

Recognition of Multiple Phases.....	163-164
Identifying Natural Supports.....	165-168
Implications for Research.....	168
Social Policies.....	169-171
Influence of SA on Participants Stories.....	171-174
Limitations and Boundaries.....	174-176
Appendices.....	153-297
Appendix A – Consent to Contact and Interview Consent Forms	178-185
Appendix B – Interview Protocol.....	186-209
Appendix C – Coding Scheme Iterations.....	210-220
Appendix D – Preliminary Themes and Sub-Themes of Recovery.....	221-223
Appendix E – Evidence of Recovery.....	224-230
Appendix F – All Data in Support of the Eight Meta-Themes.....	231-307
Appendix G – Within-Case Narrative Summaries.....	308-332

LIST OF TABLES

Table 1 – Description of Derivation of Final Sample

Table 2 – Description of Groups Not Included in Final Sample

Table 3 – Summary of Groups Not Included in Final Sample

Table 4 – Description of Groups Included in Final Sample

Table 5 – Summary of Demographic Characteristics of Participants

Table 6 - Comparison Between Cases Included in Within-Case Analysis and Cases Not Included

Table 7 - The Phases of Recovery

INTRODUCTION

This study explores how participants in a mutual-help organization, Schizophrenics Anonymous, experience and describe “recovery” from schizophrenia. There is a lot of confusion surrounding the word recovery when it is used in reference to individuals with schizophrenia. This confusion goes beyond simple semantics, because how recovery is understood impacts how schizophrenia is conceptualized, how people with schizophrenia think about themselves, and how services are provided (Farkas, 1996; Harding, 1986). Traditional views about schizophrenia, which have been shaped by the medical model, discourage all hope for recovery (Kramer & Gagne, 1997). A diagnosis of schizophrenia is still viewed by many professionals as indicative of a deteriorating course and poor outcome. This view of schizophrenia, which minimizes the possibility for recovery, does not accurately reflect the experiences of many individuals who have been diagnosed with this illness. In contrast to the hopelessness that is often conveyed with this diagnosis, first person accounts provide evidence that many individuals have found ways to live fulfilling and productive lives in spite of the debilitating symptoms of schizophrenia. Mutual-help groups provide an opportunity to explore recovery from the perspective of individuals with schizophrenia, because they are consumer run and for the most part they espouse the belief that recovery from schizophrenia is possible and a process in which each and every person is entitled to participate (Walker-Davis, 1995).

Mutual-help groups differ from professionally run mental health settings on a

number of important dimensions. Most importantly, they are consumer controlled and lack the hierarchy and reliance on professional experts that characterize professional mental health settings (Kurtz, 1997). Instead, mutual-help groups operate on the assumptions that all members can be both the helper and helpee (Rappaport, Reischl, & Zimmerman, 1992) and that members gain expertise through lived experience with the problem, not professional training (Borkman, 1991; Kurtz, 1997). Therefore, mutual-help groups may allow individuals to develop understandings and definitions of recovery based on their own and other members' experiences. Such understandings and definitions of recovery may differ from those typically found in professionally controlled settings, where conceptualizations of schizophrenia as a chronic, progressive illness still dominate.

Developing an understanding of what recovery means to individuals who have schizophrenia can help to change the dominant conceptualization of schizophrenia from a chronic illness with a poor prognosis to a condition that allows for recovery and for many individuals to lead fulfilling and productive lives. Such a shift is necessary, if we are to be successful in creating psychosocial rehabilitation and clinical services and settings that truly promote recovery (DeMasi, Markowitz, Videka-Sherman, Sofka, Knight, & Carpinello, 1996).

BACKGROUND

Until recently, there were few people in the mental health field who believed recovery from schizophrenia was possible. However, in the last decade the possibility of recovery from schizophrenia has begun to gain more credibility. Three factors have contributed to this changing understanding of schizophrenia. First, recent longitudinal and cross-sectional research has challenged the view of schizophrenia as a chronic illness

with a poor prognosis (Harding, Zubin, & Strauss, 1987; 1992; McGlashan, 1988). These studies have demonstrated that schizophrenia is an illness with varied courses and outcomes, with about a third of the people diagnosed, achieving full recovery (Davidson & McGlashan, 1997; Harding, 1992; Harding, Strauss, Hafez & Liberman, 1987; McGlashan, 1988).

The second factor that has contributed to changing beliefs about recovery from schizophrenia, is the recognition that traditional conceptualizations of recovery, as an outcome or end state, do not adequately capture the process that individuals undertake in their efforts to live with this illness (Harding, 1986; Frese & Walker Davis, 1997). The growing consumer/survivor self-help movement and the publishing of personal accounts of schizophrenia and recovery (e.g. Deegan, 1988), are two factors that have challenged the adequacy of traditional conceptualizations of recovery based solely on outcomes or an end state.

The mental health consumer/survivor self-help movement has increased awareness of the role that individuals with mental illness can play in their own recovery. It has facilitated this by redefining the role of individuals with mental illness from passive recipients of services to active participants in their own recovery and in the recovery of others. One way this has been accomplished is by the development of a broad array of groups and programs that are run by persons with mental illness. While the specific goals and methods of these organizations vary, they tend to share an emphasis on expertise gained through experience, voluntary participation, individual or societal change, as well as, self-determination, self-reliance, self-production, and self-empowerment (Kurtz, 1997). Inclusion of individuals with a mental illness diagnosis in service provision helps

others to view them and others diagnosed with mental illness as experts on their own illness and recovery.

The publishing of personal accounts of recovery from schizophrenia in professional journals has also influenced emerging conceptualizations of schizophrenia and recovery (e.g., Schizophrenia Bulletin 1988; 1990). These personal accounts have provided numerous examples of how individuals with a mental illness view recovery as a non-linear process that involves successes and set backs, rather than as an outcome or an end state. Publishing personal accounts of mental illness and recovery, in professional and academic journals that are widely disseminated to practitioners and researchers, has provided consumers with a growing voice in the definition of recovery and has contributed to our changing conceptualizations of schizophrenia and recovery.

The third factor that has informed the emerging conceptualization of recovery from schizophrenia is the application of other models of illness, health, recovery, and disability that have developed outside of the mental health field. The medical model, which still dominates in clinical and rehabilitation settings and focuses on illness and pathology, symptom alleviation, deficits, and cure, may negatively impact recovery. For example, Fisher (1994) in a discussion of his own recovery argues that the neurobiological model of mental illness directly interfered with his recovery by depriving him of his self-determination and sense of responsibility. One example of how other models can broaden our thinking about schizophrenia and recovery is the application of knowledge about recovery from trauma or physical illness to the understanding of recovery from mental illness. For example, in the field of physical disability, recovery does not mean that the injury or symptoms of the illness disappear, that a person returns

to the pre-illness or pre-injury level of functioning, or that the person is "cured". The experience of a trauma or illness is expected to change the way individuals understand or view themselves and their relationship to the world and others and recovery involves learning to live a productive, meaningful, and fulfilling life within the constraints of ones' disability. In the physical disability field, the conceptualization of recovery as a return to previous functioning would be synonymous with equating recovery with the restored functioning of one's legs if paralyzed or one's eyes if blind. The application of such an absolute standard of recovery to mental illness, which does not incorporate the changes a person experiences in how they understand themselves or the world, may be equally unrealistic and undesirable.

Although there is mounting empirical evidence that recovery is possible, increased visibility of consumer definitions of recovery, and application of new models to the understanding of recovery from schizophrenia, the traditional definitions and measures of recovery still dominate the professional literature. Traditional definitions of schizophrenia and recovery used by mental health professionals and researchers tend to focus primarily on "outcomes." "Outcomes" refer to an individual's level of functioning in one or more specific domains. Examples of these domains include: psychiatric functioning (e.g., frequency of hospitalization, remission of symptoms, and medication/treatment compliance), vocational functioning (e.g., working part-time or full-time in competitive or sheltered employment), and social functioning (e.g., social skills, social network size) (e.g., Dickerson, 1997; Strauss, Bowers & Keith, 1982; Strauss & Carpenter, 1972; Wynne, 1988). When the process or "course" (i.e. how an individual's illness manifests itself over time) of illness is considered, it is primarily used to predict outcome or chance

of recovery. For example, a poor or deteriorating course would predict a bad outcome with little chance of recovery as described above.

There are several potential problems with an outcome-oriented definition of recovery. First, "outcome" focuses our attention on an end state, which assumes that there is an identifiable point in time at which we can expect people with schizophrenia to reach that end state. When outcomes are measured at a particular point in time it is assumed that individuals have been given adequate time to achieve a certain level of recovery. However, as longitudinal empirical research has demonstrated, schizophrenia has a varied course (Davidson & McGlashan, 1997; Harding, et al., 1987; Harding, 1992; McGlashan, 1988) and also as Harding (1986) points out, one investigator's outcome is just a point in another investigator's course – the time at which outcome is measured really just indicates the end of the research project, not some meaningful point in an individual's recovery.

A second problematic feature of using outcomes to determine recovery involves making judgements about how an individual should function in specific domains (e.g., psychiatric functioning, vocational functioning, and social functioning). These judgements are often made by comparing an individual's current functioning and adjustment either to societal norms or to the individual's pre-morbid functioning. Because there are no agreed on societal norms, these norms often reflect the values of the professional or researcher and may not accurately reflect what is important to a specific individual in their own recovery. Comparing an individual's current functioning to their pre-morbid functioning does not take into account fundamental changes in self that result from experiencing mental illness and the subsequent losses and traumas (e.g., loss of job,

relationships, sense of value and worth, iatrogenic treatment effects).

Recovery has been described in personal accounts, written by mental health consumers and survivors, not as a cure or an outcome in specific domains as described above, but instead as a process. It has been described as a process, a way of life, an attitude, a way of approaching the day's challenges, and of accepting certain limitations in one's life (Deegan, 1988; 1993). Anthony (1993a) summarizes these published personal accounts of recovery by stating that recovery is "...a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles, and living a satisfying, hopeful, and productive life with a new sense of meaning or purpose despite the limitations caused by illness" (p. 23). This definition of recovery challenges the notion of a linear "course" leading to a specific "outcome" because it describes recovery as a unique cycle of adaptations and growth.

Understanding recovery from schizophrenia from the individual's perspective is important in order to change the way that schizophrenia is conceptualized and to understand how to promote recovery through appropriate supports, policies, and mental health and rehabilitation services. Although personal narratives have been instrumental in giving voice to the perspectives of recovery by people diagnosed with mental illness, systematic explorations of recovery across individuals are needed to better understand the process of recovery and to provide a foundation for changing our conceptualization of schizophrenia to include recovery. As described in the personal accounts of individuals with mental illness, mental health services are often unsuccessful in addressing many of the psychosocial aspects of being diagnosed with schizophrenia. These include experiences of loss and social isolation (Link, Struening, Rahav, Phelan, & Nuttbrook,

1997; Perese, 1997); a loss of relationships and connectedness to others (Ruocchio, 1991; Spaniol & Koehler, 1998); a decrease in self-worth and value (Deegan, 1993); and a feeling of hopelessness and helplessness (Kramer & Gagne, 1997; Lovejoy, 1984). Perhaps traditional mental health services have been inadequate in addressing these needs because they are based on conceptualizations of schizophrenia that do not convey hope for recovery and they are focused on achieving outcomes with little understanding of the process of recovery that may lead to those outcomes.

One setting that does promote a belief in recovery is mutual-help groups, which have developed as an alternative or adjunct to more traditional mental health services (Markowitz, et al, 1996). Mutual-help groups are controlled by persons with mental illness and provide an opportunity for persons diagnosed with mental illness to come together and use their own experiences to collectively define and promote recovery. These settings promote self-determination (Zinman, 1987), empowerment (Rappaport et al., 1992), and the value of shared experience (Borkman, 1991) in the healing process. Participation in mutual-help groups encourages individuals with mental illness to think about their own recovery and to believe it is possible. As such, mutual-help groups provide a setting in which to explore recovery as it is defined and experienced by individuals with schizophrenia who are involved in what they define as the process of recovery.

Overview of Literature Review

To understand the value of exploring recovery from the perspective of individuals with schizophrenia in a mutual-help setting, two bodies of literature will be reviewed - the literature on schizophrenia and the literature on mutual-help. First, a brief overview

of schizophrenia will be presented including how the dominant conceptualizations of schizophrenia evolved and how they have shaped the way we address the problem of schizophrenia and recovery. Second, literature describing the challenges to recovery posed by having a diagnosis of schizophrenia will be presented. Finally, the literature on mutual-help settings will be reviewed by focusing on how they provide a context in which consumers can engage in and understand the process of recovery.

Literature Review

Impact of Schizophrenia on Society and Individuals

Schizophrenia is identified as the most severe of the major adult psychiatric illnesses. In the United States, approximately 2 to 3 million persons have a diagnosis of schizophrenia at any one time, and approximately 1 in every 100 people is diagnosed in their lifetime (DSM-IV). For a one year period, schizophrenia has been estimated to cost the United States 19 billion dollars in direct expenditures, including treatment and non-treatment related (e.g., the cost of the criminal justice system used by individuals with schizophrenia) expenditures, and 46 billion dollars in lost productivity (Wyatt, Henter, Leary, & Taylor, 1995).

The impact of a diagnosis of schizophrenia on individuals' lives is complex. One way that schizophrenia manifests itself in the lives of individuals is through the direct experience of symptoms. The DSM-IV (1994), the major diagnostic system used in the United States, describes a constellation of symptoms that are characteristic of schizophrenia, including a range of cognitive and emotional disturbances that are categorized as either positive or negative. Positive symptoms encompass cognitions or behaviors on either one of two dimensions. The disorganized dimension includes

disorganized speech (e.g., loosening of associations and incoherence) and disorganized behavior (e.g., agitation, disheveled appearance, and difficulty in performing daily activities). The psychotic dimension includes delusions, or erroneous beliefs that may involve a misinterpretation of perceptions or experiences, and hallucinations, which may occur in any of the sensory modalities, with auditory hallucinations the most common. Negative symptoms encompass a diminution or loss of functioning and include restrictions in the range and intensity of emotional expression, fluency and productivity of thought and speech (alogia), and difficulty in initiating goal directed behavior (avolition). Whether or not the negative symptoms are actually symptoms of schizophrenia or caused by neuroleptic medications taken to alleviate some of the positive symptoms is unclear (Zubin, 1985). The impact of these experiences on an individual's ability to navigate life, as well as how others perceive them, can be devastating.

Personal accounts of the experience of living with schizophrenia describe how symptoms can disrupt a person's life. Ruocchio (1994) describes the frustration of experiencing disorganized thought and speech as "agony in not being able to communicate one's mind" (p. 107) due to her own inadequacy "to use language to express what lies buried so deeply inside me, even when I am lucid, makes words a curse that blocks the proverbial light within the tunnel, and I am alone with my darkness" (p. 106). The psychotic dimension of schizophrenia is often described as terrifying and confusing. Common beliefs are that "people were trying to get rid of me...that the radio programs and movies and television programs were talking about me" (Fortner and Steel, 1997, p. 113). Delusions and hallucinations interfere with a person's ability to function socially

because they contribute to a feeling of interpersonal terror "a fear of reaching out and an even greater fear of allowing anyone to get close" (Rucchio, 1997, p. 105). In addition to experiencing frightening and often debilitating symptoms, individuals must also endure our culture's negative perceptions of and reactions to people with schizophrenia, including the use of pejorative language, that conveys to people with mental illness that they are less valued than others in society (Hatfield & Lefley, 1993). Stereotypes, stigma, and the experience of discrimination cause additional suffering and create additional barriers to recovery for individuals with schizophrenia, which extend beyond their experience of symptoms.

Despite ongoing public education campaigns, stigma and discrimination are still prevalent in the United States (Fraser, 1994). Stigma and discrimination push individuals with mental illness to the social and economic margins of society through discriminatory practices both on an individual and systemic level. A recent national survey by Wahl (1998) explored the experience of stigma and discrimination of 1,300 individuals diagnosed with schizophrenia, bipolar disorder, or major depression. The survey found: 1 in 3 consumers had been turned down for a job for which they were qualified because of a psychiatric label; 1 in 3 consumers were turned down for health insurance because of a diagnosis of mental illness; 1 in 5 consumers had been turned down when they tried to volunteer their services because of a psychiatric diagnosis; and 50 percent of all consumers surveyed indicated they have often or very often overheard others such as friends, co-workers, and even mental health professionals make hurtful or offensive comments about mental illness. Exclusion from valued work roles and employment settings can diminish a person's feelings of self-worth (Perese, 1997) and also the

availability of economic resources to engage in social activities that are essential to establishing and maintaining social relationships (Davidson & Staynor, 1997; Fraser, 1994). Limited opportunities for participating in valued work roles, living in poverty, and the experience of stigma and discrimination, coupled with the symptoms of the illness, all contribute to the social marginalization of individuals with schizophrenia.

One indication of social marginalization is the extent to which individuals with schizophrenia are isolated or not connected to other people. There is an extensive body of literature that examines the characteristics of social networks of individuals with schizophrenia and which demonstrates that they have significantly smaller social networks than the general population (Brugha, Wing, Brewin, MacCarty, & Lesage, 1993; Holmes-Eber & Riger, 1990; Meeks & Murrell, 1994). In addition, the social networks of individuals with schizophrenia are composed of a greater proportion of kin (e.g., parents) and formal relationships (e.g., mental health professionals) and a lower proportion of friends than the general population (Brugha et al, 1993; Cresswell, Kuipers, & Power, 1992; Meeks & Murrell, 1994). One important way to understand social marginalization is to examine how individuals with schizophrenia experience their social position and relationships with other people.

Individuals with schizophrenia report experiencing feelings of alienation (DeNiro, 1995), loneliness (Gerstein, Bates, & Reindl, 1987; Perese, 1997), and social isolation (DeNiro, 1995; Hirschberg, 1985; Meeks & Murrell, 1994; Sorensen & Mors, 1992). DeNiro (1995), in a qualitative study of 20 persons hospitalized with a diagnosis of schizophrenia, found experiences of loneliness, social isolation, and lack of solidarity with a group or sense of not belonging, to be pervasive. Perese (1997) reported similar

findings in a study looking at the relationship between unmet needs and quality of life for individuals with schizophrenia living in the community. The 73 respondents in this study identified the following unmet needs: having a friend (62%), a role in life (61%), membership in a group (56%), and self-identity (55%). These studies indicate that individuals with schizophrenia experience a high degree of social marginalization which are manifested in feelings of alienation, a lack of connection to other people, a lack of a sense of belonging to a group, and loneliness.

Social isolation, loneliness, and alienation have been related to symptom severity (Hirschberg, 1985), stress (Gerstein et al., 1987), recurrent hospitalizations (Sorensen & Mors, 1992), feelings of worthlessness (Deegan, 1988), and decreased feelings of well-being and quality of life (Link et al., 1997; Perese, 1997; Rosenfield, 1997). For example, three of the unmet needs identified by Perese (1997), which reflect social isolation (i.e. needing a friend, needing a role in life and needing membership in a group), were significantly negatively correlated with quality of life. Participants in this study also indicated that to be without a job was to be thought of as worthless. In her study, DeNiro (1995) also reported that feelings of loneliness, social isolation and lack of solidarity or sense of belonging, resulting from unemployment, exclusion, and rejection from other social settings and statuses, were associated with feeling that one was not valued or needed by society.

In summary, the symptoms of schizophrenia can be devastating, but they represent only one aspect of what many individuals with schizophrenia experience and must recover from. Experiences of stigma, discrimination, and disadvantage, which result in economic and social marginalization, also play a primary role in the suffering

experienced by these individuals. The greatest personal costs of schizophrenia are not necessarily directly associated with the experience of symptoms, but with the social and economic marginalization, and feelings of decreased self worth and value, that can accompany a diagnosis of schizophrenia. Stigma and discrimination, the root causes of social and economic marginalization, are based on stereotypes which are caused by how schizophrenia is understood and what a diagnosis of schizophrenia is believed to indicate about a person. Including an understanding of recovery in our conceptualization of schizophrenia may help to change the stereotypes of people diagnosed with schizophrenia that result in stigma and discrimination. Therefore, it is important to examine how schizophrenia is currently conceptualized and how this conceptualization has evolved.

Conceptualizations of Schizophrenia: How they came to be and their impact on recovery

The dominant conceptualization of schizophrenia emerged over one hundred years ago. Manfred Bleuler (1857-1939) and Emil Kraepelin (1855-1926) were two of the greatest influences on how we view schizophrenia and on our understanding of its course and outcome. Emil Kraepelin used the term dementia praecox to describe a subgroup of symptoms that were due to a single illness with an early onset (praecox) and a deteriorating course that results in an eventual deterioration in intellectual functioning (dementia) (Warner, 1985). Since Kraepelin developed the criteria for dementia praecox, prognosis has been predictive of an individual's diagnosis, with good outcome cases diagnosed as manic depression and bad outcome cases diagnosed as schizophrenia (Harding et al., 1992; Harding, Zubin, & Strauss, 1987).

In contrast to Kraepelin, M. Bleuler focused more on the nature of the symptoms and less on the course. This led him to reject the term dementia praecox and to instead

propose the term schizophrenia to describe a split (schizo) in the mind (phren) between perception and reality (Torrey, 1980). Although M. Bleuler focused less on course and prognosis, the notion of schizophrenia as having a poor prognosis and outcome has endured in the clinical and empirical understanding of this phenomenon. Although the DSM-IV is more optimistic about the course and outcome of schizophrenia than earlier versions of the DSM (i.e. DSM III-R), it still propagates the view expressed above. The DSM-IV states that "Complete remission (i.e. a return to full pre-morbid functioning) is probably not common in this disorder. Of those who remain ill, some appear to have a relatively stable course, whereas others show a progressive worsening associated with severe disability" (p. 282).

Zubin, Steinhauer and Condray (1991) argue that this view of schizophrenia, what Harding and Zahniser (1994) identify as the myth of "Once a schizophrenic, always a schizophrenic" (p. 141), has been reinforced by clinical experience, which focuses primarily on individuals with the most chronic and recidivist patterns, thus creating a biased view of the outcome of schizophrenia. Harding and Zahniser (1994) suggest that even Kraepelin and Bleuler, were influenced by what they call "the clinician's illusion," which occurs when clinicians repeatedly see the most ill and recidivistic cases as "typical." This can leave individuals, their families, and mental health professionals with a sense of hopelessness and despair (Deegan, 1988).

Harding and colleagues identify problems in many studies of measurement, diagnosis, and sampling that make it appear that schizophrenia has a worse outcome than it does (Harding & Zahniser, 1994; Harding et al., 1987). One of the most pervasive problems in short and long-term follow-up studies is the use of "outcomes" as defined

only as "recovered" or "unrecovered" (Harding et al., 1992) and the narrow definition of recovery as the relief from symptoms and disabilities (Coursey, Alford, & Safarjan, 1997). Carpenter and Strauss (1991) argue that viewing outcomes in this unidimensional manner is misleading and does not account for other aspects of human functioning. Taking this a step further, Strauss (1994) argues that the concepts of course and outcome, when used to describe illness and recovery for individuals with schizophrenia, represent only a very narrow range of how people experience their illness and recovery. Davidson and Strauss (1995) argue that the use of models that focus on disease and disorder, to the exclusion of other aspects of human functioning, underlie the narrow focus of most outcome research on schizophrenia. Disease and disorder models assume that health and illness are distinct states, and that these two states cannot co-exist. Therefore, in order to achieve recovery or a state of health, the disease and symptoms must be eradicated (Fabrega, 1979).

Another problem with the use of outcomes as measures of recovery is that they lose their meaning as an end state when different lengths of follow-up periods are considered. Length of follow-up period determines when outcomes are measured, thus one investigator's outcome is another's course or end state (Harding, 1986). Short and long term follow-up studies encompass time periods ranging from six months to thirty-two years (e.g., Harding et al., 1987) with the length of a study being determined arbitrarily by the length of the research project or by some notion of how long it takes to recover. However, as demonstrated by long-term outcome studies, recovery does not occur at a specific time and schizophrenia is manifested differently across individuals producing variations in course and outcome.

By reviewing outcomes in long-term, early course, and cross-cultural studies, Davidson and McGlashan (1997) demonstrate variations depending on how outcomes are measured. They argue that there are variations in outcomes across individuals, between groups of individuals when sociocultural and historical context are considered, and within any given individual when different domains of functioning are examined. Harding (1988) also describes varying courses and outcomes by identifying eight different course patterns based on combinations of acute versus chronic onset and simple versus undulating course, with outcomes ranging from recovered to severely incapacitated. These alternative views of schizophrenia as an illness with varying outcomes and courses challenges the notion that "a schizophrenic is a schizophrenic is a schizophrenic" (Harding & Zahniser, 1994; p. 141) which has been perpetuated through the development of stereotypes and traditional conceptualizations of schizophrenia. As Harding and Zahniser (1994) point out, within the same diagnostic category of schizophrenia there are many individual differences and variations in life histories that lead to substantial heterogeneity in manifestation of the illness, as well as different treatment and service needs of the individual. To address this heterogeneity, they suggest attention to the whole person, including their individual differences, in order to encourage patients to view themselves as persons with schizophrenia rather than as "schizophrenics." Based on the variations in course and the heterogeneity of outcomes, it is inappropriate to make generalizations about how schizophrenia will manifest itself in the course of a person's life, based on outcomes, which are measured at one point in time.

Although there is considerable evidence for the heterogeneity of outcomes and course in schizophrenia, the evidence is often disputed based on a diagnostic practice

carried over from the time of Kraepelin. Any indication of good outcome or recovery is viewed as a problem with diagnosis and handled in one of two ways (Carpenter & Strauss, 1991; Harding et al., 1992; Harding et al., 1987). Individuals with good outcome are either argued to not have "true" schizophrenia or they are moved to another diagnostic category to account for their better outcome (i.e. manic depression) (Davidson & McGlashan, 1997; Harding et al., 1992; Harding & Strauss, 1984). Therefore, only individuals with a poor outcome are considered to have "true" schizophrenia and to remain in the diagnostic category of schizophrenia.

A final issue that has added to the confusion in the literature on schizophrenia and recovery is the sampling bias of many of the early long-term follow-up studies. The samples used by Kraepelin in developing his understanding of schizophrenia were selected from patients who remained continuously institutionalized, while Blueyer's samples were often lost to follow-up (Harding et al., 1992). Many other long-term follow-up studies have used samples that are biased towards over inclusion of institutionalized individuals because of their accessibility (Davidson & Strauss, 1997). This is problematic because of the impact institutionalization has on individual functioning and outcome (Goffman, 1961). In addition, sampling only institutionalized individuals or individuals still involved with the mental health system excludes those individuals who are no longer involved with these services or settings and are more likely to be further along in recovery. This reinforces negative expectations for recovery by sampling only individuals most in need of prolonged high intensity treatment.

Conceptualizations of schizophrenia as a chronic illness with a poor prognosis have made recovery seem impossible and have consequently limited its exploration.

Definitions of recovery as an outcome or end state have further restricted our understanding of it by making assumptions about how long it should take people to recover and what are appropriate outcomes. Finally, the issues of measurement, diagnosis, and sampling have all played a role in perpetuating and maintaining the pessimistic beliefs of clinicians and researchers about whether or not recovery is even possible for individuals with schizophrenia, which impacts services and opportunities for individuals diagnosed with schizophrenia.

The prevailing beliefs about schizophrenia as a chronic, progressive illness with a poor prognosis have shaped treatment and services, limited professionals ability to fully understanding individuals with schizophrenia, and influenced what they convey to individuals about their chances for recovery. Personal accounts of individuals with schizophrenia discuss how these prevalent and persistent beliefs about schizophrenia leave patients and their families without hope (Chamberlin, 1979; Lovejoy, 1984). One way that hopelessness is conveyed is through language that reflects negative and pessimistic beliefs about schizophrenia and recovery (Spaniol and Catteneo, 1997). One indication of this is the relative absence of the word “recovery” from the professional journals that focus on schizophrenia (Corin & Lauzon, 1994). Deegan (1988) discusses hope as one of the cornerstones for recovery. Therefore, to promote a sense of hope, and to make recovery possible, a new conceptualization of schizophrenia must be adopted which more accurately reflects the experience of people with schizophrenia and their real chances of recovery.

Changing Conceptualizations of Schizophrenia to Include Recovery

Strauss (1994b; 1992) calls for a new conceptualization of schizophrenia based on the accumulating evidence for recovery and Coursey, et al. (1997) argue that this transformation in how serious mental illness is thought about is currently occurring. This change in thinking is largely due to longitudinal studies that indicate that the recovery rate is higher than originally believed (Coursey et al., 1997), and evidence that schizophrenia is an illness with heterogeneous outcomes and courses (Davidson & McGlashan, 1997). For example, Harding, et al. (1987) have reviewed long-term recovery rates and found that recovered or significantly improved rates ranged from 46% to 68% with a weighted mean of 55%. Torrey (1995) reviewed all studies done to date and estimated that 30 years after onset 25% of persons diagnosed with schizophrenia were completely recovered and an additional 25% were much improved. The criteria for “recovery” used in these studies include: no current signs or symptoms of any mental illness; no current medications; working, relating well to family and friends; integration into the community; and adherence to behavioral norms (Harding, et al., 1987; Harding & Zahniser, 1994; Torrey, 1995). Although the definition of recovery used in these studies may not reflect or be the same as consumers' definitions of recovery, they have been useful in influencing the professional conceptualizations of schizophrenia to include the possibility of recovery.

A second factor influencing the changing conceptualization of schizophrenia has been the mental health consumer/survivor self-help movement, which has increased the involvement of individuals with mental illness in mental health service delivery in a variety of roles as consultants, treatment team members, providers, and advocates for

themselves and others (Marsh, Koeske, Schmidt, Martz, & Redpath, 1997). The mental health self-help movement grew out of the psychiatric survivor, ex-patient movement that started in the United States in the early 1970's to counteract the feelings of powerlessness experienced by individuals in the mental health system (Chamberlin, 1990; Chamberlin & Rogers, 1990). Two of the guiding principles of the movement are self-definition (Slack, 1995) and self-determination (Walker-Davis, 1995). One way that these principles have been put into practice is to create and operate self-help programs as alternatives to professionally controlled treatment and settings. These programs allow individuals with mental illness to control their own organizations and programs and to offer each other their expertise regarding their subjective experience of mental illness and mental health services (Marsh et al., 1997). As a consequence, individuals with mental illness are being viewed as more competent and knowledgeable by some mental health professionals, which provides greater credibility to the voices of mental health consumer/survivors in the on-going discussion about schizophrenia, recovery, and the development and delivery of mental health services.

A third factor influencing the conceptualization of schizophrenia is the use of alternative models to understand mental illness. Strauss (1994b) argues that models of disorder, and specifically the dominant biomedical model, have restricted our understanding of schizophrenia to aspects that can be readily classified and measured. The use of models of disorder, which focus primarily on pathology and disease, exclude individuals' strengths and the examination of the processes of health and recovery (Davidson and Strauss, 1995; Marsh, et al., 1997). Engel (1980) goes a step further and refers to the biomedical model as dogma because it maintains its influence through

authority and tradition while no longer helping to generate new knowledge.

The shortcomings of the biomedical model in understanding schizophrenia and the impact it has on individual lives is well captured in the words of Dr. Patricia Deegan, a clinical psychologist and consumer survivor. She states that: "Those of us who have been labeled with mental illness are first and foremost human beings. We are more than the sum of the electrochemical activity of our brain. We are people. We are people who have experienced great distress and who face the challenge of recovery" (p. 92, 1995). She draws attention to how the medical model fails individuals with schizophrenia by narrowly focusing on biological functioning and disorder to the exclusion of other aspects of the person.

Based on these criticisms of the biomedical model, alternative models have been proposed to understand schizophrenia. Engel (1980) proposes the biopsychosocial model, which captures the complex interactions between biological, psychological, social, and environmental factors. Davidson and Strauss (1995) build on Engel's model and propose a life-context model that uses the person's life as the framework to understand the multiple dimensions of disorder, health, and recovery. Models of rehabilitation from the field of medicine have also been used to understand disability from psychiatric illness in new ways (e.g., Anthony, 1982). So, although the medical model has instigated exploration into biological and neurological aspects of mental illness, and has helped release families from victim blaming theories such as "the schizophrenogenic mother," it has also limited our understanding of the complexity of schizophrenia and recovery. On the other hand, the use of new models in understanding schizophrenia is helping to change the conceptualization of schizophrenia to include the

possibility of recovery.

Although there have been several forces working to change the conceptualization of schizophrenia to include the possibility of recovery, there is still little attention to the phenomenon of recovery in the professional literature. There are several reasons for this ranging from the practical difficulties of conducting research on a complex, multi-dimensional, and often-unobservable concept, to conceptual limitations imposed by the persistent dominant beliefs about schizophrenia, which do not include the possibility of recovery. Deegan (1988) attributes the dearth of research on recovery to the practical barriers of researching a complex concept, and states that recovery "...cannot be completely described with traditional scientific, psychiatric, or psychological language" (p. 12). Anthony (1993a) agrees that recovery is a complex and multi-dimensional concept that is not amenable to a single measure, and that requires both quantitative and qualitative research with an emphasis on understanding recovery from the perspective of those who are experiencing it. Other active proponents of incorporating consumers' definitions of recovery into research and treatment agendas (e.g., Anthony, 1991; 1993a; 1993b; Spaniol & Koehler, 1998) have noted that the process of recovery has not been investigated from the perspective of those who are experiencing it, except through the writing of personal accounts, which are often dismissed as subjective and biased. Although personal accounts have been helpful in calling attention to the importance of consumer perspectives of recovery, a systematic exploration of the recovery process is needed in order to change the way schizophrenia and recovery conceptualized.

Historically, the exclusion of consumer experiences of schizophrenia and recovery from the knowledge base of mental health treatment has impeded the

development of interventions and settings that promote recovery. Although there are new roles for individuals with mental illness in the mental health system, and conceptualizations of schizophrenia and recovery are changing, there is a recognition that concepts of recovery and coping have not been widely incorporated into mental health services (Blanch, Fisher, Tucker, Walsh, & Chassman, 1993). A better understanding of how individuals with schizophrenia understand and experience recovery may provide a broader conceptual base for incorporating recovery into mental health services and helping us to understand the value of alternative settings.

Recovery

Consumer Understandings of Recovery.

Many rich descriptions of the process of recovery are found in the narratives of individuals with mental illness. Some are written by people who identify with the ex-patients movement (e.g., Chamberlin, 1990; Deegan, 1993), some are written by consumers who have become professionals in the mental health field (i.e. "prosumers"), and some are written by people who have chosen to not be associated with other consumers or professionals in any formal context. Regardless of affiliation, these personal narratives of mental illness and recovery have many similar themes that emerge across stories.

One of the important themes that emerge from personal narratives concerns recognizing what it is that people are recovering from. Personal narratives describe the need to recover not only from the symptoms of schizophrenia, but also from recurrent traumas that occur through treatment practices and the experience of stigma and discrimination (Anonymous, 1989; Deegan, 1993; Leete, 1987; Unizicker, 1989).

Spaniol and Koehler (1998), through their work with individuals with mental illness, identify specific treatment practices that traumatize individuals. These include: negative professional attitudes, lack of appropriate assisting skills of professionals (e.g., undermine self determination), devaluing and disempowering programs, and lack of enriching opportunities (e.g., valued work or social roles). Although mental health programs and treatments are designed with good intentions, they are not always perceived as beneficial and are sometimes even perceived as harmful by persons who experience them (Slack, 1995).

Personal narratives also describe the need to recover from the psychological losses and traumas that result from a diagnosis of a mental illness. These losses and traumas are summarized as: loss of sense of self; loss of power; loss of meaning and purpose; and loss of hope (Spaniol, Gagne, & Koehler, 1998). These experiences of trauma and loss are discussed in personal narratives as significant barriers to recovery and as aspects of their experience, which are seldom addressed by traditional interventions that primarily focus on the symptoms associated with the illness. Many of the elements of the recovery process, as described by individuals with mental illness, are things that address both the traumas inflicted by well-meaning professionals and services and the experiences of loss that are brought about by a diagnosis of mental illness. For example, hope is identified as necessary for recovery but also as something that can be lost in the process of treatment due to pessimistic attitudes about recovery from schizophrenia (Deegan, 1988; 1993; Houghton, 1982; Lovejoy, 1984; Unzicker, 1989; Weingarten, 1994). Therefore, it is important to address the traumatic experiences and losses that are expressed in personal narratives, if we are to understand that recovery

entails more than just alleviating symptoms (Farkas, 1996; Marsh et al., 1997).

Not only do personal narratives discuss what people are recovering from, but they also touch on some of the characteristics of recovery. Taking control of one's life is one critical aspect of recovery (Deegan, 1993). In a dialogue between consumer-practitioners and psychiatrists in New York state, the following are identified as key to recovery: taking control of one's own recovery; realizing that no one else can fix or heal you; and playing an active role in treatment (Marsh et al., 1997). Deegan (1993) stresses that recovery for her means trying "to stay in the drivers' seat of my life...I don't let my illness run me over" (p. 374). Another important aspect of recovery is recognizing that it is an ongoing process, that involves acceptance of who one is not, and what one cannot do or accomplish, in order to discover who one can be and what one can do (Deegan, 1988; Houghton, 1982; Weingarten, 1989). It is a process that involves small steps (Orrin, 1994) and accepts relapse not as a failure, but an opportunity to grow and to learn about one's limitations (Deegan, 1988). In the wake of illness and disability, developing a new sense of meaning and purpose in one's life is also crucial to recovery (Deegan, 1988; Houghton, 1982). Some of these characteristics of recovery are beginning to be acknowledged and explored by professionals.

Individuals with mental illness, either using their personal experience as a guide to discuss recovery or directly recounting their own experience, have done most of the writing about the process of recovery (Anthony, 1994). However, a few attempts have been made by professionals and researchers in the psychiatric rehabilitation field to summarize accounts of recovery from the consumer's perspective. Hatfield (1994) equates recovery with a process of change and growth, which includes regaining control

over important aspects of life and living a life of significant meaning. Anthony (1994) also promotes a view of recovery that includes growing beyond the catastrophe of mental illness, developing new meaning and purpose in one's life, and taking charge of one's life even if one cannot control one's symptoms. This emphasis on the process of "recovering" (i.e. how you do it) rather than the end state of being "recovered" (i.e. what you've done), is a key element in understanding recovery from the perspective of individuals with mental illness. A limited number of professionals and researchers are starting to take notice of the importance of viewing recovery as a process and discussing and investigating recovery as a process instead of only as an outcome.

Spaniol and Koehler (1998) offer a definition of recovery that encompasses recovery as a process, an outcome, and a vision. As a process, recovery is a common human phenomenon that we all experience at some point after injury, illness, loss or trauma. The process includes healing physically and emotionally; adjusting one's attitudes, feelings, perceptions, beliefs, roles and goals in life; and engaging in a process of self-discovery, self-renewal, and transformation. Recovery as a process also involves creating a new personal vision for oneself. As an outcome, recovery is engaging in work, having friends, and living in a place of one's own choosing. This is the aspect of recovery most often embraced by researchers or professionals. As a vision, recovery should be the goal of all mental health programs and services and should provide the principles and values to guide the planning and implementation of mental health services (Anthony, 1993c). Although the process of recovery, as defined and understood by consumers, is gaining visibility and acceptance in certain professional circles, especially psychiatric rehabilitation, there is little empirical research on the recovery process from

the perspective of the individual experiencing schizophrenia.

Empirical Studies on Consumer Experiences and Understandings of Recovery.

There have been only a handful of empirical studies that have explored the process of recovery. Within the mental health literature, many of these empirical investigations have focused on one specific mechanism or aspect of recovery. For example, Davidson and Strauss (1992) focus on the importance of sense of self in improvement from mental illness. There is a larger body of literature focusing on recovery from physical illness and injury that explores recovery from the perspective of the individual experiencing the problem (Harding, 1986). The empirical studies focused on in this section are those that discuss recovery as a process.

One aspect of the process of recovery that is commonly focused on by researchers in the fields of psychology and sociology is the change in how people view and feel about themselves. This aspect of recovery has been described as a change in one's sense of self (Davidson and Strauss, 1992; 1995); a change in personal or social identity (Estroff, 1989); or a change in self-concept (Townsend, 1976; Townsend & Rakfelt, 1985). Authors of these studies all explore how the experience of mental or physical illness changes a person's sense of who they are or their identity. Estroff (1989) argues that schizophrenia is an "I am illness," which causes people to redefine their sense of identity in terms of the illness. Recovery from such an illness requires the rediscovery or remaking of a person's identity or sense of self, in order to integrate the illness experience into the individual's own personhood.

Although there have been some investigations of the process of changes in self in recovery from mental illness (e.g., Davidson & Strauss, 1992; 1995; Estroff, 1989; Purdie

& McLennan, 1993; Neimeyer & Stewart, 1996; Young, 1988), a great deal of this literature focuses on physical illness and emanates primarily from the field of sociology (e.g., Bury, 1982; Charmaz, 1983; 1987; 1995; Corbin & Strauss, 1987). It can be argued that recovery from physical illness or injury and mental illness are similar, because recovery from all trauma involves growing beyond the catastrophic effects of illness and developing new meaning and purpose in one's life (Farkas, 1986; Harding, 1986).

Charmaz (1983) explores the impact of chronic illness on the sense of self. Using a grounded theory approach and in-depth interviews with 57 chronically ill adults, she describes a loss of self as occurring when the consequences of chronic illness diminish control over one's life and create barriers to valued social relations and roles that help define and validate one's sense of self. In a similar study, Bury (1982) examines chronic physical illness as a biographical disruption, which impacts a person's structures of explanation and meaning and also a person's relationships and material resources. Similarly, Williams (1984) examines chronic physical illness as a disruption between body, self, and the world, but uses the framework of narrative reconstruction to understand how people have incorporated their illness into their biography in order to make sense out of it. Although these studies focus on physical illness, they broaden our understanding of the impact of chronic illness and draw attention to the importance of redefining or remaking of a person's identity or sense of self in recovery.

Exploring the role of self in recovery, Morse (1997) performed a qualitative meta-analysis of three studies of medical illness and two studies of psychiatric illness. From this, she developed a stage theory of recovery that focuses on redefining the self in response to illness. The five stages of her theory are: (1) vigilance, (2) disruption -

enduring to survive, (3) enduring to live- striving to regain self, (4) suffering - striving to restore self, and (5) learning to live with the altered self. This stage theory is similar to the role of a sense of self in recovery that is explicated by Davidson and Strauss (1992; 1995).

Davidson and Strauss (1992; 1995) explore the importance of a sense of self in recovery by examining the lived experience of 66 participants in the Yale Longitudinal Study of Prolonged Psychiatric Disorder. Based on the self-report data of these participants Davidson and Strauss (1992) identified four basic aspects of the recovery process which involve the rediscovery, reconstruction, and utilization of a more functional sense of self. These four aspects are: (1) discovering the possibility of a more functional sense of self than either existed before the illness or an additional aspect of the self which was unacknowledged before the illness, (2) assessing strengths and weaknesses of this self and possibilities for change, (3) utilizing some aspects of the self and integrating the results as reflecting one's actual capabilities, and (4) using an enhanced sense of self to provide refuge from one's illness and stigma.

These studies, which explore the impact of illness on self, and the role of self in the recovery process, provide one interesting framework to understand the recovery process. They recognize the impact that illness has on a person's identity, as well as the need to grow and change as a result of the illness. These studies do not assume that recovery is a return to the previous self that existed before illness or that a return to the previous self is desirable or the goal of recovery. Most importantly, these studies go beyond the traditional focus on symptoms, functioning, and outcomes by exploring potential recovery processes and by recognizing that an altered sense of self is the result

of experiencing serious illness.

An altered sense of self is especially salient for individuals with schizophrenia because of the stigma and negative stereotypes that surround the diagnosis. However, because of discrimination and the limitations imposed by their disability, individuals with schizophrenia often have restricted access to settings, social roles, and relationships that would help to facilitate the development of a positive sense of self. Therefore, participation in settings which provide opportunities to engage in activities that promote feelings of competency and mastery, as well as opportunities to participate in valued social roles and identities will help individuals to restore a functional sense of self in the face of serious illness or injury (Davidson & Strauss, 1992; 1995; Estroff, 1989; Charmaz, 1983; 1987).

The studies and personal narratives discussed above contribute to our understanding of what settings, opportunities, and experiences help to facilitate recovery. Settings that foster a sense of hope and increase opportunities to feel valued and worthy are identified as being especially important in recovery (Deegan, 1988; Houghton, 1982; Leete, 1987; Lovejoy, 1984). Hope, which is a key component of facilitating recovery, is often acquired through knowing others who are in recovery or having a person believe in you when you do not believe in yourself (Deegan, 1993). Recovery is discussed as something that you do with the help of other people (Deegan, 1988; 1993; Fisher, 1994; Lovejoy, 1984; Unzicker, 1989), but that cannot be done for you (Deegan, 1993; Leete, 1994). The experience of talking and listening to other's stories of schizophrenia and recovery has also been identified as necessary for the healing process (Slack, 1995). Therefore, settings, which provide the opportunity to develop relationships, engage in

valued social roles, develop skills and competencies and which promote hope play an important role in facilitating the process of recovery for individuals with schizophrenia. Mutual-help groups are one type of setting that can provide these experiences to people with schizophrenia.

Role of Mutual-Help Groups in Recovery

In general, participation in self-help or mutual-help groups has become increasingly popular in the United States as a way to address a variety of problems, including psychiatric problems and their associated traumas. It is estimated that over 25 million Americans have participated in a self-help group at some point in their lifetime, and that groups for individuals with a mental illness or emotional problem are the second most frequented type of group (Kessler, Mickelson, & Zhao, 1997). Self-help groups or mutual-aid organizations have developed as an adjunct or alternative to more traditional mental health services (Markowitz et al., 1996). Often these groups or organizations are able to provide a qualitatively different experience from what is available in other settings based on the unique values and principles of self help.

Mutual-help groups and organizations share many of the same values and goals of the larger self-help movement. Although they have been defined and conceptualized in many different ways, the term mutual help is used throughout this study to express the egalitarian and communal aspect of groups (Humphreys & Rappaport, 1994) and to reflect the presence of the mutual exchange of information and support. Humphreys and Rappaport (1994) and Borkman (1991) both define mutual-help groups as voluntary associations or organizations of people who share some status, problem, or common predicament that results in difficulties that the groups try to address. In addition, mutual-

help groups are settings that are consumer run and have values determined by their members based on experience with a shared problem. In this setting, definitions of recovery are based on members' experiences with recovery, not on what professionals think recovery should be.

There are several ways that mutual-help groups help to promote recovery. One way is through redefining the problem as less deviant and therefore less stigmatizing (Steinman & Traunstein, 1976). It has been suggested that, mutual-help groups facilitate this by functioning as narrative communities. (Cain, 1991; Humphreys, 1993; Rappaport, 1993; Rappaport & Simkins, 1991; Roberts, Salem, Rappaport, Toro, Luke, & Seidman, 1999). When individuals adopt a community's narrative as their own, this alters their personal narrative and problem definition. Cain (1991) showed that over time members of AA altered the story of their alcoholism until it more closely reflected that of AA's community narrative which is essential for achieving success and recovery through the AA program. Rappaport and Simkins (1991) examined the role of community narratives (i.e. telling and retelling of shared stories) in healing and empowering individuals within a religious setting and Deegan (1988) notes that the emphasis of community narratives found in most religious settings on each person's value and the acceptance of responsibility is especially important in promoting recovery. Slack (1995) discusses how listening to stories of pain, suffering, courage and recovery, and the process of articulating and making sense of your own story within this context of sharing, is necessary for recovery. Conceptualizing mutual-help settings as normative narrative communities helps to provide a framework for understanding how these settings can promote the process of recovery by helping people to redefine themselves and understand

their illness.

A second way that participating in mutual-help groups can promote recovery is by providing individuals with schizophrenia opportunities to engage in valued activities and social roles that may not be available in other spheres of their life (Levine, 1988; Reissman, 1965). For example, mutual-help settings provide the opportunity to give and receive social support (Roberts, Luke, Rappaport, Seidman, Toro, & Reischl, 1991; Roberts et al., 1999). This is especially important for individuals with schizophrenia who are often only on the receiving end of help and support, which is a less valued role in American culture than being the provider of help and support (Maton, 1988).

A third way that mutual-help groups promote recovery is by instilling hope. Hope has been identified as one of the cornerstones of recovery (Deegan, 1988) and is often acquired by having other people believe in you when you do not (Spaniol & Koehler, 1998) or by being exposed to role models who are working on recovery and successfully coping with their illness (Deegan, 1993; Leete, 1987). Powell's (1975) conceptualization of mutual-help groups as referent groups provides some insight into how these groups may foster hope. One of the six change mechanisms identified by Powell (1975) is the provision of role models who have overcome their problems, but who have also been there. Role models who share stories of struggle and recovery can be inspiring and motivating, as well as instructive (Deegan, 1988; Slack, 1995).

A fourth way that mutual-help groups can help facilitate recovery is by combating feelings of social isolation, loneliness, and alienation, which result from the social marginalization of individuals with schizophrenia. It has been demonstrated that mutual-help groups provide members with a network of relationships and social support

(Humphreys, 1997; Maton, 1988; Rappaport, Seidman, Toro, MacFadden, Reischl, Roberts, Salem, Stein, & Zimmerman, 1985; Roberts et al, 1999). The importance of having people to talk to is emphasized by Slack (1995) who describes how the simple act of talking and listening helped him to reconnect with people after years of being socially isolated. Providing social support and opportunities to make friends and connections with other people is an important aspect of mutual-help groups, especially for those persons who are socially marginalized.

Summary of the Role of Mutual-Help Settings in Recovery.

Steinman and Traunstein (1976) argue that one of the most fundamental aspects of mutual-help is that stigmatized individuals come to perceive and define their problem differently than the rest of society. Mutual-help organizations can be conceptualized as normative narrative communities that provide an alternate understanding of recovery (Cain, 1991; Humphreys, 1993; Rappaport, 1993; Rappaport & Simkins, 1991) by offering specific ideologies about the problem and its solution (Antze, 1965). Specifically, mutual-help groups promote the possibility of recovery from schizophrenia by espousing a community narrative that includes the possibility of recovery and conveying hope by providing role models and examples of people at all different stages of recovery. Most importantly, mutual-help organizations provide a new definition of recovery, based on the experiential expertise (Borkman, 1991) of individuals with mental illness acquired through their experiences with recovery, which may not be available in other types of settings.

CONTRIBUTIONS OF THE STUDY

This study was undertaken because the process of recovery is clearly important and salient in the lives of consumers, survivors, and ex-patients (Deegan, 1988; 1993; Houghton, 1982; Lally, 1989; Leete, 1987; 1989; Lovejoy, 1984; Payne, 1992; Unizicker, 1989). However, there have been few empirical studies that explore the process of recovery from the perspective of the person who has schizophrenia (e.g., Corin & Lauzon, 1994; Davidson & Strauss, 1992; Purdie & McLennan, 1993). In many of the studies that do engage persons with schizophrenia in describing their experiences of recovery, the researcher or professional (rather than the person with schizophrenia) defines what it means to be recovered or in recovery (e.g. Sullivan, 1994). This entails making a judgement about what recovery means for the person and does not take into account their individual values, needs, or expectations for their own life, or their role in their own recovery. Conventional approaches to researching mental illness and recovery treat the person with mental illness as a passive participant, to be investigated and acted upon by others, providing additional experiences of powerlessness and loss, which are too commonly experienced by individuals with a mental illness (Davidson, Stayner, Lambert, Smith, & Sledge, 1997; Estroff, 1989). This study systematically explores the process of recovery, from the perspective of the individual experiencing it, by allowing individuals to tell their own story using their own words. A mutual-help organization that facilitates consumer definitions and understandings of the recovery process provides an ideal context for exploring what recovery from schizophrenia means to individuals who are struggling with this illness.

Research Questions

This study addresses the following research questions to enhance our understanding of what recovery means to individuals who have schizophrenia.

1. What are the important elements of recovery from schizophrenia by participants in Schizophrenics Anonymous, a mutual-help organization?
2. What are participants' personal stories of mental illness (personal narratives) and recovery how are these experienced over time?

It is important to address these questions, because until recently recovery was defined solely by professionals, researchers, and policy makers who had no direct experience with either schizophrenia or recovery. As a consequence, recovery was often defined as an outcome or set of outcomes that were based on the medical model (i.e. symptom remission) or based on the values of those who were doing the defining with little consideration for the individual's life context or other aspects of their self not captured under the medical model. As mental health consumers and survivors have gained a greater voice in services, research, and mental health policy it has become apparent that their understanding of recovery is different from how recovery has been traditionally understood and measured. Therefore, it is important to empirically explore what recovery means to individuals diagnosed with schizophrenia in order to include their understanding of recovery in services, research, and mental health policy.

The first research question asks what are the elements of recovery as defined by those who are experiencing it. It attempts to capture how SA participants, individuals with schizophrenia, describe recovery in their own lives, without being restricted by traditional definitions of recovery (e.g., remission of symptoms). However, while simultaneously reading the recovery literature and conducting the interviews, it became

apparent that recovery consists of more than just independent components, but is instead a longitudinal process carried out in the context of individual lives. Therefore in order to capture this more dynamic quality of recovery, research question two was developed. The second research question attempts to understand how individuals move through the recovery process over time

METHODS

Study Design

Theoretical Framework

This study explores the process of recovery from schizophrenia in a mutual-help organization using an interpretive framework. An interpretive framework emphasizes the exploration of first-person subjective experiences with the goal of discovering the meaning of a phenomenon (i.e. recovery) or experience within a particular social context (i.e. Schizophrenics Anonymous) (Holstein & Gubrium, 1995; Schwandt, 1994). An interpretive approach attempts to understand the intended meaning of a text, in the author's own terms, by making a creative connection between the text and the interpreter's own experiences and context, while assuming that the values, biases, and assumptions of the interpreter are an inescapable and undeniable aspect of the process of interpretation (Tappan, 1997).

Deciding to study recovery as the phenomenon of interest and the manner in which the subsequent analysis was carried out was influenced by my own values, biases, and assumptions. My values, biases, and assumptions have been formed through years of studying and reading about serious mental illness, involvement with the SA organization and a number of different community based mental health organizations, and my role as a

sibling of someone with schizophrenia.

Reading the literature and studying mental illness helped shaped the way I understood the text of the interviews and is one of the factors that influenced my interpretation of the data. The idea to study recovery was something that emerged as I listened to SA participants tell their stories during the interviews. In their stories, I began to recognize some of the same themes or ideas that were discussed in the literature, especially in the personal narratives of mental health consumers and survivors. This iterative process of moving back and forth between what I was hearing in the interviews and what I was reading in the literature continued throughout the interviewing period and early analysis of the data. So, even though SA participants did not necessarily identify what they were talking about as recovery, I recognized the similarities between what they were talking about and what mental health consumers and survivors and others interested in the phenomenon of recovery had discussed in personal narratives and theoretical discussions of recovery. This process of using the literature based in the experience of mental health consumers and survivors to impose meaning on the interview text is not incompatible with the interpretive framework, because the interpretive approach accepts the interpreters own knowledge, values, or biases as inevitable

A second factor that influenced my thinking about recovery and schizophrenia is my involvement with the SA organization. At the time I started data analysis for this project, I had been involved with the SA organization for approximately 3 years. By this time, I was very familiar with the 6 steps of recovery and the organization's philosophy of self help and peer support. My involvement with the organization, including: attendance at numerous organizational meetings and conferences; conducting formal

interviews; and engaging in informal conversations all helped to inform my understanding of what recovery means to SA as an organization as well as to individual members. This understanding helped me to identify themes of recovery that were not explicitly labeled as such by participants.

A third factor that influencing my biases, values, and assumptions around schizophrenia and recovery is my involvement with a number of community based mental health organizations. The organizations that I have been involved with hold a diverse set of beliefs about both the cause and treatment of mental illness and are dominated by different groups of stakeholders. I have been involved with NAMI (National Alliance for the Mentally Ill), an advocacy organization consisting primarily of parents and relatives of individuals with mental illness, for approximately 6 years. NAMI's ideology is grounded in the medical model, which shapes the organizations views of etiology and treatment of mental illness and is one of the driving forces for medicalizing mental illness. I have also been involved with IAPSRs (International Association for Psychosocial Rehabilitation Services), a professional organization interested in developing and supporting psychosocial services for people with mental illness. This organization is less oriented towards the medical model and advocates for more psychosocial approaches to treatment and recovery. I have also been involved with a few peer-run organizations, which hold a wide spectrum of beliefs about the etiology and treatment of mental illness, but which in general believe in the value of peer support and involvement in the mental health system. My own beliefs and assumptions about schizophrenia and recovery acknowledge and respect the multiple realities inherent in any complex problem or issue and reflect more of a synthesis of these different ideologies

than an adherence to one single belief system.

A final factor that has influenced my values, beliefs, and assumptions around mental illness and recovery is my experience as the sister of a person diagnosed with schizophrenia. The experience of having a sibling diagnosed with schizophrenia humanized mental illness for me before I began to explore it intellectually. It forced me to see each person diagnosed with mental illness as not just a diagnosis, but as a person who has relationships with family and others and who desires to get better no matter what it looks like from the outside. It has reminded me to see each person in their entirety and to treat everyone, especially mental health consumers and survivors, with respect and dignity.

All of these experiences have shaped the way that I approach my work and my understanding of the phenomenon of recovery from schizophrenia. Reading the literature and studying mental illness over the years has led me to believe that recovery is possible for all people diagnosed with mental illness and that it is essential to include the perspective of mental health consumers and survivors in any dialogue concerning mental health issues. My involvement with SA has convinced me of the value of peer-led organizations and of expertise acquired through lived experience. My involvement in numerous community based mental health organizations has reinforced the notion that there is not one truth or one way to approach a problem, but multiple perspectives, each with its own contribution to make. My role as a sibling has taught me to approach my work with compassion and to appreciate the small steps that people take to help themselves. An interpretive framework encourages researchers to acknowledge their assumptions, values, and biases in order to make visible the filter through which

interpretations are made.

Within the interpretive framework, a phenomenological interview approach, which is primarily concerned with how individuals construct and assign meaning to their experience and the phenomenon of interest (Bogdan & Bilken, 1992) with the recognition that all knowledge is situated in a local culture and embedded within a specific setting (Holstein & Gubrium, 1995), is used. This approach was chosen because it represents a commitment to the description and understanding of subjective experience through first-person accounts and descriptions of actual experience (Davidson, 1994; Evered & Louis, 1981), which is compatible with the interpretive framework described above. This allows recovery to be understood within the context of the lives of the individuals with schizophrenia and the social context of a mutual-help group.

By allowing individuals to describe their own recovery, they are viewed as the expert in this process and not acted upon as a passive object of investigation, which undermines the process of recovery (Davidson et al., 1997; Estroff, 1989). An interpretive framework and a phenomenological approach are used for this study, because the assumptions and goals of these approaches are compatible with the purpose of this study and with my own values, assumptions, and biases.

Use of Qualitative Methods

An interpretive, phenomenological approach to inquiry requires the use of methods that are consistent with the goals of rich description, understanding, and meaning. In general, the use of an inductive qualitative approach is the most suitable for exploring the type of questions addressed in this study, which focus on understanding the meaning and process of recovery within a specific context (Bogdan & Bilken, 1992;

Maxwell, 1996). Merriam (1988) agrees that the focus of qualitative research should be on process and states that “the interest [in a qualitative study] is in process rather than outcome” (p. xii). One of the key arguments for exploring recovery from the perspective of individuals with schizophrenia is to try and understand the process, which has been neglected in the traditional study of recovery.

Researchers studying schizophrenia and mutual-help settings have become more aware of the need to use other methods of inquiry in order to understand the meaning that individuals attach to their experience, as well as to recognize the expertise and skills that they have acquired from their experience (e.g., Davidson & Strauss, 1995; Davidson et al., 1997; Hatfield & Lefley, 1993). The use of qualitative methods, and specifically open-ended interviews, has been suggested in order to understand the role of individuals in their own recovery process and to respect their role in defining and engaging in their own recovery process (Davidson & Strauss, 1995; Davidson et al., 1997). Hatfield and Lefley (1993) suggest the use of qualitative methods in order to recognize the individual with schizophrenia as the expert on their own process of recovery, which is compatible with the belief that individuals are the experts on their own life (Kearney, Murphy & Rosenbaum; 1994; Kerruish, 1995). It has also been suggested that qualitative methods are best suited to explore certain processes in mutual-help settings (Tebes and Kraemer, 1991), perhaps because they are better suited for exploring processes than quantitative modes of inquiry (Bogdan & Bilken, 1992; Maxwell, 1996; Merriam, 1988).

Therefore, to address the research questions stated above, recovery is explored through qualitative, open-ended interviews conducted in such a way as to elicit the person’s story of their mental illness, their recovery, and their experience in

Schizophrenics Anonymous.

Setting Description

Schizophrenics Anonymous (SA) is a self-help (mutual-help) organization for persons with schizophrenia and related illnesses that was founded in the Detroit area in 1985 by a woman with schizophrenia. The organization's format and ideology resembles that of Alcoholics Anonymous in that there are weekly meetings for members, steps for recovery, a program philosophy, and mutual support between meetings (P., John, 1997). Also, similar to AA, SA does not engage in advocacy for individuals with mental illness or allow the name of the organization to be used to endorse political causes.

The SA program, as indicated in their mission statement, promotes recovery through the use of a six-step program and a variety of other guiding principles. SA's official mission statement consists of five goals:

1. To help restore dignity and sense of purpose for persons who are working for recovery from schizophrenia or related disorders.
2. To offer fellowship, positive support, and companionship in order to achieve good mental health.
3. To improve our attitudes about our lives and our illness.
4. To provide members with the latest information regarding schizophrenia.
5. To encourage members to take positive steps leading to recovery from the illness.

The mission statement provides a set of values or goals that help form the foundation of the SA community narrative. The 6 steps of recovery (Mental Health Association of Michigan, 1992) provide tools for members to work on recovery and they include:

1. I surrender...I admit I need help. I can't do it alone.
2. I choose...I choose to be well. I take full responsibility for my choices and realize that the choices I make directly influence the quality of my days.
3. I believe...I now come to believe that I have great inner resources and I will try to use these resources to help myself and others.
4. I forgive...I forgive myself for all the mistakes I have made. I also forgive and release everyone who has injured or harmed me in any way.
5. I understand...I now realize that erroneous, self-defeating thinking contributes to my problems, unhappiness, failures, and fears. I am ready to have my belief system altered so my life can be transformed.
6. I decide...I make a decision to turn my life over to the care of God, as I understand Him, surrendering my will and false beliefs. I ask to be changed in depth.

One difference between SA and other twelve-step groups is that there is a greater flexibility in working the steps. For instance, there is no expectation that members will work the steps sequentially or that they will even be addressed or used at all by some groups (Walsh, 1994). Another difference is that religious discussions are not encouraged, except in the broad sense of spirituality. SA members are encouraged to recognize their spirituality as it pertains to finding meaning or a higher purpose in their lives, but not to promote a specific religion or religious identity. Also, the SA group philosophy focuses on cooperation with mental health professionals. SA views itself as an adjunct to treatment, rather than as an alternative or replacement for professional services. The SA philosophy emphasizes that all individuals can engage in the process of recovery regardless of symptom severity or other circumstances. This belief is compatible with the broader self-help principle that everyone has a right to recovery (Frese & Walker-Davis, 1997; Walker-Davis, 1995). In addition to providing the

foundation and tools for recovery (e.g., 6 steps for recovery), SA has also been described as providing a home for individuals with schizophrenia and a setting in which to receive peer support and acceptance (P., John, 1997). For individuals who are often socially isolated, this may be an invaluable benefit of participating in SA.

Each SA group meets at a set time and place (typically weekly), and is headed by a SA leader and in some cases also a co-leader. SA leaders are, in most cases, members of SA who have schizophrenia and who take primary responsibility for leading the group. Although the SA program has a suggested format for running the groups, there is flexibility in how this format is implemented, which results in a lot of variation between groups. Groups vary considerably with regard to attendance, leader experience, use of the program and literature, and social context or group setting (i.e. churches, community mental health centers, or a local Big Boy restaurant). These variations of group format may also affect the narrative that develops in a specific group.

Project Description and Procedures

This study is part of a larger evaluation study of SA, which did not have describing recovery as its' explicit purpose. However, during the process of conducting the interviews for the larger study, recovery emerged as a salient experience embedded in the participants' stories of their involvement in SA and the stories of their experiences of mental illness. I identified these themes as being descriptive of recovery because at the time I was conducting the interviews I was also reading a compendium of personal narratives written by persons diagnosed with mental illness as well literature grounded in the principles of psychosocial rehabilitation. Also, one of the express purposes of SA is to promote recovery. So, although recovery was not specifically asked about in the

interviews, these themes did emerge and the conceptualization of them as recovery stemmed from my knowledge of the interviews and the mission and purpose of SA and how recovery was being described in personal narratives and the psychosocial rehabilitation literature. However, because this study did not have understanding recovery as its' explicit purpose, a count of the cases that included recovery themes was conducted to ensure that themes of recovery occurred across cases (e.g., Kearney, et al., 1994).

Prior to doing the preliminary analysis, a list of possible recovery themes was developed based on the characteristics of recovery discussed in personal narratives written by individuals with mental illness and on the limited empirical research on the process of recovery (see Appendix D, p. 221-223, for the list of recovery themes). This list was also expanded to include aspects of recovery not previously identified, but which emerged from the interviews. Using the themes identified as described above, a preliminary analysis of all 46 interviews was undertaken to provide evidence of how recovery emerges in the interviews. First, a count of the number of cases (interviews) that had one or more recovery themes emerge was conducted. This preliminary analysis revealed 12 interviews that did not contain a single recovery theme as defined by the preliminary themes and subthemes found in Appendix D (refer to Appendix D, p. 221-223, for the themes and subthemes). Second, specific examples of the themes of recovery were identified (refer to Appendix E, p. 224-230, for these examples and for a summary of these findings). So, although the larger evaluation study did not explicitly address recovery, there was evidence that the experience of recovery is an important component of many of the participants' experiences and stories.

This study is based on two activities which were carried out within the context of the larger study: (1) semi-structured in-depth interviews with members and leaders of Schizophrenics Anonymous; and (2) exploration of SA's written materials. The focus of this study is on the data collected from the semi-structured interview, because the study's goal is to provide description and understanding of the process of recovery from the individual's perspective. Exploration of SA's written materials provides a way to understand how SA's teachings and philosophy influence the experience and understanding of recovery throughout the analysis and interpretation of the data.

Although the procedures and measures used in this study are identical to those approved by the Michigan State University Committee on Human Subjects Research (UCRHIS) for use in the larger evaluation study, a separate UCHRIS application was submitted and subsequently approved for this study.

Group Consent Procedures

To establish contact with prospective groups and interviewees, the SA expansion coordinator (an employee of the Mental Health Association of Michigan), sent a letter to all SA group leaders in Michigan describing the study and asking the leader to inform the expansion coordinator if he or she did not want to be contacted by the research team to be invited to have the group participate in the study. The leaders discussed it with the group and if the group was interested, a visit was scheduled. At this point in the process, no groups declined to be contacted so all groups were called by a member of the research team, invited to participate in the study, and to schedule a time for a research team member to visit. A member of the research team visited the group, administered a survey and informed the group about possible future opportunities to take part in an interview. If

the group expressed interest in participating in the interview phase of the study, the group was put on a list to contact in the future to participate in the interview phase of the study.

Group Sample

At the time the interviews were conducted there were 26 active SA groups in Michigan. After 12 groups were eliminated due to lack of current attendance (N=3), driving distance (N=1), lack of use of SA program or principles and large size (N=1), and groups' location in inpatient hospital or prison settings (N=5), a total of 14 groups were selected to participate in the study (please refer to Table 2, p. 335). Two of the eligible 14 groups declined to participate, for a group response rate of 86% (12/14).

Interview Consent Procedures

The leaders of each of the 12 SA groups were phoned and informed about the overall purpose of the study. They were asked whether they felt their group would be interested in participating. They were then asked to get permission from the group members for one of the research team members to visit the group to discuss the study and specifically the interview process. A member of the research team visited each group, explained the study and the interview process, and invited members to fill out a "Consent to Contact Form" (see Appendix A, p. 178-185) if they were interested in participating.

At the time the group was visited, a member of the research team asked the leader(s) to estimate the total number of current group members if it was different from who was volunteering to participate in the study. Based on the aggregated estimates of the total number of current group members given by leaders at the time the interviews took place, 72% (69/96) of the SA members volunteered to participate in the study. Members were told during this visit that they would receive ten dollars to participate in

the one to two-hour interview and that the interview could be conducted at a place of their choosing. The “Consent to Contact Form” provided information on how to get in touch with the individual, as well as information about their role and involvement with the SA organization (see Appendix A, p. 178-185).

In addition to completing the “Consent to Contact Form,” if the participant took part in the interview they were required to sign one of three different consent forms, depending on their role within the organization (see Appendix A, p. 178-185). This formal consent form was signed by the participant prior to beginning the interview, but after the participant had a chance to read it and after the interviewer reviewed the important elements of anonymity, confidentiality, voluntary participation, and risks of participation. Before the interview commenced, the participant was reminded that at any time during the interview they could refuse to answer specific questions or to discontinue participation in the study.

Interview Sample

Not all SA members who volunteered to participate (N=69) in the interviews were selected due to limited resources and the in-depth nature of the interview. The participants were purposively selected on dimensions that the research team felt could influence the participant’s experience of being a member of a SA group (Berg, 1995; Miles & Huberman, 1994).

The three selection criteria are examined in terms of their relationship to recovery in the following ways. First, participants were selected according to how long they had been involved in the SA group they were attending at the time data collection took place. Those who have been involved in the group longer could have more exposure to the

group's values and philosophy, which promote change and beliefs about recovery. Second, participants were selected according to the different roles that they occupy within their groups or within the larger SA organization (i.e. member or leader). Different roles within the group or organization promote different competencies and opportunities for redefining one's sense of self through participation in social roles. Sense of self, feelings of competence, and participation in social roles are all discussed as important aspects of recovery by individuals with mental illness. Finally, participants were selected according to their group membership. Groups vary in their use of the SA program, the availability of role models, and mechanisms for sharing stories, which may influence the experience of recovery. All three of the criteria used to purposively select participants for the original study can be viewed as potentially impacting the experience of recovery.

Specifically, the criteria that participants were selected on include: (a) length of participation (1=involved with SA 2-6 months, 2=involved with SA for over 6 months up to 2 years; 3=involved with SA for over 2 years); (b) role within the group or organization (1=member, 2=group leader, or 3=organizational leader defined as an individual who is involved in the SA organization in addition to, or instead of running a group); and (c) Schizophrenics Anonymous group membership (12 groups are represented in the final sample). All group and organizational leaders were interviewed, but because of the large number of possible participants who were members, one SA group member was randomly selected from each of the 3 "length of participation" categories. This allowed for the selection of only 3 members from each SA group while maintaining the credibility of the sample (Miles & Huberman, 1994) and ensuring that

each “length of participation” category was adequately represented in the final sample. For example, in group two, of the members who volunteered to participate there were 3 members who had been members of the group for over 2 years, 2 members who had been members of the group for between 6 months to 2 years, and 2 members who had been members for between 2 to 6 months. Because it was not practical to include all members of a particular group, one member was randomly selected from the members involved for more than 2 years, one member was randomly selected from the members involved for between 6 months and 2 years, and one member was randomly selected from members involved for between 2 to 6 months. Ideally, this sampling procedure would result in 3 members being sampled from each group. However, in some instances there were not members in all categories or only one or two members attending a specific group during the time that the interviews took place. In these cases, all members were selected for participation regardless of length of involvement. In addition, all members from two groups that had just recently started at the time of the interviews were included in the interviews in order to follow them longitudinally as case studies of group development for the larger evaluation study.

The final sample selected for participation consisted of all organizational leaders and/or group leaders of active SA groups in Michigan (N=19), and a random selection of members based on the sampling criteria discussed above (N=30). Initially, all of the group and/or organizational leaders agreed to participate, but two group leaders (from the same group) subsequently refused participation, resulting in a final response rate for organizational and group leaders of 89% (17/19). In addition, 1 member was hospitalized before the interview could commence, for a member response rate of 97% (29/30). The

overall response rate for group leaders, organizational leaders, and members was 94% (46/49) (see Table 1, p. 333-334, for a complete description of the final sample).

Semi-Structured, In-Depth Interviews

The interviews were conducted with an emphasis on allowing individuals to tell their story within a semi-structured format in order to ensure that certain aspects of their experiences were covered that were important for the larger evaluation study. The interview protocol (see Appendix B, p. 186-209) consists of four sections: (1) the participant's story about their involvement in Schizophrenics Anonymous; (2) the participant's story of their mental illness; (3) questions concerning interpersonal relationships and social support; and (4) demographic information and mental health service utilization. Each section of the interview consisted of a number of questions with the most open-ended question starting the section, except in the case of section (4), which consisted of mostly closed ended demographic questions. Each question also had a list of pre-determined probes, which were used if the participant did not touch on certain aspects of their experience within their story. However, the interviewers were not restricted to the predetermined probes and were allowed to develop their own probes based on the content and flow of the particular interview.

The interview began by asking the participant to tell the story of their involvement in SA. This question was followed by more specific questions about their involvement with SA, which were only asked if they were not brought up in the participant's story. The second section began by asking the participant to tell their story of their mental illness. Again, this question was followed by a series of more specific questions that were asked if they did not emerge from the participant's story. The third section

consisted of both open-ended questions about social support and forced response questions asking about the participant's satisfaction with relationships and social support. The last section focused on eliciting demographic and mental health service utilization data. Most of the questions in this section entailed one or two word responses or provided multiple response options from which the participant was asked to choose.

All the interviews were conducted in settings of the participants' choice, which included: individuals' homes, restaurants, mental health agencies, or other community settings (e.g., library). Interviewers took notes on the content of the interviews, as well as questions that arose during the interview. As participants addressed specific questions or probes they were checked off on the interview protocol to verify that they had been covered and would not need to be addressed again. In addition, all sections of the interviews were audio taped except for the demographics section. This allowed the interviewers to pursue meaning by asking the participants for examples of what they were describing or by asking additional questions (Fontana & Frey, 1994) to ensure that the interviewer and participant shared a common understanding of the phenomenon.

The interviews varied in length, with the shortest interview tape lasting 45 minutes and the longest interview tape lasting 6 hours. Often longer interviews were conducted in more than one session depending on the participant's preference and two to three sessions were needed to complete an interview on many occasions. Only one participant, after completing half of the interview, chose not to complete the interview when the interviewer tried to schedule a second session, due to reasons not disclosed to the interviewer.

After each interview was completed it was transcribed verbatim by a professional

transcriber, and then checked for accuracy by listening to the entire interview tape and comparing the transcribed text with the spoken words. During this process all identifying information was removed from the transcribed document to maintain the anonymity and confidentiality of the participants.

The interviews were conducted by myself, and another graduate research assistant, both who had been working on the larger evaluation study for at least one year.

Exploration of SA's Written Materials and Exploring Variation Across Groups

The second activity of this study involved the exploration of SA's program materials and literature. These materials were developed in 1987 and continue to be revised and expanded to reflect the organization's purpose, goals, and beliefs about recovery. They also provide a description of the structure and format used in conducting SA groups. These program materials were used to arrive at an understanding of how the SA organization formally describes and understands the process of recovery and how the group structure and format are used to facilitate this process. However, it is important to note that individual groups vary in the extent to which they use the literature and incorporate the organizations belief system or community narrative into their group. This could influence how and to what extent particular groups influence participants' experiences of the recovery process.

Interpretation and Analysis Methods

Because I conducted this study after I was familiar with the data, I had some ideas about what would emerge from the analysis. Not only had I conducted the majority of the interviews, but I had spent time listening to the interviews, discussing the interview content with other research team members, and checking the interviews for accuracy. So,

prior to even beginning the analysis I had started to develop a framework for interpretation, which included that recovery is an on-going process that consists of some phases. In order to confirm this initial understanding of the data, I undertook the rigorous analysis as described below.

In a qualitative study, the purpose of activities during the stages of analysis and interpretation are to explore and understand the data collected (Miles & Huberman, 1994). In this study, the aim of the analysis is to describe and understand the process of recovery from the perspective of individuals with schizophrenia within a mutual-help setting, through the analysis of interviews and program literature. An inductive thematic content analysis was used as the primary analysis tool to explore and understand the data. The first-order analysis involved the following steps in the order presented: (a) reduction of the empirical materials; (b) cross-case analysis; and (c) within-case analysis. The second-order analysis involved a more iterative process between the cross and within-case analysis, which will be described in greater detail in the following sections.

Data Reduction

This task involved condensing the interview transcripts and program documents into a manageable and meaningful format. Miles and Huberman (1994) describe this process as "...selecting, focusing, simplifying, abstracting, and transforming the data that appear in written-up field notes or transcriptions...a form of analysis that sharpens, sorts, focuses, discards, and organizes data in such a way that 'final' conclusions can be drawn and verified" (p. 11).

The interview transcripts, after being transcribed verbatim and checked for accuracy, were formatted and sorted to facilitate data analysis. Each interview was

formatted by identifying questions that were listed on the interview protocol and asked in the interview with the question number listed on the interview protocol. The interviewers questions, probes, and utterances were also converted into all capital letters so that they could be distinguished from the interviewees responses. Then the interviews were saved as text-only documents and imported into NU*DIST, a computer software package for qualitative research, which facilitates data management, data reduction, and thematic content analysis. After the documents were imported into NU*DIST, the documents were sorted by question so that all responses to a specific question could be read and analyzed simultaneously, which helped to facilitate the cross-case analysis. Each document was also preserved in its entirety for use in the within-case analysis.

In general, the guidelines of Miles and Huberman (1994) were followed in the development of the analysis strategy. During the first-order analysis, a cross-case analysis was used to explore the first research question and a within-case analysis was used to explore the second research question.

Cross-Case Level Analysis

After reducing the data, a cross-case analysis was used to explore themes of recovery across individual cases (Miles & Huberman, 1994). The purpose of this strategy is to identify themes of recovery that are common across cases and to code each case using these themes.

Research Question #1: How do people with schizophrenia, in Schizophrenics Anonymous, a mutual-help organization, experience and describe recovery? All interview transcripts were read to identify themes and create an emergent-coding frame around recovery. A constant comparative method, as described by Lincoln & Guba

(1985), and based on the work of Glaser & Strauss (1967), was used to arrive at the themes and patterns. This involves “categorizing” or bringing together information units that look alike or feel alike in content until each unit of information has been examined and put with other units of information that are similar. When a significant number of units of information were assigned to a group, Lincoln and Guba (1985) suggest 6 to 8, then a memo was written to explicate the properties of the category based on the characteristics of the units of information contained in the group. A name was then assigned to the category that captured the essence of the properties or rules defining the category. All subsequent units of information were then excluded or included in the category based on their fit with the rules and properties of the category.

As the coding categories were developed, an iterative process was used to move back and forth between the interview transcripts and the coding categories. Each time a theme was revised or a new theme added coding was started at the beginning of the first document. This was done until the themes became discrete and consistent in meaning. Eventually a framework emerged that consisted of 22 themes, 9 meta-themes, and 4 phases, which will be discussed in detail in the results section.

Within Case Level Analysis

After the cross-case analysis was completed, the within-case analysis was undertaken in order to address the second research question. A within case analysis was used to maintain the coherence of the individual’s story (Mishler, 1986) so that recovery could be explored as a longitudinal and contextual process, while developing a more integrated, longitudinal, and holistic view of the individual that may be absent when performing only a cross-case analysis. This is important because one of the factors that is

discussed as important in facilitating recovery is viewing individuals holistically in order to better understand their unique life contexts (Davidson & Strauss, 1992; Deegan, 1988). The initial purpose of undertaking a within-case analysis was to address research question two by creating a coherent narrative and then exploring how participants' stories of their mental illness and recovery develop over time. However, after completing the cross-case analysis the focus of the within-case analysis shifted to examine how participants move through the four phases of recovery, which were identified in the cross-case analysis.

Research Question #2: Based on the findings of the cross-case analysis, the second research question was refined to address the question of whether and how participants described movement through the identified phases of recovery. First, all interviews were read for completeness and detail. In reading the individual interviews, it became apparent that the individual stories varied in quality. The quality of stories varied in the amount of detail provided, the degree to which events were linked over time, and the overall coherence. For some participants, this was clearly the first time they had ever been asked questions of this nature and they had not had time to reflect on or develop a complete and coherent story. For other participants it seemed that their experience of symptoms interfered with their ability to convey a complete and coherent story. Because of the varied quality of the stories, case summaries or narratives were only written for those interviews that contained enough detail and sequencing of events to create a meaningful summary. This resulted in writing case summaries for 30 stories and not writing summaries for 16.

The case summaries or narratives were written to reveal important themes about each person's experience with mental illness and recovery (Miles & Huberman, 1994).

The case summaries included background characteristics and life events or feelings that emerged as important in the individual's story, and which may be linked to the process of recovery. Specifically, information was included that would facilitate addressing the second research question, which asked how participants move through the four phases of recovery. To address this question, each case summary included: (1) background information on the participant, including their participation in SA, mental health history, and basic demographics; (2) how they described their own recovery process, including the themes identified in the cross-case analysis if they were present and other characteristics of recovery they identified (e.g., "it took a long time" or "it is unique to each individual"); and (3) what contextual factors they described as important to their recovery process. After creating these 30 case summaries, the case summaries and in some cases the original interviews were re-analyzed to identify which participants or case summaries identified being in the fourth phase of recovery (as identified in the cross-case analysis) at some time in the course of their story of mental illness and recovery. Fifteen participants were identified as meeting this criterion and were subsequently chosen for inclusion in the within-case analysis, because it was felt that they could best represent the nature of the recovery process over time. The case summaries were then used to look across cases to see if there were commonalities in the way participants moved through the recovery process as reflected in the 15 individual case summaries.

Although the cross and within-case analysis strategies are presented separately, in fact they were carried out in a more iterative process. For example, first the content analysis for the cross-case analysis was carried out to identify recovery themes and meta-themes. Next, the within-case analysis was conducted looking for, among other things,

the recovery themes identified in the cross-case analysis. Then, the within-case analysis was used to understand how the themes and meta-themes of recovery should be organized, which resulted in organizing the meta-themes around 4 phases of recovery. Finally, after the 4 phases of recovery were identified, they were used to select which case summaries would be included in the final within-case analysis. Therefore, the cross and within-case analyses were not independent, but were instead used to inform each other during various stages of analysis and interpretation.

RESULTS AND DISCUSSION

First, I present demographic information, including reported satisfaction with specific life domains, on all participants. Second, I provide a comparison between the cases used in the within-case analysis (N=15) and cases excluded from the within-case analysis (N=31). These groups are compared on demographic characteristics, the sampling criteria used to stratify the original sample (i.e. length of participation in SA, role in group – member or leader, and group membership), and reported satisfaction with specific life domains. This comparison helps address whether or not the group and member characteristics used to stratify the sample were meaningful and whether or not there were any significant differences between the 2 groups. Third, I address the first research question by presenting the results and discussion of the cross-case analysis followed by a brief summary. Fourth, I address the second research question by presenting the results and discussion of the within-case analysis followed by a brief summary. Because the presentation of qualitative data simultaneously involves both description and discussion, I present the results of both the cross-case and within-case analysis in conjunction with relevant literature and discussion to enhance the

interpretation of the results. Finally, after I present both the cross-case and within-case results, I present an implications and conclusions section.

In all cases, participants' names have been replaced by pseudonyms and other identifying information has been removed or altered to protect the identity of the participant. All verbatim quotes are referenced by an interview identification number, which appears in parentheses after the verbatim text.

Description of Participants

Table 5 on page 65-67 summarizes the demographic characteristics of all of the participants. The majority of participants (57%, $n=26$) are women and White (85%, $n=39$). Participants have an average age of 42 years old (range 22 to 74 years old; $SD=10.96$) and many (30%, $n=14$) have completed a college degree (AA, BA or graduate degree). Many of the participants at the time of data collection were not participating in socially and culturally valued roles. For example, most participants were not working (65%, $n=30$), did not have children (76%, $n=34$), and had never been married (73%, $n=33$), even though the average age of participants was 42 years old.

Although the majority of the participants (65%, $n=3$) subsisted primarily on Social Security Disability payments and only a minority (33%, $n=15$) reported being mostly or extremely happy with their current level of financial support, most (61%, $n=28$) managed to live independently in their own apartment or house, either with a roommate, intimate partner, or alone. Further, a majority of the participants (62%, $n=28$) reported being mostly or extremely happy with their current living situation, which indicates that for most participants their housing needs are being adequately addressed.

All of the participants in this study have experienced mental illness and the

subsequent treatments. The majority of participants reported a diagnosis of schizophrenia (62%, $n=26$), all reported taking medication for psychiatric reasons (100%, $n=45$), and for the 41 participants (89% of participants) who had been hospitalized for psychiatric reasons, the average number of hospitalizations was 8 (range 1 to 50; $SD=10.96$). In addition, most of the participants (81%, $n=34$) reported being mostly or extremely satisfied with their current mental health treatment.

The demographic characteristics of the participants in this study are similar to the demographic characteristics of a broader sample of SA participants that was surveyed in the Fall of 1996. One-hundred and sixty-seven SA participants (131 SA members and 36 SA leaders) from 19 of the 23 SA groups in Michigan were surveyed on a number of dimensions including demographic characteristics (A full description of the methods and sample derivation can be found in Salem, Reischl, Gallacher, and Weaver Randall, 1999). Forty percent of the SA participants surveyed were women and 69% were white. Their average age was 41 with a range from 19 to 70 years of age, which is almost identical to the current sample. Fifty-two percent had graduated from high school and an additional 29% had a college degree (AA, BA, or graduate degree), which is similar to the current participants educational background. Also similar to the current participants, the majority of the participants never married (65%), were unemployed (66%) and were receiving disability benefits (72%). However, despite their financial limitations, many of the participants (45%) lived independently in their own home or apartment. Finally, most participants were diagnosed with schizophrenia (74%) or schizo-affective disorder (13%) and almost all participants (94%) had been hospitalized for psychiatric reasons, with a mean of 6 hospitalizations. This psychiatric history mirrors the experiences of the current

participants. The slight variations in the frequencies between the two samples may be due to the slightly greater proportion of leaders in the current sample (37%) versus the surveyed sample (30%). In the surveyed sample, there were significant differences between members and leaders on a number of different dimensions including gender, educational level, and living situation. However, overall, the demographic characteristics of the two samples are very similar

The demographic characteristics of participants in this current study are also representative, in general, of people who participate in self-help groups in the United States. According to Kessler et al (1997), women are more likely than men to participate in self-help groups, married people have lower rates of participation and blacks are only half as likely as whites to participate in self-help groups overall. However, as the authors note, these results are somewhat deceptive because “they confound the demographic correlates of having problems with the demographic correlates of using self-help groups to manage these problems.” (p. 33)

Table 5

Participant Demographics

Characteristic	Category	%	<u>n</u>
Gender	Male	43.5%	20
	Female	56.5%	26
Age	Mean = 41.96 (SD = 10.96)	Range 22-74 years old	
Ethnicity	White	84.8%	39
	African American	8.7%	4
	Hispanic	4.3%	2
	Other	2.2%	1
Married	Never Married	73.3%	33
	Currently Married	8.9%	4
	Divorced or	17.8%	8
	Widowed		
Children	None	73.9%	34
	One	11.1%	5
	Two or more	11.1%	5
Education	Some High School	13.0%	6
	High School Graduate	39.1%	18
	Some College	17.4%	8
	Associates Degree	13.0%	6
	Bachelors Degree	13.0%	6
	Graduate Degree	4.3%	2
Employment	Not Employed	65.2%	30
	Competitive Employment	21.7%	10
	Transitional or Sheltered	13.0%	6
Months Since Last Worked	Mean = 95 months (SD = 89.34)	Range 1 – 336 months	
Income Sources	SSI/SSD	65.2%	30
	Earned Income	28.3%	13
	Pension/Retirement	6.5%	3
	Family Member	26.1%	12
Religion	Yes	71.7%	33
	No	28.3%	13

Housing	Independent House or Apt.	60.9%	28
	Family	17.4%	8
	Supervised Apartment	10.9%	5
	Group Home or AFC	8.7%	4
	Homeless Shelter	2.2%	1
Diagnosis	Schizophrenia	61.9%	26
	Schizo-Affective Disorder	16.7%	7
	Manic-Depression	11.9%	5
	Other	9.5%	4
Mental health services currently participate in	Individual or Group Therapy	46.7%	21
	Medication Management	56.8%	25
	Case Management	31.1%	14
	Drop-In Center or Clubhouse	37.8%	17
Satisfaction with mental health services	Extremely Satisfied	40.5%	17
	Mostly Satisfied	40.5%	17
	Somewhat Satisfied	11.9%	5
	A Little Satisfied	2.4%	1
	Not at all Satisfied	4.8%	2
Satisfaction with social support	Extremely Satisfied	22.7%	10
	Mostly Satisfied	40.9%	18
	Somewhat Satisfied	18.2%	8
	A Little Satisfied	15.9%	7
	Not at all Satisfied	2.3%	1
Satisfaction with time spent	Extremely Satisfied	13.3%	6
	Mostly Satisfied	33.3%	15
	Somewhat Satisfied	31.1%	14
	A Little Satisfied	15.6%	7
	Not at all Satisfied	6.7%	3
Satisfaction with current living situation	Extremely Satisfied	37.8%	17
	Mostly Satisfied	24.4%	11
	Somewhat Satisfied	26.7%	12
	A Little Satisfied	4.4%	2
	Not at all Satisfied	6.7%	3

Satisfaction with financial resources	Extremely Satisfied	17.8%	8
	Mostly Satisfied	15.6%	7
	Somewhat Satisfied	33.3%	15
	A Little Satisfied	15.6%	7
	Not at all Satisfied	17.8%	8

Comparison between Two Groups

Participants included in the within-case analysis were compared with participants not included in the within-case analysis on demographic characteristics, satisfaction with specific life domains, and the original sampling criteria, including characteristics of the group that is attended by the participant. Please refer to Table 6 on pages 69-73 for a complete comparison of the two groups.

Chi-Square and Independent Sample t- tests were used to test the differences between those participants included in the within-case analysis and those participants not included. There were significant differences in role and tenure in SA between participants' who were included in the within-case analysis and those who were not. Participants included in the within-case analysis were significantly more likely to be group leaders ($n=11$, 73%) than participants not included in the within-case analysis ($n=6$, 19%), $\chi^2(1, N=46) = 12.64, p=.000$. Participants included in the within-case analysis were also involved in the SA organization for a significantly longer period of time ($m=2.67$, $SD=.72$) than participants not included in the within-case analysis ($m=1.84$, $SD=.86$), $t(44) = .3213, p=.002$. There were also significant differences between the characteristics of groups attended by those included in the within-case analysis compared to those not included. Fifty-five percent ($n=5$) of participants included in the within-case analysis attended groups that were led by leaders who were trained by the original leaders compared to 16% ($n=6$) of participants not included in the within-case, $\chi^2(1, N=42) = 6.20, p=.013$.¹ Forty-six percent ($n=5$) of participants included in the

¹ In the Chi-Square analysis 1 cell had an expected count of 2.88. Because this is less than the recommended expected count of 5, the significance of this finding could be called into question. However, some authors have argued that an expected count of 5 is too stringent a criteria and that less stringent criteria may be appropriate in some circumstances.

within-case analysis attended groups that were held in community settings compared to 13% ($n=4$) of those not included in the within-case analysis, $\chi^2 (1, N = 42) = 5.110$, $p=.024^2$. Participants in the within-case analysis were also significantly more satisfied with their mental health services ($\underline{m} = 4.571$, $SD = .514$) than participants not included in the within-case analysis ($\underline{m} = 3.857$, $SD = 1.15$), $t (40) = 2.214$, $p=.033$.

² 1 cell has an expected count of 2.36, which is less than the recommended expected count of 5. See footnote 1 for an explanation of the implications of this low expected count.

Table 6

Comparison between Cases Included and Not Included in Within-Case Analysis

Characteristi	Category	Cases Included in Within Case <u>n</u> (%) or <u>m</u> (mean)	Cases Not Included in Within Case <u>n</u> (%) or <u>m</u> (mean)	Statistical Significance χ^2 , or <u>t</u> -test
Length of Participation In SA	6 months or less = 1 6 months to 2 years = 2 More than 2 years = 3	<u>M</u> = 2.67; <u>SD</u> = .72	<u>M</u> = 1.84; <u>SD</u> = .72	<u>t</u> (44) = -.3213, <u>p</u> = .002*
Member Status	Member Leader	4 (26.7%) 11 (73.3%)	25 (80.6%) 6 (19.4%)	χ^2 (1, <u>N</u> = 46) = 12.64, <u>p</u> = .000*
Group ID	Group 01 Group 02 Group 03 Group 04 Group 05 Group 06 Group 07 Group 08 Group 09 Group 10 Group 11 Group 12 Organizational leader – not currently attending an SA group	1 (6.7%) 1 (6.7%) 2 (13.3%) 1 (6.7%) 2 (13.3%) 0 0 0 0 0 1 (6.7%) 3 (20%) 4 (26.7%)	3 (9.7%) 1 (3.2%) 2 (6.5%) 3 (9.7%) 4 (12.9%) 3 (9.7%) 3 (9.7%) 2 (6.5%) 2 (6.5%) 7 (22.6%) 1 (3.2%) 0 0	
Group Setting	Community Other (Drop-In Center, Clubhouse, CMH)	5 (45.5%) 6 (55.6%)	4 (12.9%) 27 (87.1%)	χ^2 (1, <u>N</u> = 42) = 5.110, <u>p</u> = .024**

Table 6 - continued

Group Led By Central Leader	Central Leader	6 (54.5%)	5 (16.1%)	$\chi^2 (1, N = 42) = 6.20, p=.013^{**}$
	Not Central Leader	5 (45.5%)	26 (83.9%)	
Gender	Male	4 (26.7%)	16 (51.6%)	$\chi^2 (1, N = 46) = 2.560, p=.110$
	Female	11 (73.3%)	15 (48.4%)	
Age		$\bar{M} = 42.93$ yrs ol (SD=11.07), range (22-67)	$\bar{M} = 41.48$ yrs ol (SD=11.05), range (24-74)	$t (40) = .417, p=.679$
Ethnicity	White	14 (93.3%)	25 (80.6%)	$\chi^2 (1, N = 46) = 1.261, p=.399$
	Non-White	1 (6.7%)	6 (19.4%)	
Married	Never Married, Divorce or Widowed	11 (73.4%)	28 (94.4%)	$\chi^2 (1, N = 45) = 8.780, p=.009^{**}$
	Currently Married	4 (26.7%)	2 (6.7%)	
Children	None	9 (60%)	25 (83.3%)	$\chi^2 (1, N = 45) = 2.948, p=.140$
	One or more children	6 (40.0%)	5 (16.7%)	
Education	Some High School	0	6 (19.4%)	
	High School Graduate	4 (26.7%)	14 (45.2%)	
	Some College	2 (13.3%)	6 (19.4%)	
	Associates Degree	4 (26.7%)	2 (6.5%)	
	Bachelors Degree	3 (20.0%)	3 (9.7%)	
	Graduate Degree	2 (13.3%)	0	
Employed	Not Employed	7 (46.7%)	23 (74.2%)	$\chi^2 (1, N = 46) = 3.377, p=.066$
	Employed	8 (53.3%)	8 (25.8%)	
Months Since Last Worked				$t (28) = .510, p=.611$
Income Sources	SSI/SSD	8 (53.3%)	22 (71.0%)	
	Earned Income	7 (46.7%)	6 (19.4%)	
	Other	0	3 (9.7%)	

Table 6 - continued

Religion	Yes	12 (80%)	10 (32.3%)	$\chi^2 (1, N = 46) = .749, p=.497$
	No	3 (20.0%)	6 (19.4%)	
Housing	Independent House or Apt.	13 (86.7%)	15 (48.4%)	χ^2 between independent housing and all other categories $\chi^2 (1, N = 45) = .625, p=.695$
	Family	0	8 (25.8%)	
	Supervised Apartment	1 (6.7%)	4 (12.9%)	
	Group Home or AFC	1 (6.7%)	3 (9.7%)	
	Homeless Shelter	0	1 (3.2%)	
Diagnosis	Schizophrenia	10 (66.7%)	16 (59.3%)	χ^2 between schizophrenia and all other categories $\chi^2 (1, N = 42) = .224, p=.636$
	Schizo-Affective Disorder	4 (26.7%)	3 (11.1%)	
	Manic-Depression	0	5 (18.5%)	
	Other	1 (6.7%)	3 (11.1%)	
Mental health services currently participate	Individual or Group Therapy	8 (53.3%)	13 (43.3%)	
	Medication Management	9 (60.0%)	16 (55.2%)	
	Case Management	4 (26.7%)	10 (33.3%)	
	Drop-In Center or Clubhouse	3 (21.4%)	14 (45.2%)	
Satisfaction with mental health services	Extremely Satisfied	$\underline{M} = 4.571$;	$\underline{M} = 3.857$	$t (40) = 2.214, p=.033^*$
	Mostly Satisfied	$SD = .5136$	$SD = 1.15$	
	Somewhat Satisfied			
	A Little Satisfied			
	Not at all Satisfied			
Satisfaction with social support	Extremely Satisfied	$\underline{M} = 4.0$	$\underline{M} = 3.5$	$t (42) = 1.673, p=.103$
	Mostly Satisfied	$SD = .7845$	$SD = 1.1671$	
	Somewhat Satisfied			
	A Little Satisfied			
	Not at all Satisfied			

Table 6 - Continued

Satisfaction with how spend time	Extremely Satisfied Mostly Satisfied Somewhat Satisfied A Little Satisfied Not at all Satisfied	$\underline{M} = 3.533$ $SD = .833$	$\underline{M} = 3.20$ $SD = 1.214$	$\underline{t} (43) = .954,$ $p = .346$
Satisfaction with current living situation	Extremely Satisfied Mostly Satisfied Somewhat Satisfied A Little Satisfied Not at all Satisfied	$\underline{M} = 4.533$ $SD = .833$	$\underline{M} = 3.466$ $SD = 1.195$	$\underline{t} (42) = 1.673,$ $p = .103,$
Satisfaction with financial resources	Extremely Satisfied Mostly Satisfied Somewhat Satisfied A Little Satisfied Not at all Satisfied	$\underline{M} = 3.47$ $SD = 1.06$	$\underline{M} = 2.77$ $SD = 1.41$	$\underline{t} (43) = 1.698,$ $p = .097,$

*Significant at $p < .05$

**One or more cells have expected counts of less than 5, which is the criteria recommended to meet the assumptions of the Chi Square Test for Independence. However, some authors have argued that an expected count of 5 is needlessly stringent and that lower criteria can satisfy this assumption in some circumstances.

Results and Discussion of the Cross-Case Analysis

Research Question #1: How do people with mental illness in Schizophrenics Anonymous, a mutual-help setting, experience and describe recovery? This question focuses on understanding how participants in SA experience the recovery process in their own lives. I did not include references made to recovery in general, or how other people might experience recovery, in this analysis. However, I included both what participants' described as their current and past experiences of recovery, because the purpose of this research question is to capture the full spectrum of how participants experienced the recovery process and not just how they currently experience or engage in the recovery process.

In the first stage of the analysis, I identified twenty-two themes of recovery that occurred across participants. I assigned each theme a unique name to reflect the properties of the text coded at that theme followed by a brief description including its conceptual relationship to other themes or meta-themes. I provide two sources of evidence for each theme: (1) a count of the number of cases in which a particular theme emerged and (2) four or five of the most illustrative quotes. All of the verbatim text in support of each theme can be found in Appendix F.

Next, I organized the themes into nine meta-themes based on the degree to which they played related functions in the recovery process. I identified these meta-themes by performing a second-order analysis of the twenty-two themes, which lead to grouping themes together according to their similarities in meaning, substance, and function in the recovery process. Finally, where appropriate I combined meta-themes into four phases that represented distinct aspects of the recovery process.

Overall, the cross-case analysis revealed that the way in which each participant experiences recovery is highly individualized and unique. However, from participants' unique experiences, I was able to identify many commonalities in experience across participants in terms of how they experienced certain aspects of recovery. From these shared experiences, I identified 4 phases: (1) mourning and grief; (2) awareness and recognition; (3) redefinition and transformation; and (4) enhanced well-being and quality of life (Please refer to Table 7). The earlier stages of analysis, as described above, as well as my own biases and assumptions resulted in the identification of these 4 phases of recovery.

Developing the 4 phases was an iterative process which involved: (1) using the work of others who have empirically studied (e.g., Young and Ensing, 1999), theorized (e.g., Baxter & Diehl, 1998; Hatfield, 1994; Ragins, 1994; Risman, Kidder, Campbell, Caras, DuMont, Fisher, Johnson, Kaufmann, Knight, Loder, Penny, Townsend, & Van Tosh, 1999; Spaniol, Gagne, & Koehler, 1999), or written about recovery in their personal published accounts (e.g., Anonymous, 1989; 1996; Deegan, 1993), (2) using the 15 within-case summaries to develop the 4 phases and understand the relationships between them, (3) using the insights I gained about the recovery process through my involvement in the SA organization and hearing SA participants informally talk about the recovery process, and (4) tapping into my own assumptions and biases including optimism – that things get better over time -and that things tend to occur in a certain order. All of these sources contributed to my own beliefs, biases, and assumptions about the recovery process and played a role in how I understood the conceptual relationship between the themes, meta-themes, and phases (please refer to Table 7 for a list of phases

and meta-themes) and how I grouped the meta-themes into the 4 phases of recovery as presented in Table 7. In Table 7, I identify meta-themes by Roman numerals and themes by capital letters.

Table 7

Four Phases of the Recovery Process

<u>PHASES OF THE RECOVERY PROCESS</u>			
Phase 1 - Mourning and Grief (<u>n</u> =12, 46%)	Phase 2 – Recognition and Awareness (<u>n</u> =33, 72%)	Phase 3 –Redefinition and Transformation (<u>n</u> =38, 83%)	Phase 4 –Enhanced Well-being and Quality of Life (<u>n</u> =32, 69%)
<u>I. Mourning and Grief</u>	<u>I. Recognition and Awareness (<u>n</u>=33, 72%)</u>	<u>I. Change in Attitudes or Beliefs About Schizophrenia and Self (<u>n</u>=30, 65%):</u>	<u>I. Forming a Positive Sense of Self (<u>n</u>=23, 50%):</u>
A. Loss of Hope and Feelings of Despair (<u>n</u> =5, 11%)	A. Recognizing how schizophrenia manifests itself in ones' life (<u>n</u> =10, 22%)	A. Changing beliefs about the nature of schizophrenia (<u>n</u> =25, 69%)	A. Regaining sense of value and worth (<u>n</u> =20, 43%)
B. Anger at Illness, Self, and World (<u>n</u> =4, 9%)	B. Recognizing how schizophrenia disrupts "normal" life course and participation in age appropriate roles (<u>n</u> =19, 41%)	B. Changing beliefs about self (<u>n</u> =32, 70%)	B. Forgiving ones' self and others (<u>n</u> =5, 11%)
C. Denial (<u>n</u> =6, 13%)	C. Recognizing how schizophrenia has increased social isolation and marginalization (<u>n</u> =27, 59%)	<u>II. Learning How to Live with Schizophrenia (<u>n</u>=26, 57%):</u> A. Managing symptoms and illness (<u>n</u> =19, 41%) B. Recognizing need for help (<u>n</u> =10, 22%)	C. Recognizing that one has grown (<u>n</u> =12, 26%)
	D. Recognizing how schizophrenia has disrupted ones' sense of self (<u>n</u> =5, 11%)	<u>III. Redefining Expectations and Goals (<u>n</u>=16, 35%):</u> A. Redefining expectations for life within the context of a disability (<u>n</u> =9, 20%) B. Developing goals, hopes, and dreams (<u>n</u> =10, 22%)	<u>II. Developing a New Way of Approaching Life (<u>n</u>=16, 35%):</u> A. Focusing on the positive (<u>n</u> =9, 20%) B. Choosing to be well (<u>n</u> =7, 15%) C. Learning to value everyday (<u>n</u> =5, 11%)
		<u>IV. Developing Strategies for Change (<u>n</u>=23, 50%):</u> A. Identifying areas of specific change (<u>n</u> =9, 20%) B. Overcoming fear and impediments (<u>n</u> =14, 30%) B. Identifying abilities and skills (<u>n</u> =9, 20%)	<u>III. Accomplishing Valued Goals (<u>n</u>=11, 24%)</u> <u>IV. Finding Meaning and Purpose (<u>n</u>=16, 35%)</u>

The phases identified in this study are similar in meaning and content to the phases, stages, or elements of recovery, which have been described by others who have theorized about the recovery process (e.g., Baxter & Diehl, 1998; Hatfield, 1994; Ragins, 1994; Risman, Kidder, Campbell, Caras, DuMont, Fisher, Johnson, Kaufmann, Knight, Loder, Penny, Townsend, & Van Tosh, 1999; Spaniol, Gagne, & Koehler, 1999) or described recovery in their personal narratives (e.g., Anonymous, 1989; 1993; Deegan, 1993). They are also consistent with the findings of the few researchers who have empirically studied the recovery process from serious mental illness (e.g., Davidson & Strauss, 1992; Young & Ensing, 1999).

Phase 1: Grief and Mourning (n=12, 26%)

Grief and Mourning is the first phase (meta-theme) of the recovery process. Twelve SA participants described reacting to a diagnosis of schizophrenia and its impact on their life with: (a) feelings of hopelessness and despair, (b) denial of the illness, or (c) feelings of anger towards ones' self, others, and/or the world. They described these feelings as resulting from the hopelessness and stereotypes conveyed with a diagnosis of schizophrenia and from the subsequent losses that are associated with the illness and described in the discussion of phase two (e.g., loss of job, loss of friends, etc.). Although this may seem to challenge the notion of recovery, both mental health consumers and researchers have described the recovery process as starting with feelings of anguish, anger, loss, grief, and mourning (Anthony, 1993; Deegan, 1993; Lefley, 1996; Ralph, Risman, & Kidder, 1999; Spaniol et al., 1999). A work group led by Ralph (1999), and comprised primarily of mental health consumers and researchers, developed a conceptual model of recovery which describes the recovery process as starting with anguish,

including feelings of despair due to being labeled mentally ill, hopelessness, lack of meaning and purpose, and the experience of pain and dysfunction. Lefley (1996), a researcher, also theorizes that grief and mourning occur after one awakens from being submerged in symptoms and realizes the losses and trauma that they have experienced. Another prominent researcher in the field of psychiatric rehabilitation describes the first phase of recovery as consisting of being overwhelmed by the illness, which includes feelings of distress and hopelessness (Spaniol et al., 1999). Anthony (1993) describes a similar range of emotions experienced by individuals as they move through the recovery process as encompassing depression, guilt, isolation, suspiciousness, and anger. In addition an advocacy group, The Friends of the Psychiatrically Disabled, in an unpublished position paper on recovery, include grief and mourning and feelings of shock, anger, sadness, and denial in their understanding of the recovery process. Finally, first-person accounts of the recovery process also identify mourning lost hopes and dreams as an important component of moving forward with ones' life (e.g., Anonymous, 1989). Deegan (1993), based on her personal experience, argues that recovery includes feelings of anguish and despair, which often follow the gradual acceptance of illness and its consequences.

Many individuals react to receiving a diagnosis of schizophrenia or recognizing the impact of it on their life, with feelings of hopelessness or anger. Others react by denying that they have such a stigmatizing illness. This denial has been attributed to multiple causes including: a neurological deficit of the disorder (Amador et al, 1991), a psychological defense or coping mechanism to protect one's identity (McGlashan &

Carpenter, 1976), or a consequence of the illness' affect on one's cognitive processes (Frese, 1997).

A. Loss of hope or feelings of despair (N=5, 11%)

One of the most prevalent experiences among persons diagnosed with schizophrenia is the loss of hope or feelings of despair. This sense of hopelessness and despair is related to the negative beliefs that are associated with a diagnosis of schizophrenia (i.e. "the prognosis of doom") (Deegan, 1993) and also to the iatrogenic effects of treatment (Leete, 1987). Few participants in this study described currently experiencing hopelessness or feelings of despair at the time of the interview or in the recent past. However, more participants described experiencing hopelessness or despair after learning of their diagnosis of schizophrenia and before becoming involved in SA and meeting other people diagnosed with mental illness. Therefore, many of the descriptions of hopelessness or feelings of despair are retrospective and not very detailed. Oftentimes participants captured this period in their life by describing suicidal feelings or suicide attempts.

"Anyways, so I got discharged and for about a year, I didn't even feel like doing anything. ...In spring of '81 I began to consider suicide. Then finally, things were getting worse and worse. The whole thing with the typewriters getting loud again and stuff. Then in October of '81, I took like 72 Navane." (07-01-05)³

"I was thinking suicide but nobody knew that. My self esteem was very, very low because I was very, very skinny. You know, guys would pick on me. The girls were starting to, you know, develop boobs and all that and I thought I didn't fit in. You know. I felt ugly. I said well, I wanted to give up" (12-01-03)

"I made a suicide attempt while my wife was divorcing me." (14-02-11.1)

³ This number represents the interview identification number which can be used in conjunction with Appendix F if the reader wants to view more of the interview text that surrounds the quotes that are excerpted in this section.

The 2 participants in this study who expressed current feelings of loss of hope and despair were in their mid-20s, recently diagnosed, and were still acutely experiencing a sense of loss and failure in the realms of work, school, and friendships.

“... I'm different. I just, I don't think I'll ever be a normal, really a normal person. I'm just scared I'm never gonna get married or anything. I'm never gonna be successful. I've always been the nerd and the outsider.” (18-02-16)

“When I saw some of the lower functioning people, it kinda made me think is this what I'm gonna be like some day?...I don't believe that it ever could get better....I've attempted [suicide] four times since I got sick. I guess feeling that there's no hope for me. And I know, I know one or two people, yeah, two as a matter of fact, in the group, that make about as much money as the average person does in a year and all the rest of them either live in group homes or on disability. A lot of that, feeling like my life may have to stay horrible. I mean, just for the rest of my life....It's made me really wonder if I should stay on this earth or if I should just go lay in front of a moving train. Because I had a lot of fear every day that my life may never get any better and the only thing that's gonna happen is that I'm gonna get older, older, and pretty soon I'll have to worry about physical health problems and you know, my parents are gonna die and, you know, really, I wonder how am I gonna survive.” (25-02-10)

In support of this finding, Landeen, Pawlick, Woodside, Kirkpatrick, & Byrne (2000) found that persons diagnosed with schizophrenia experience a greater level of hopelessness than others without psychiatric diagnoses. Deegan (1988) recognizes the pervasiveness of hopelessness and describes acquiring a sense of hope as the turning point or a cornerstone in the recovery process. Responding with hopelessness and despair is one reaction to a diagnosis of schizophrenia. Another way that participants responded to a diagnosis of schizophrenia is with anger at the illness, the world or themselves.

B. Anger at illness, world, & self (n=4, 9%)

Four participants described being angry, including being angry at schizophrenia for interfering with ones' goals and dreams.

“It's hard sometimes, you know. When you have to look back, it was ugly. This is an ugly illness. I gotta tell you, I hate it. I hate every day of it. I want my job back.... I had a loss. It's been a loss for a long time....I'm not good at anything anymore. I hate this illness. I hate it.” (05-01-11.1)

“Just that I get short of temper. I never get angry. I feel angry all the time.” (14-02-11.1)

“... the fact that I may have to live with something wrong in my life just really, makes me really pissed off, I guess.” (25-02-10)

“Which my mind is not too bad now. But I still can't go out and work and do this and do that. Sometimes it makes me mad.” (28-01-15)

Although anger is often pathologized or viewed as a symptom of the illness, it can also be viewed as a normal and healthy reaction to the experience of loss and the injustices brought about by discrimination (Anthony, 1993c). Expressing anger is a sign that a person acknowledges and recognizes how schizophrenia has impacted their life and is aware of the negative perceptions associated with schizophrenia. Another way that participants reacted to a diagnosis of schizophrenia is by denying its existence, denying that they have a problem, or attributing their problems to a different source.

C. Denial of illness (n=6, 13%)

Denial of having schizophrenia or seeking alternative explanations for one's current problems is another reaction to receiving a diagnosis that is perceived in such a negative manner by both lay persons and professionals. Six participants described both their current beliefs that reflected alternative explanations for their problems besides mental illness and how they had denied the existence of a serious problem in the past.

“I like to think that I'm not really mentally ill because I feel I was justified in, justified in behaving out of, out of sync with the community because there was something going on in my life at that time that really represented a strange and biological magic, you know. Black magic, sort of like.” (02-02-11)

“I didn't accept it at first. I began partially accepting it in spring of 1988. I had

been hospitalized 3 times, each time I had gone off my medications before being hospitalized.” (03-02-11.1)

“Actually, I don't think I have schizophrenia. ...I don't know. I really don't think I'm a schizophrenic. I do believe I have mental illness but I really don't, not sure exactly what it is, or if it's anything.” (18-02-16)

“... I learned that I might not have [schizophrenia]. I might have just had an emotional breakdown at the time.” (24-02-10)

Denying being “sick” or attributing ones’ problems to other causes (e.g., drug abuse) is one way to protect or maintain a positive sense of self in the face of such a strong negative identity threat. Denying that one's problem is schizophrenia may also be a mechanism for maintaining hope. In this context, denial of having schizophrenia is an adaptive response, which may help maintain positive identity (Pettie & Triolo, 1999), hope (Deegan, 1996), and subjective quality of life (Kravetz, Faust, & David, 2000). Denial of schizophrenia is a component of the recovery process because it demonstrates that a person is trying to make sense of their experience and to manage it in a way that promotes survival and fits with their understanding of themselves.

Some people and organizations in the mental health community believe that denial of ones’ mental illness is in and of itself a symptom of schizophrenia. For example, Amador, et al (1991) argue that “unawareness of illness” in schizophrenia may stem directly from the pathophysiology of the disorder. Organizations such as NAMI (the National Alliance for the Mentally Ill), which is grounded in the same medical model, argue that a person with schizophrenia cannot know they are ill because the part of them that is ill (i.e. the brain) is the part that does the knowing. Deegan (1996), in discussing her own personal journey through recovery tells how she experienced anger, indignation, sadness, and anguish after she emerged from denial.

In summary, this first phase, Mourning and Grief, captures how participants reacted to receiving a diagnosis of schizophrenia and its subsequent consequences. Feelings of hopelessness, despair, and anger are often a consequence of the messages conveyed with a diagnosis of schizophrenia (Deegan, 1996; Harding et al, 1992) or the encroachment of the illness on ones' identity as people start to view themselves as a "schizophrenic" (Deegan, 1993; Lally, 1989). However, feelings of hopelessness, despair, and anger are not symptoms of the illness as is oftentimes believed, but instead a normal reaction to a person's situation (Anthony, 1993; Deegan, 1993). Deegan (1988) describes denial as a reaction necessary to survival in the early stages of the recovery process.

There are several reasons why it is important to include grief and mourning in the recovery process. Including this process validates the entire experience that people go through when they are confronted by a mental illness. It recognizes that people experience some very real and painful losses as a result of mental illness and allows us to take a more holistic approach to understanding the person (Strauss, 1992). It does not pathologize feelings of anger, sadness, or despair, which are viewed as normal reactions to loss in the grief and mourning process (Anthony, 1993). Finally, Deegan (1993) argues that recovery needs to start wherever people are with their illness without making judgments about whether they are in recovery or not. Identifying and expressing these feelings is important to the recovery process because it can help people move beyond them and to identify areas of change.

Phase 2: Awareness and Recognition (n=33, 72%)

The second phase, Awareness and Recognition, consists of understanding the impact of schizophrenia on ones' life and self. In this phase, participants described myriad ways that they recognized how schizophrenia has impacted their life. In addition to how the illness manifests itself in each individual's life, people begin to acknowledge the secondary consequences of the illness. The impact of schizophrenia includes not only the direct manifestations of the illness (e.g., experience of symptoms), but the disruption in social roles and independence (e.g., disrupts normal life course, loss of job, and interferes with self-sufficiency), social marginalization (e.g., treated and viewed differently by others and feelings of loneliness and isolation), and negative feelings about ones' self (e.g., feelings of shame, low self-esteem, and worthlessness). Deegan (1996) and Anthony (1993) both argue that recovering from the symptoms of mental illness is the easy part, but that recovering from the effects of poverty, second-class citizenship, and iatrogenic treatment effects is the true challenge. Blanch et al. (1997), based on a dialogue with consumers and practitioners, also describe the importance of including the secondary assaults of stigma, discrimination, and abuse in recovery. This phase is very important to the recovery process because it is from this assessment of how schizophrenia has impacted ones' life that a person decides how they want to proceed or what they need to do in order to move beyond the illness and its consequences to develop a life that is comfortable, meaningful, and fulfilling.

I. Recognition and Awareness

One of the most basic components of the process of recovery involves identifying, understanding, and eventually coming to terms with how a diagnosis, such as

schizophrenia, impacts ones' life. The themes that capture how participants described their understanding of the impact of schizophrenia on their lives fall into four categories. These categories, include: (1) recognizing how schizophrenia manifests in ones' life; (2) recognizing how schizophrenia disrupts "normal" life course and participation in age appropriate roles (e.g., loss of job, interferes with self-sufficiency); (3) recognizing how schizophrenia impairs social connections (i.e. treated and viewed differently, feelings of loneliness and isolation); and (4) recognizing how schizophrenia has negatively affected feelings about self (i.e. impaired identity, feelings of shame, low self-esteem, and worthlessness).

Oftentimes these four categories are interrelated. For example, participants described how the experience of symptoms, such as hearing voices and visual hallucinations, made them feel socially marginalized or unable to participate in valued roles, such as work. Participants also described how being socially marginalized or unable to participate in age appropriate roles, impacted their feelings of self worth and esteem and positive identity.

Understanding and identifying how schizophrenia has impacted ones' life is an essential step in the recovery process, because it allows a person to assess what they have lost, what they have learned about themselves, others, and the world, and what they need to do in order to rebuild their lives and work on their recovery. The process of recovery does not just involve recovering from the symptoms, but it also involves recovering from the disruptions and losses associated with schizophrenia, the social marginalization, and the negative perceptions and feelings about ones' self. The four primary ways that participants described schizophrenia as impacting their life are described below.

A. Recognizing how schizophrenia manifests itself in one's life (n=10, 22%).

Ten participants described how the experience of symptoms including loose associations, poor concentration, disturbing thoughts, hearing voices, and experiencing anxiety and depression interfered with their day-to-day functioning and impacted their ability to fit in, relate to other people, and participate in work and other valued activities. The more these experiences interfered with ones' ability to participate in work or to be accepted in social situations the more they are perceived as a problem by participants.

"You've probably become aware some of my thought processes. They don't work too well. All the past, the concentration is gone, memory is gone. And the thoughts are brutal" (14-02-11.1)

"I'm not really able to communicate with people the way I used to. A lot of the time, I find myself stumbling over words and just not having the right thing to say." (25-02-10)

"You feel sort of a like a social outcast. Not, I don't feel a stigma, not because of the stigma of the illness, I don't feel that. It's in myself. ...I experience things that other people don't..." (28-01-15)

"Well, the constant issue I had with my delusions. I'll bring that in a lot because I constantly have delusions. It may not seem that way but when I'm at work, I can be in the stacks of books, straightening or whatever, and I'll be laughing. Not, out loud, ha ha ha, like that. Just kind of chuckling to myself and smiling and I think that looks kinda weird." (33-02-05)

Participants were able to identify their experiences of voices, delusions, and impaired cognitive functioning as manifestations of schizophrenia. Insight or understanding of these distressing experiences and how others react to the behavioral manifestations of symptoms helps one to accept them, regulate them, compensate for them, live with them, or overcome them. Sullivan (1994), in a qualitative study of 54 respondents who were judged to be successfully living with schizophrenia, based on their vocational and residential status, found that being able to identify symptoms and taking

action to counter act them was key to being able to work and live independently.

Recognizing these experiences as manifestations of schizophrenia helps participants to understand how they experience the world differently from others and to develop ways of dealing with this. Although being able to identify and understand ones' symptoms is important, it is equally important for people to recognize the less direct ways that schizophrenia has impacted their life (Anthony, 1993; Deegan, 1996). Participants identified several ways that having a diagnosis of schizophrenia has disrupted their life course and their ability to participate in age appropriate roles. Oftentimes these disruptions lead to social marginalization and an altered sense of self.

B. Recognizing how schizophrenia disrupts “normal” life course and participation in age appropriate roles (n=19, 41%).

Nineteen participants described how schizophrenia disrupted what is often thought of as a “normal” life course or participation in “normal” roles and activities. Participants described recognizing how having experiences that are associated with a mental illness (e.g., mental health treatments, symptoms) and not having other “normal” experiences (e.g., going to college, working) have impacted their sense of self and identity as well as feelings of self worth and value. They also described feeling set apart from their peers or old friends, as not having anything in common with them, or feeling as if they have “lost time.” Experiencing a different developmental trajectory is a common experience for people who have not taken part in normative social roles.

“I think that if I was a normal person I would be in college, partying, hanging out with my friends, probably living with my mother, mooching off her. So I think that I'm quite a different person because of my illness and the things that I have been through.” (10-01-10)

“Most of us had a sense of promise that got disrupted. Most of us, there is

kind of a pariah thing... my life was wiped out in a sense. The tract of my life was kind of just, things have never been the same as they were in 1980. 1981, I had, this past Saturday we had a reunion with all the gang both from high school and college. And you know, I'm different from them. They have normal lives. I don't have any of the vestiges of a normal life." (21-01-00)

"Most of us don't work. It's hard Most of us, are living with our families, or alone. We haven't been married. We've been in and out of the hospital a lot. ...I feel like I've lost about ten years. I wasn't able to get married. I've been engaged quite a few times but it's interfered with that. My job, being able to hold a job, it's terrible.... You know, instead of living with people my own age, you know, doing things people my age do and having a nice car or being married or a nice career, you know, that's what I had planned." (28-01-15)

"I almost feel like everybody kinda goes through some changes between birth and adolescence and adulthood. And it's like mine's taking up by illness and suffering." (48-02-16)

Acknowledging this different life course and the perceived losses is important to the recovery process because it allows a person to eventually move on and to chart a new course for their life by building meaning out of their past experiences and losses and redefining what is important to them within the context of their disability.

The loss of a job or the ability to work is one of the most salient ways that participants' life courses were disrupted. Losing a job or being unable to work was often attributed to discrimination or the impact of symptoms and medication side effects on their ability to function at work.

"I can't work or I start cracking up." (07-01-05)

"... they didn't have a job for me because I was mentally ill. You know, that was discrimination but I just didn't seek getting help.... I'll probably never ever work in a work place using what I know." (11-01-03)

"Well, it's made me unemployable. So it's hard to support myself." (19-02-13)

"The loss of status in jobs.... And I think it stopped me from getting a promotion at work. (35-01-00)

"... it keeps me from holding a good job and I don't draw much. I only draw

\$485 a month. And I've got section 8 so that's the only reason I can pay my rent. I'm a nurse and I don't think that I could take the mental strain of being a nurse." (38-01-38)

Work is one of the most valued adult roles in our society and not working lowers a persons' social status, increases their dependency on others, and impacts their feelings of self-esteem and self-worth (Rogers, 1995). The process of recovery entails recognizing this loss, mourning this loss, and eventually developing strategies to cope with this loss.

Participants described how not being able to work increased their dependency on others including their parents, public assistance, such as Social Security Disability and Medicaid, and professional service providers. In addition, they recognized that dependence on the Government and others sometimes fostered feelings of insecurity and worthlessness.

"... I just stay on disability and work these menial part time jobs to earn extra money because at least I have that safety net. You know, and to get back on disability, they make it so tough to get back on it, then I would have went out there and tried to find a full time job. But I don't have any interest in doing that. Because they make it so darn tough to get back on. And I don't want to be homeless and lose this." (11-01-03)

"And we're all on some type of public assistance, dealing with Medicaid and all this stuff....I have to live, I'm always on edge that they're gonna drop me. SS, you know, I'm on SSD, on Medicaid, you know, constantly worries me. I'm at the mercy of the state, you know, and how they are going to vote in Congress and instead of being independent and holding a job and having a life." (28-01-15)

"...I only draw \$485 a month. And I've got section 8 so that's the only reason I can pay my rent. ...[I'm] not able to drive any more. I used to drive. I'm not able anymore. Because I got a fear of driving. And I have to depend on people to take me. Mary picks me up to come to volunteer every day. And I have to have somebody take me to the doctor. And take me to the grocery store." (38-01-38)

The process of recovery involves recognizing how schizophrenia impacts ones'

ability to work and be self-sufficient and often necessitates reliance on Government benefits or other people to help with the necessary tasks and responsibilities of everyday life. Charmaz (1983) found that not participating in work greatly increased feelings of social isolation and a loss of self for persons with chronic physical illnesses. Loss of status in jobs, becoming dependent on Government assistance, and lack of participation in other meaningful adult roles can increase feelings of vulnerability and worthless and social marginalization.

C. Recognizing how schizophrenia has increased social isolation and marginalization (n=27, 59%).

Twenty-seven participants described ways in which schizophrenia, hospitalization, or behaviors resulting from the illness made them feel socially marginalized. This is the issue brought up by the greatest number of participants across all of the phases and themes and is thus extremely prevalent for participants. Most participants recognized that they were treated differently by family, co-workers, or friends after they were diagnosed with schizophrenia or returned from the hospital. The treatment experienced by participants ranges from direct discrimination in social and work settings to more subtle forms of devaluation in the context of personal relationships, including being treated as incompetent, fragile, or potentially violent. The ways in which people with schizophrenia are treated reflect some of the prominent beliefs or stereotypes about people who have a mental illness, which include that people with mental illness are childlike, incompetent, cannot take stress, and are violent (Fraser, 1994). Participants described the various ways in which they experienced stigma and discrimination.

“That we are people, we have souls, we have feelings, and for us not to be treated like trash and pushed aside. That there are ways of helping us, and

I wish that people would wake up and get these programs started and start doing more for us because we can be helped. That is what people don't understand, it's like from the very beginning, the first people to be burned in the fires were schizophrenic people. In Hitler's ovens, that was the first people to be burned. Like they weren't even people, like they were dogs. Not even dogs, it was like they were rocks, just throw them in the fire. It's almost still continuing that way." (10-01-10)

"... there were times when people tried to remind me that I was mentally ill, to intimidate me... Or they tried to diminish me because I had this other thing attached to me." (08-01-02.1)

"... there is kind of a pariah thing that we've all experienced...as soon as the word schizophrenia gets introduced to a relationship, things alter pretty quickly." (21-01-00)

Being aware of the stigma and discrimination attached to a diagnosis of schizophrenia often times resulted in participants hiding their mental illness or not seeking help.

"I thought I would shunned so I never put it on an application or anything. So I was afraid to even tell anyone." (29-02-02)

"And sometimes it has a little bit of fear. Sometimes you meet somebody who doesn't have a mental illness and they know nothing about it and nothing what you've been through, you're kinda afraid to tell them because they might not wanta be, continue friend with you because they're afraid you might, you know, go crazy on them. And you know, they kinda judge you, judge you like a book sometimes. They say don't judge a book by its cover but I feel with a mental illness, I think a lot of mentally ill people get judged and some of them aren't, a lot of them aren't treated fairly because there's a lot of very intelligent mentally ill people. And people think because they're mentally ill you're not, you know, you don't have a brain." (45-02-38)

Several participants described how a diagnosis of schizophrenia has disrupted and strained their relationships with their family and their friends.

"Well, it put a strain on my relationships with my family." (14-02-11.1)

"As far as being treated, I feel like my family treats me differently. Like sometimes I feel as if, my one sister told me, well, we just don't have anything in common." (35-01-00)

"... I applied for a driver's license and I took, I passed the driver's test, passed the paper test and I got my license. But I had no car to drive. My mother had

the car. And she would not let me drive alone. She had to be in the car with me all the time. So it was not long after that that I was in the hospital again, depression, and, let's see." (41-01-40)

Participants described how being treated differently by others and being set apart from others by their experience with mental illness made them feel socially isolated and alone. They also described how they often felt like they were alone or isolated in the experience of their symptoms (e.g., hearing voices, having delusions, struggling with anxieties or depression), because most people do not share these same experiences. Oftentimes participants described feeling like they no longer "fit in" with their old friends or like they no longer have anything in common with other people leading "normal" lives. Many participants were not working and therefore did not have a work setting in which to develop new relationships. These factors make sustaining old relationships or developing new friendships difficult.

"... I felt I was all alone. I felt isolated and that's a terrible feeling, you know. You feel like you're shut out from the world. All of a sudden the people at the VA said my God, you're schizophrenic, and I'm going my God, what the hell is that? I just went through a terrible ordeal... I lost some really good friends. I grew up with these guys and I've known them since I was probably either 8 or 9. We used to caddie together." (11-01-03)

"Well, most of my friends, when they found out that I got sick, just stopped talking to me completely. And I haven't heard from some of them in three years... Well, that didn't happen with all of them. Most of them I had stopped talking to within the last two years before that, because of the fact that I was getting depressed and I guess slowly I was going out of my mind at that time. I just started to become isolated... Yeah, it began to change a couple of years before, gradually. It began. But yeah, after I was diagnosed, I guess word was out that I was a freak so nobody wanted anything to do with me... There really is nobody who's that important in my life. And I miss it a lot. I'm extremely lonely." (25-02-10)

The process of recovery involves recognizing how a diagnosis of schizophrenia alters ones' connections to others resulting in social marginalization, isolation, and

feelings of loneliness. The stigma and discrimination that accompany a diagnosis of schizophrenia change a person's social and familial relationships, can marginalize them from settings in which to form new social relationships (Davidson & Stayner, 1997), and can interfere with access to social and economic resources (Link et al., 1987). Charmaz (1983), in a study of persons with chronic physical illness, linked increased social isolation and marginalization, or what she termed "living a restricted life" (p. 170), to a decrease in positive identity and feelings of self-esteem and worth. The inability to work and the subsequent loss of jobs and social status gained through work, feeling out of step from other people in your age group, lacking connections to other people with similar experiences, being dependent on an unpredictable system of care to meet your basic needs, and the feeling of stigma and experience of discrimination, all work to increase a person's social marginalization which can impact ones' identity and feelings of self esteem and self worth. After acknowledging how schizophrenia has disrupted ones' connections to others, participants can then compensate for this in a variety of ways (e.g., by forming new relationships, which do not devalue or threaten ones' positive identity; by not allowing others' perceptions of them to affect their sense of self – developing a thick skin).

D. Recognizing how schizophrenia has disrupted ones' sense of self (n=5, 11%).

Eleven participants described how learning that one has schizophrenia disrupts their sense of self and identity by replacing ones' previous understanding of self with negative images of what it means to be "schizophrenic." The stigma attached to a diagnosis of schizophrenia often conveys stereotypes and negative images about mental illness that are applied to the person by others and by the person to himself or herself (Link, 1987;

Link et al, 1997; Thoits, 1985). A diagnosis of schizophrenia can also make people feel judged, criticized, not accepted, out of place, embarrassed or ashamed of their actions or their very being. Deegan (1993) describes in her personal narrative of recovery how the only images that were available to her to help her understand what it meant to have schizophrenia were stereotypes that perpetuated views of people with schizophrenia as violent, crazy, bad, or lazy. The juxtaposition of ones' beliefs about ones' previous self with images of what it means to be "schizophrenic" can create uncertainty or confusion about ones' feelings and beliefs about ones' self (Pettie & Triolo, 1999).

Some participants described the confusion that they experienced around their identity in the wake of a diagnosis of schizophrenia and how social isolation and a lack of connection to others with similar experiences contributed to their confusion.

"...I wanted to find some identity. I didn't know what my identity was.... You've gotta teach the person so they have some deep beliefs about what they're experiencing. So they can help themselves, you know? I was just left alone like in the mess for all those years as far as I was concerned. What is wrong with me? What am I? How evil am I? And what am I all about, you know? And then every time I heard I was a good person, I had potential, I didn't believe it because I also knew that I was mentally ill. I was crazy. I didn't think mentally ill. I thought I was insane, you know? So then I'd think, well, maybe I'm a mad scientist, you know? But I couldn't give myself credit for anything because I always had the insanity to attach to it." (08-01-02.1)

"Why was I this way and how come and is there anybody else? You know, it was just really strange. Like maybe I was an alien or something, you know? So it helped me get down to earth because I was out there alone with this illness that all these other people were telling me it was schizophrenia. I read about it in books but I've never seen anybody in real life with schizophrenia. So I was quite confused. I didn't know why I was the way I was and plus, the doctors didn't really give me that much information about it.... So I think that I'm quite a different person because of my illness and the things that I have been through." (10-01-10)

Some of the specific ways that participants described their positive sense of self becoming disrupted is through feelings of shame, low self-esteem, and worthlessness that

can be a result of having a diagnosis of schizophrenia and of some of the manifestations of the illness. The negative stereotypes associated with a diagnosis of schizophrenia as well as not having the vestiges of what is considered a “normal” life – a job, a family, kids, and money, all contributed to their feelings of worthlessness and low self esteem.

“I felt shameful because I wasn't able to go through boot camp in the right amount of time. I wasn't able to complete schooling. It's just like now you're another failure upon a failure.” (11-01-03)

“... I have this thing about facing the world the way that I am right now. I'm so dissatisfied with myself that I just, I don't want anyone to see me this way.” (25-02-10)

“I felt like a failure. I felt like I had to start my life all over again. I felt like I had damaged my reputation. Because of the illness, you know, making me really do wacky things. I was embarrassed.” (35-01-00)

Participants recognized how a diagnosis of schizophrenia impacted their feelings of self-esteem, self-worth and value. They also identified why a diagnosis of schizophrenia impacts their sense of self, including the stigma and discrimination associated with schizophrenia, the feelings of inadequacy which have resulted from not being able to achieve certain goals in life, and the embarrassment and shame which result from the manifestation of symptoms. This experience is summed up in one person's anonymous account of mental illness as they describe the impact of their illness as “eradicating [their] sense of self” (p. 25) (Anonymous, 1993).

Pettie and Triolo (1999) argue that the juxtaposition of ones' previous self as healthy and competent with images of what it means to be “schizophrenic” can create an identity crisis, which involves being uncertain about ones' feelings and beliefs about ones' self. They view the struggle of resolving this crisis as essential to the recovery process because it allows one to develop a new, possibly more valued identity, which reflects

one's current values and belief system. Therefore, recognizing how schizophrenia has impacted ones' sense of self is important to developing greater self-understanding. This is an important component of the recovery process because it allows participants to begin the process of developing a renewed sense of self.

In summary, the second phase of the recovery process, Awareness and Recognition, demonstrates that participants recognized that schizophrenia has impacted their life in myriad ways. Other authors have identified processes that are similar to the phase of Awareness and Recognition in this study. For example, Hatfield (1994) argues that the recovery process starts with acceptance, which she defines as coming to terms with the illness and its impact on one's life. Ralph et al. (1999) identify awareness or awakening as the second stage of their recovery model and it includes recognizing what causes anguish, recognizing that change can take place, and that the pain of current situation exceeds the pain of changing. Cain (1991), in exploring recovery from Alcoholism, identifies a process of reinterpretation or reconstitution of ones' past as a time when people reflect back on their life and reinterpret events or experiences in the context of their understanding of their problem. Eventually this becomes important in reconstructing a new identity. Amador, et al. (1991), in a review of the literature on insight or awareness in schizophrenia, conclude that insight consists of four distinct dimensions the first of which is awareness of the signs, symptoms, and consequences of illness. They conclude that having insight into one's illness and the consequences of it contribute positively to compliance with treatment and clinical outcomes. Ragins (1996), borrowing from the trauma recovery model, also supports the notion that persons diagnosed with mental illness must recognize and acknowledge that mental illness has

impacted their life in order to move on. He states that persons diagnosed with mental illness "must accept their victimization in order to stop being victims and to instead become survivors" (p. 10). In a similar vein, Baxter and Diehl (1998), drawing on conceptual models of loss, state that during the course of recovery from loss, one often searches for ways to conceptualize the loss and tries to answer questions such as "How do I cope with this and get back on my feet" (p. 350).

In the phase, Recognition and Awareness, one of the most salient losses described by participants is the loss of a job or the ability to work. Not only is this a significant event in and of itself, but it is related to other losses (e.g., loss of independence), negative feelings about ones' self (e.g., feelings of low self-esteem and self-confidence), loss of connections to others, and inability to find meaning and purpose in life. Anthony (1993) and Deegan (1993) describe overcoming the secondary consequences of a diagnosis of schizophrenia, such as losing a job or no longer having access to valued work roles, as the true challenge in the recovery process. The Matrix Research Institute, based on data from the National Institutes of Mental Health, reports that there are a little over 3 million adults with psychiatric disabilities between the ages of 18-69 in the United States, but that only between 10 to 30 percent are employed. This is the lowest rate of employment for any disability group in the Nation. Notably, an estimated 70 percent of those 3 million adults say they want to work. The importance of work clearly emerges from the cross-case analysis undertaken in this study and is supported by others who have described work as both a goal and influence in the recovery process (Arns & Linney, 1993). Recognizing and acknowledging the losses and disruptions that have been caused by schizophrenia is an important step in the recovery process because it allows

participants to realistically assess their situation and develop a strategy to move forward or make positive changes in their life (Lunt, 2000).

Phase 3: Redefinition and Transformation (n=38, 83%)

Thirty-eight participants experienced the third phase of the recovery process, Redefinition or Transformation, which consists of four components (meta-themes): (1) change in attitudes or beliefs about schizophrenia and self, (2) learning to live with schizophrenia, (3) redefining expectations and goals, and (4) developing strategies for change. The name of this phase implies that participants not only attached new meaning to certain events or aspects of their life, but that they also begin to undergo a process of change or transformation. These four components capture the change process through which participants move as they regain a sense of hope, try to make sense of their experience with schizophrenia, and redefine themselves and their lives in light of that experience. Two of the components, learning to live with schizophrenia and developing strategies for change, consist of actions participants take to cope with schizophrenia or to create positive change within their life. The other two components deal with changing ones' attitudes or beliefs. Both changing attitudes and beliefs and taking action are important elements of the recovery process as identified by Young & Ensing, (1999).

The first component (meta-theme) of this phase, changes in attitudes and beliefs about schizophrenia and ones' self, captures how one starts to make sense of schizophrenia by developing a belief system that fits with ones' experience and facilitates ones' recovery. The second component, learning to live with schizophrenia, describes how participants learn to manage their illness and the actions they take to manage and control schizophrenia and its associated problems. The third component, redefining

expectations and goals, entails redefining expectations for ones' life within the context of a disability and redefining ones' goals, hopes, and dreams. The final component, developing strategies for change, entails developing strategies and taking action towards realizing new goals. Participants accomplish this by overcoming barriers and engaging in activities or settings that allow participants to identify areas of change.

I. Change in Attitudes or Beliefs about Schizophrenia and Self (n=30, 65%)

For 30 participants the process of recovery involves changing their attitudes or beliefs about their illness and themselves. Oftentimes participants described these changes as related, with changes in one precipitating changes in another. As illustrated above, a diagnosis of schizophrenia can negatively impact a persons' sense of self and convey a sense of hopelessness and despair because of the negative stereotypes associated with schizophrenia and the subsequent loss of valued roles and status. Participants described how changing ones' perceptions of schizophrenia, through knowing others who are diagnosed with mental illness or becoming more knowledgeable about different theories of schizophrenia, allowed them to regain or restore a sense of hope for their life and increase their positive feelings of self. In addition, participants described how being exposed to positive images of people diagnosed with schizophrenia counters ones' negative beliefs about what it means to be "schizophrenic" and facilitates acceptance of schizophrenia. Changing ones' attitudes and beliefs about schizophrenia, to more accurately reflect what it means to have schizophrenia, is integral to being able to overcome the stereotypes and misconceptions, to accept a diagnosis of schizophrenia, and to restore a sense of hope. One participant summed up how integral changing ones' attitudes and beliefs is to the process of recovery.

“...So what you believe is so damn important to your recovery.” (08-01-02.1)

A. Change in beliefs about the nature of schizophrenia (n=25, 54%)

Oftentimes a diagnosis of schizophrenia conveys a sense of pessimism and hopelessness (Harding et al., 1987; 1992). Twenty-five participants described some fundamental ways in which they came to understand schizophrenia differently, which helped to promote hope, facilitate positive coping, accept a diagnosis of schizophrenia, and ultimately accept ones' self. These included: (1) overcoming the stereotypes associated with schizophrenia and developing positive images of people diagnosed with schizophrenia; (2) understanding that schizophrenia is here to stay; (3) learning to accept set backs and relapses; (4) understanding that schizophrenia is a no fault illness; and (5) believing that recovery is possible.

1) Overcoming the stereotypes - forming positive images of people with schizophrenia (n=12, 26%). Overcoming stereotypes associated with schizophrenia is important to the recovery process because it allows participants to see the myriad ways that schizophrenia manifests itself and challenges the myth that Harding and Zahniser (1994) summarized as "a schizophrenic is a schizophrenic is a schizophrenic" (p. 141). It gives participants hope that people can live successful and productive lives in spite of having a diagnosis of schizophrenia and helps them to realize that a diagnosis of schizophrenia does not need to limit ones' expectations or dreams or lead to a sense of hopelessness. Twelve participants described overcoming stereotypes and forming positive images of people with schizophrenia as important to the recovery process.

“...hearing about them [other SA members] getting better encourages me to keep doing better because it can be done. That sort of thing. You know, when somebody says they've gone back to work, that's something that's just so

encouraging for me. That one day I'll be able to hold down a job." (10-01-10)

"...productive life even if you are mentally ill. Edgar Allen Poe, Van Gough, Michelangelo names all these people. I almost think it's sort of that mental illness is sort of the genius gene. Sort of breaks you some from the average people who have very bigoted views." (18-02-16)

"But she was holding a full time job. She had been through the hospital thing. She was taking her meds. She was seeing her psychiatrist. The whole, you know, a big portion of the experience that people that have this illness, in a big way she had experience and she was making it." (21-01-00)

"...there have been a lot of surprising, worthwhile people, outstanding people who have had schizophrenia, like Abraham Lincoln was supposed to have been schizophrenic....Edison was eccentric. People are worth something no matter what their condition. And if you have a mental illness that doesn't mean that you can't be productive or make life worthwhile. While there is life there is hope." (41-01-40)

"Uh, we did get a notation once that was quite interesting about this man who was working for his English degree in college, got sick, worked his illness until he became a hospital administrator and it is known that he has this disease. And nobody is making excuses and the man is doing great. It, so things like that, we get things that give us hope." (48-02-16)

When participants get to know others with schizophrenia their stereotypes are challenged, especially the stereotype that people with schizophrenia are violent, and they realize that people with schizophrenia are just like other people.

"...even though I was schizophrenic, I still had that fear that, you know, how people that don't have schizophrenia have fear against schizophrenics, like they're crazy and they're going to attack you and you know, all these wild stories. So I myself was scared of that. So I was really nervous....I saw all these smiling faces when I went in and everybody was just like normal and nobody even looked like they would be schizophrenic, you know?" (10-01-10)

"Yeah, it might sound silly, but anyways, if someone had said, oh, I want you to meet my friend who has schizophrenia, I would get scared and say no. Now I would say, Oh, I would be more than happy to meet them, please bring them over. Let's have coffee together. Let's get together. You see?" (29-02-02)

"[I thought] I don't belong here. These people are schizophrenics for God's

sakes. They might kill me, you know. You know, I don't wanta, I don't wanta get in an argument with them. But my impression of, I was shocked because they seem very normal. I mean, there's one guy that's, he's going to college He told me he's on the dean's list ..." (44-02-38)

Overcoming stereotypes of schizophrenia is an important component of the recovery process because it can help restore hope, a positive identity, and facilitate acceptance of a diagnosis and ones' self. Perhaps overcoming negative stereotypes also makes accepting that schizophrenia may be a life-long illness more palatable.

2) Understanding that schizophrenia is here to stay (n=6, 13%). Six participants described how accepting that schizophrenia is a life long illness forces them to learn to live with it.

"Well, if they've got schizophrenia, they've got to realize that it isn't going to go away. And you've gotta live with. And other people have to live with them." (01-02-11.1)

"It's a life long thing." (6-01-04)

"And so well, this is, this is a long term illness, you know. They didn't know about schizophrenia back then." (41-01-40)

"Just that's the way it goes, I guess. You know, you can't say okay, I want it to go away. But you can get it to a point where you can function semi, you know, good. I mean, it's normal for somebody to have good days and bad days..." (45-02-38)

Published personal narratives of mental illness and recovery support the importance of understanding schizophrenia as a life long illness. As one person wrote in their published personal account of recovery "...only after I accepted the illness as chronic could I really do something about improving my life. I had to learn that I could not wish away the illness; I could not will it not to be so." (p. 635) (Anonymous, 1989). Another author recalls in his story of recovery how he would "sit out life" (p. 15) until he could be his perfect self, which did not include experiencing any symptoms of mental illness (Anonymous, 1993). Once he realized

that mental illness would probably always be a part of his life he decided to stop putting his life on hold and to work within his limitations and disability to accomplish the things in life that he valued. This is an important component of the recovery process because it leads people to develop long-term coping strategies, such as taking medication or accepting ups and downs. When schizophrenia is viewed as a life-long illness it becomes easier to view set backs and relapses, as part of the recovery process instead of as failures.

3) Learning to accept set backs & relapses (n=5, 11%). Five participants learned to accept set backs and relapses as part of the recovery process and that they need not be viewed as catastrophic or a failure. Orrin (1994), in her personal account of recovery, views relapses as part of her recovery and not as failures. Accepting set backs and relapses allows a person to pick up the pieces and move forward without feeling like they failed or there is no hope for success. Also knowing that having a relapse is not a failure or a catastrophe encourages people to take risks or challenges which may precipitate a relapse. Deegan (1993) even frames her relapses in a more positive light by calling them "breakthroughs" instead of "breakdowns" (p.10).

"I could be whole and know that I could have a break and still recover and move on." (08-01-02.1)

"I'm not always stable, I have ups and downs during the year." (09-01-14)

"And a set back doesn't mean that you're not successful and success has a lot of different meanings." (20-01-00)

"...it also gave me hope that, you know, it's not impossible to overcome something like this. Which is something that I'm still struggling with but there are people who seem to get by okay. Every now and then, they may have a few setbacks but I guess that's something I'm gonna have to expect." (25-02-10)

4) Understanding that schizophrenia is a no fault illness (n=7, 15%).

Understanding schizophrenia as a no-fault illness helps to remove blame for the illness from the person labeled with schizophrenia, their family members, or others who may have caused them harm. For some participants, understanding schizophrenia as a no-fault illness is important to the recovery process because it allows them to move forward by forgiving themselves and others, as well as providing a non-threatening way to integrate schizophrenia with ones' sense of self. Seven participants described understanding schizophrenia as a no fault illness as important to their recovery process.

“But I said no, it's a chemical imbalance in the brain ...Somebody might say, well, it's all my mother's fault. What I would say to them is I thought it was, too. I blamed my mother for years. But my mother did the best she could and I realize that this is a no-fault illness. It's not my mother's fault and it's not my fault. It's a no-fault illness, too. A lot of them thought it was a weakness of character, like I did. I just, why did I have this weakness of character and I couldn't overcome this terrible sickness.” (23-01-00)

“They emphasize that the illness is like having cancer or something. It's not that you're bad or anything. It's a chemical imbalance.” (28-01-15)

“I went there several times and I was so upset...I said Mary, I will never go back there again because he had me so scared and I don't think this has nothing to do with Satan. It's an illness, it's a physical thing, it's brain chemistry and I will never go back to him again. I was insulted, humiliated.” (29-02-02)

“I have a disorder that causes me to have a hurt limbic system. ... It wasn't mom and dad's fault. It goes back to what I understand. I have been told not unkindly that I inherited a bunch of junk chromosomes. See, schizophrenia is pasted along on chromosome pair 21. That's basically all I know about it.” (48-02-16)

For some participants, understanding schizophrenia as biological in nature and as a “no fault” illness is important to the recovery process because it allows them to separate it from their sense of self, normalize it, and forgive themselves and others. NAMI (National Alliance for the Mentally Ill), one of the most powerful advocacy organizations, played a key

role in changing the understanding of schizophrenia from a psychological illness, with its genesis in the dysfunctional family, to an illness caused by faulty neurotransmitters or a broken brain (McLean, 1990). This redefinition was viewed by the organization as necessary to remove the blame for the illness from the family and individual and to improve treatment (McLean, 1990). However, some have argued that a biological or medical explanation of schizophrenia hinders their recovery because it deprives them of any sense of control or self determination (e.g., Fisher, 1996). These two perspectives represent opposite extremes on a continuum of beliefs about the causation of schizophrenia. It is likely that most people's beliefs fall somewhere in the middle. In a study done with 81 persons diagnosed with mental illness, Kravetz et al., (2000) supported this view by finding that most participants viewed mental illness as caused and exacerbated by complex biopsychosocial factors.

5) *Believing that recovery is possible (n=8, 17%)*. Changing ones' beliefs about schizophrenia from an illness with a poor prognosis and no chance of recovery, to include the chance of recovery, is an important source of hope for participants. Eight participants described how they changed their understanding of schizophrenia to include the chance of recovery.

“We don't completely recover but we do recover, we do get well. We do get better. We can be successful people in society....There is hope for recovery.” (29-02-02)

“I'm coming from a mental illness, going off medication, going back to work, oh yeah, I've got a lot to look forward to.” (30-02-02)

“Cause I felt hopeless at first. You know, then I felt more hopeful....I am sure it is going to get better. I'm feeling that way.” (32-02-13)

“We all believe in each other and try to convey that there is hope for everybody.” (43-02-38)

“Each day is a new day and it's gonna work. I have that attitude. It's gonna

work.” (49-02-04)

Changing ones' beliefs about schizophrenia to incorporate more positive images of people with schizophrenia and to more accurately reflect the nature of the illness is important to the recovery process because it helps to restore and maintain hope in times of distress and to encourage the development of positive coping strategies (Kruger, 2000). Also, how one understands schizophrenia can also have implications for how one understands ones' self with a diagnosis of schizophrenia.

B. Changed beliefs about self (n=32, 70%)

A diagnosis of schizophrenia challenges and disrupts a person's sense of self or their beliefs about who they are, where they fit in the world, and who is in control of their life. As described in phase two, the impact of schizophrenia on ones' life makes people feel alienated and alone in their experiences and illness, as if they do not have anything in common with other people. In this element of phase 3, 32 participants described a number of ways in which they changed their beliefs about themselves including discovering a sense of belonging and acceptance and accepting ones' self with a diagnosis of schizophrenia. They also described how it is important to accept responsibility for ones' actions and behaviors and to realize that one does have choices. The process of recovery involves discovering that one is not alone, accepting the diagnosis of schizophrenia, accepting ones' self with schizophrenia, and taking responsibility for ones' self.

1) That one is not alone in their experience or illness (n =15, 33%). In the second phase, participants described how schizophrenia impacted their life by making them feel alone, isolated, not understood, and marginalized. Fifteen participants described how realizing

that one is *not* alone allows them to develop a sense of belonging and enhanced well-being.

“Then everybody went around and told their story and I told my story, too. And when I left, I had this great feeling of relief, you know. Everything's gonna be OK. There are more people like me and everything's going to be OK and that's how I felt when I left... Like you know, just the awesome feeling of everything's going to be just fine. Because I knew that I wasn't so different than everybody else. I had something in common with them, that I had with nobody else in my life. I never knew anybody that had schizophrenia, you know?” (10-01-10)

“... I could understand that people were going through the same thing that I was and I didn't feel so isolated which was a big step right there, you know, feeling like you are not alone.... there was nobody sitting around the table to judge you or point a finger at you for things that you've done wrong. We could all relate, you know, and I think the big issue of being able to relate to one another is a big step. You know, having something in common. And let's face it, that's what most relationships are based on is something in common, you know?... just listening those first couple times, I automatically sensed, well shit, I'm not so different after all. And just that feeling of not being alone is something because there were experiences that I was scared to talk about. You know, like I mean, you tell somebody that you're gonna sit and watch the TV and you think it's talking at you, they're gonna bust out laughing, like who's this idiot, you know? But when you go to a group and you sit down and tell people, oh, I'm not so different after all. I think the bottom line with people is they want to feel accepted and common, you know? They don't want to be different.” (11-01-03)

“Since I've been coming to the group, I haven't been down. I see that other people have the same thing and then I don't really feel that depressed.” (26-02-14)

“You don't really feel like you fit in anywhere. Here [SA] you fit in. You feel sort of like a social outcast.... Like I say, you're experiencing, you have other people experiencing things you're experiencing that you can talk about. It makes you feel better, you know.” (28-01-15)

Researchers who study the impact of chronic physical illness have also found that chronic illness challenges and disrupts a person's sense of self or beliefs about who they are, where they fit in the world, and who is in control of their life (Bury, 1982; Charmaz, 1983; 1987; 1995). Charmaz (1983) attributes this loss of self to leading restricted lives including the loss of valued social roles and connections to other people. Discovering

that one is not alone and connecting to others who share similar experiences is an integral part of the recovery process because it reinforces positive feelings about one's self.

2) *Accepting the diagnosis of schizophrenia (n=21, 46%).* Accepting that one has schizophrenia can either be beneficial to the recovery process or the cause of much despair and hopelessness depending on what beliefs the person holds about schizophrenia. If a person is told that recovery is possible and has positive role models of people diagnosed with schizophrenia who are living happy, productive, and successful lives, then it is more likely that accepting schizophrenia will not produce despair and hopelessness. Twenty-one participants in this study described how accepting that they have schizophrenia is an integral component of the recovery process.

“... the first step is just, you know, you get away from, get away from denying the illness.” (21-01-00)

“But had I never taken that first step, to admit I was schizophrenic and join the group, nothing would have developed...” (08-01-02.1)

Participants also described how accepting ones' schizophrenia can facilitate accepting or seeking help in dealing with it and the problems associated with it.

“Well, I first, when I was sick, I didn't realize I was sick. I thought everybody was saying that I needed help but I wouldn't accept it. I thought there was something wrong with them....And one day I just woke up by my brother's house. I said I can't take it no more. There's something wrong and I need help.” (38-01-38)

Also, for some participants accepting schizophrenia also involves recognizing that they need to be an active participant in their own recovery process.

“Well, if they've got schizophrenia, they've got to realize that it isn't going to go away. And you've gotta live with. And other people have to live with them. And this [attending SA] is a great way to find out how you can make an advantage of it.” (01-02-11.1)

“And I think, for me, it was when I began to accept my illness. That's a big

problem - denial. Big, big thing. And when I started to accept my illness and wanted to know more about it and got a little less psychotic and was able to drive and get out....When we start accepting our illness wanta know more about it, learn how people handle it, and wanta be with other people.” (28-01-15)

For others, seeing other people with schizophrenia helped them to accept their illness and helped them to learn how to live with it.

“And I guess there were some others that I was cohabitating with that were worse than me. And that kinda strung a light on what mental illness was for me. Once I saw myself behaving in their manners, in their modes of behavior, I started to realize that hey, here I am, saying they're sick and I'm doing it myself. So I kind of got a grip and I guess you could say I did get a grip on it that I was gonna have to put an effort to participate.” (02-02-11)

“I just wasn't interested in it. I felt like, I'm just a normal person.... So I didn't really think there was anything wrong with me. Then I met other people that seemed like that they could function just like the way I did, the only thing is that they had a mental illness just like I did and they took medications to prevent them from having another episode just like me. So I just learned that there are people just like me...I felt like I didn't have any problems. I thought I was just fine. And meeting some other people, I guess I kind of learned maybe I do have some problems....I do have a mental illness....But I've also learned how to deal, how to cope with it. Which, that helps out a lot. I learned how to deal with it.” (22-02-02)

For some participants, accepting schizophrenia also means acknowledging limitations and accepting treatments or participation in activities that are tied to their illness.

“I didn't accept it at first. I began partially accepting it in spring of 1988. I had been hospitalized 3 times, each time I had gone off my medications before being hospitalized. I don't believe in it, but I needed to start taking my meds.” (03-02-11.1)

“... now that I do know that I have this illness that I, you know, just can't... I try to avoid what do you call it? Stress.” (44-02-38)

“I felt not very good about myself and I think that's why I went back because I felt like maybe I was denying the schizophrenia, trying to go to a university. Maybe I should just go to SA and recover and see what else I can do.” (33-02-05)

Hatfield (1994) argues that accepting the illness and how it has impacted ones' life is

integral to the recovery process. However, both she and Deegan (1993) also emphasize that it is important to accept it without giving in to it, allowing it to control ones' life, or letting it define ones' self. Along with accepting that one has schizophrenia it is also important to figure out how to incorporate ones' beliefs about schizophrenia with ones' beliefs about ones' self. Often changing ones' negative perceptions and beliefs about schizophrenia is integral to being able to accept one's self with a diagnosis of schizophrenia.

3) Accepting ones' self (n=14, 30%). Accepting ones' self is an important component of the recovery process and it is closely tied to accepting schizophrenia as one has come to understand it. Participants described how integrating ones' understanding and acceptance of schizophrenia with their own sense of self was integral to achieving self acceptance and a sense of value and worth. For participants this meant recognizing that schizophrenia is part of who they are and yet simultaneously putting it into perspective and not allowing it to take over or consume their sense of self or their life. Some of the participants viewed schizophrenia as separate from them self or as something they did not cause, was not a part of them, and had no control over. Viewing schizophrenia as something they did not cause helped them to forgive themselves and others and to move forward with their life. However it did not necessarily mean that they relinquished control over their symptoms or the illness or other aspects of their life. For participants, self acceptance is achieved by accepting the diagnosis of schizophrenia and either integrating or separating it from ones' sense of self, coming to terms with the impact it has had on ones' life, being realistic in ones' appraisal of the current situation, and being able to envision a positive future which includes schizophrenia. Fourteen participants described the role of accepting ones' self in the process of recovery.

“So I know I've been wool gathering again. That's how it's impacted on my life, you know? But I don't care. I used to feel bad about it but I take it like

my therapist said, "Hey, that's you. You're going to be that way all the rest of your life probably so get used to it." So I'm trying to improve my shopping skills and being a little more speedy, you know. That's about how it's impacted on my life. Now I'm not ashamed to admit my illness. I don't wear it on my sleeve but I don't conceal it. The three jobs I've applied for I very prominently told them that Fridays are a no no because I have my group. It's made me more of a person, it's given me a bigger heart. I understand myself better. I'm more tolerant." (07-01-05)

"I felt like for the first time in my life, I didn't have to run, hide, or keep trying to mask symptoms or trying to show everybody I was normal ... I was a person and I had a mental illness at the same time. I couldn't ever accept being either one of those without knowing that there was another... in other words, I didn't want to just accept myself as mentally ill, an invalid and not, even though I have abilities and I do things and then couldn't be normal all the time because, you know, the illness comes on and you can't deny it. It's apparent. So I was able to accept myself as a whole person not long after that" (08-01-02.1)

"If people didn't accept me for what I was, well then, you know... let them do whatever they want to do. I don't give a shit. I don't want to know them anyways." (11-01-03)

"... I had to re-integrate my whole personality, my whole life style. I'm starting from scratch. And I needed help doing that. I needed someone that I could talk to and say hey, I've got this problem.And then I just started to integrate it into being part of me and kinda said the heck with what everybody else thinks. You know, I've gotta do things for me and not worry about what everybody else thinks." (35-01-00)

"...No, I figure if people can't accept me for who I am, then they're just not worth being, you know, friends with." (45-02-38)

Accepting ones' self seems to be facilitated by changing ones' beliefs about schizophrenia to include more positive images of people with schizophrenia and the belief that schizophrenia is a life-long condition. It also seems to be facilitated by realizing that one is not alone and has some common experiences with others. Pettie and Triolo (1999) describe the process of accepting ones' self with schizophrenia and figuring out how to integrate the illness into identity as the critical task of recovery. Accepting ones' self with schizophrenia is an important component of the recovery process because it facilitates self understanding and

the development of a more positive sense of self.

4) Believing that one has power and control over life (n=15, 33%). Fifteen participants described the importance of not surrendering to or becoming a victim of the illness. Instead they acknowledge the role of their beliefs, actions, and will power in becoming and staying well. Participants described some of the strategies they used to gain power and control over the symptoms and illness, including: sheer will power, separating ones' self from the illness so as to not let the illness dominate their life; and talking to others with schizophrenia to put their problems in perspective. Participants also described taking responsibility for ones' self by making ones' own decisions; taking responsibility for ones' actions, feelings, and emotions; and holding ones' self accountable for the consequences of their actions.

“...[I] attribute that a lot to my therapist and my doctor. They've taught me how to deal with my illness instead of just letting it deal with me.... I will not let this mental illness ruin my life. So I fight back....I mean, you learn to take control of it before it controls you and you have nothing. It's insight...But I didn't do it until it was forced on me by my sister and my roommate, to take responsibility for myself. You know, like when I would stop taking medication, like people here do. I mean, they'd say you have to hold up your end of this. We're breaking our necks here to keep you out of the hospital and you stop taking your meds because you think you're being poisoned or whatever....I've learned that I have more control over these things than I thought I did....” (05-01-11.1)”

“I sorta just decided to take charge of my own life.” (18-02-16)

“I said what helped me the most? The most, for the sudden recovery is when I realized I had a choice. I never thought I had a choice, so I chose. But I realized, I always thought you just reacted. I didn't know that, you know what I mean?... Well, I didn't realize you have a choice. That you could choose to control your emotion or that I had a choice for not being mentally ill.... So sometimes when we, you know, that's how I want it to be so that we take responsibility. You know, and not be a victim. If you, I think it's so important to accept it as a challenge....They're things that we can do consciously to help ourselves....You have to make your own happiness....There's such a freedom, you know, when you're in charge of your own life. You know, like I say that

in my speeches because my schizophrenia ruled me for 14 years. It controlled every aspect of my life. And now, I control my schizophrenia.” (23-01-00)

“... I decide for myself, I decide to be well. I decided to be happy. And I take full responsibility for what I do.” (29-02-02)

“There's some things that you can go do. You still can make it. Because remember, it's up to you. You don't have to let your negativity take over.” (36-02-04)

Feeling that one has power or control over life is an important aspect of the recovery process because it allows a person to feel that they have control over what happens and encourages them to play an active role in making decisions that concern their life and in taking action on their own behalf. Deegan (1993) describes this aspect of her recovery process as trying "to stay in the driver's seat of my life." (p. 10).

II. Learning How to Live with Schizophrenia (n=26, 57%)

The second component of Redefinition and Transformation is learning how to live with schizophrenia. This component consists of strategies that participants have learned and developed to enable them to live successfully with schizophrenia and its associated problems. Twenty-six participants described the different ways that they learned to live with schizophrenia depending on their own unique experience of the symptoms and their personal preferences. One aspect of this involves developing different ways to manage and cope with the symptoms and illness including actively fighting the illness and the symptoms and learning which aspects of the illness and their health they can and cannot control. A second aspect of learning to live with schizophrenia involves recognizing the need for help from professionals, family members, or others with schizophrenia.

A. Managing symptoms and illness (n=19, 41%).

Nineteen participants described ways in which they learned to manage their symptoms and illness. Participants described learning the warning signs of when one is getting ill and seeking help before things get too bad as one of the key components of being able to manage one's symptoms and illness. Other ways to manage ones' symptoms and illness, as described by participants, include taking medication, learning to distinguish between what is real and what is not, monitoring stress and activity levels, and chewing gum to disguise the symptoms of Tardive Dyskinesia. Being able to manage, compensate for, and overcome ones' symptoms is a key component of the recovery process because it allows participants to self-manage their illness and to develop a sense of control and power over their illness and life.

Recognizing that many of ones' beliefs, feelings, and sensory perceptions are actually symptoms of schizophrenia is helpful to many participants because it helps them to control their symptoms, and to identify when they are starting to get sick.

"...I have learned the difference from what goes on in my head and reality. ...Totally changed me. I mean, I don't know what happened but it completely changed me. And all of a sudden, I just stopped and said, now I can tell the difference from reality and what goes on in my head. What needs to be done, what can be done. I learned all sorts of ways of coping with it, my illness and stuff like that. That's when I started really understanding the difference between reality and delusions, delusional thinking. I started learning different ways of coping with it and stuff..." (10-01-10)

"...you know, if they [voices] tell me to take off my clothes in public or something, it's... but no, I can really, I can distinguish, I don't do bad things or anything like that." (25-02-10)

"I know when I'm getting sick...I learned how to handle my illness better, knowing when I get sick." (23-01-00)

Participants identified the need to monitor and control stress and activity levels in

order to not exacerbate symptoms.

“I have to stay low key. I have to keep myself calm and I need a lot of quiet, a lot of quiet. But then too much quiet... you have to interact, you know, to keep yourself going. I'll be in that bed, my bed, you know.” (28-01-15)

“... before, I didn't know what I had. I didn't know my danger signs. ...[I] focused on trying to better myself. Learn all over again. Maybe, you know, now that I do know that I have this illness that I, you know, just can't... I try to avoid what do you call it? Stress. Stress and situations.” (44-02-38)

For some participants, the major challenge of learning to live with schizophrenia involves figuring out ways to control the unwanted thoughts. Two participants described using the following strategies to control unwanted thoughts.

“Well, I try to not take a nap during the day. I go to as many activities as I possibly can. They have a lot of activities here for us...[The activities] keep my mind off my troubles.” (14-02-11.1)

“Oh, I used to listen to music, get into listening to music, I used to listen to music and cope [with the voices and unwanted thoughts] that way.” (32-02-13)

For one participant, the primary way they learned to live with their schizophrenia is by taking their medications.

“Well, I cope by trying to take my medicines daily. [ANYTHING ELSE?] That's all.” (19-02-13)

Taking medications is one way that participants described managing their illness and for at least one participant this is all they did to manage their illness. However, as described in personal accounts of recovery, taking medications is only one method used to manage symptoms and illness and that a variety of other equally important methods are utilized for this purpose (Anonymous, 1989; Deegan, 1993).

Some participants have learned to manage the symptoms of schizophrenia or the visible side effects of medications by disguising them with more appropriate or socially

acceptable behaviors that do not attract attention. It is important to note that this does not mean that they have eradicated their symptoms, it just means they can identify their symptoms and disguise them in order to not elicit negative reactions from those around them. This is important to the recovery process because it allows people to fit in and not feel out of place or criticized for being different.

“It has to do with my tardive dyskinesia, which is one of the reasons I chew gum a lot. It helps because it gives the impression that, oh, she's chewing gum. That's why her face is moving. ...I would like not to move so much.” (34-02-05)

“Now, if I don't go singing it all the time and like grinning all the time, but there's something on my mind that made me grin. Because I'm grinning all the time. They might read you wrong when you have a big grin. I guess it all depends on how I respond to things.” (36-02-04)

Consistent with the findings of Breier and Strauss (1983), participants in this study found that either reducing activity to control stress or increasing activity to refocus energy and attention away from the symptoms was an important coping mechanism. Also consistent with the findings of this study, Carr (1988) found that listening to music was the most frequently used passive strategy to cope with one's symptoms. Frese & Walker (1997) and Leete (1994) also describes the importance of monitoring and controlling stress and activity levels in order to cope more effectively with the symptoms of schizophrenia. Taking medications is also identified by participants as one of the ways they cope with schizophrenia, which is consistent to how taking medication is discussed in the personal narratives of people diagnosed with serious mental illness (e.g., Deegan, 1993; Frese, 1997). Leete (1997) describes how she has learned to cope with the distressing thoughts and feelings brought on by her illness in ways that are socially acceptable so that she does not elicit negative reactions by others who are not familiar

with the manifestations of schizophrenia. By learning how to express symptoms in socially acceptable ways or by hiding them, participants are less likely to provoke a negative response by the mental health system (i.e. increasing medication or being hospitalized) and are better able to fit in and participate in a variety of settings. Also being able to identify ones' symptoms and when they are no longer controlled allows a person to seek help when needed.

B. Recognizing need for help (n=10, 22%).

Recognizing that one needs help from family, friends, peers, or professionals in dealing with schizophrenia and the associated problems is an important component of the recovery process, because it indicates that a person has accepted that they do have problems and are actively trying to ameliorate them. Before a person can recognize the need for help they must first accept that they are having problems and understand their problems in such a way as to precipitate seeking out or asking for help. Ten participants described recognizing the need for help from others and the futility of trying to do it alone.

"I knew I needed all the help I could get, you know, support." (12-01-03)

"And I started to depend on a dialogue instead of the usual soul searching that's done, you know, it's like a self thing. I started to depend on the dialogue with other people. I've been carrying on this conversation now, the same one for a long time." (14-02-11.1)

"... you admit that you have a problem and you need some help." (26-02-14)

"It was my first experience with any mentally ill patients on group togetherness. I'd never been for this. I always felt that it was wrong and I kept everything to myself. After attending one meeting ...I realized yes, I do need help. I do choose to be well and I want to be a happy..." (29-02-02)

Oftentimes this is a difficult step for people to take, because, as it is described in one personal narrative of mental illness and recovery, the message that they have gotten

throughout their life is that asking for help indicates weakness of character (Anonymous, 1993). So, not only does recognizing a need for help indicate acceptance of ones' problems and taking an active role in ones' recovery, but in some cases it shows a persons' ability to stand up to the subtle negative messages that society sends about seeking help and the negative implications this has for ones' character.

Ralph (1997) also argues that recognizing the need for help and that one cannot do it alone is important to the recovery process. This means that the person is ready to recognize that they have a problem and that they need help in ameliorating it. Seeking help is one way to start to take control of or fight against the illness.

Carr (1988) describes the experience of schizophrenia as "a learning process in which patients make active attempts to master the illness and not have it dominate them" (p. 12). Learning to live successfully with schizophrenia is a process that involves learning to manage ones' illness, especially the symptoms and side effects from medication, and learning to recognize when help is needed and being able to accept it. Personal accounts of mental illness and recovery discuss a variety of ways that people come to understand their illness and learn to live with it (Anonymous, 1989; 1993; Deegan, 1993; Koehler, 1993; Weingarten, 1994). Deegan (1993) describes using medication, hospitals, nature, and her relationship with God and friends to handle the vagaries of her illness. Weingarten (1994) emphasizes the need to recognize ones' susceptibility to certain states, such as depression or anxiety, and to develop proactive coping methods. He describes using therapy and work and creating a healthy life style as some of the ways that he does this. As participants learn to manage and control their illness more effectively they are able to dedicate more of their time, energy, and personal resources towards moving forward with their life instead of being solely consumed the illness.

III. Redefining Goals and Expectations (n=16, 35%)

Redefining ones' expectations and goals is the third component of the Redefinition and Transformation phase. Redefining ones' expectations and goals entails using ones' recognition and awareness of how schizophrenia has impacted ones' life, how the experience has changed ones' values and beliefs, and figuring out ways to move forward. Sixteen participants described the process of redefining their goals and expectations as important to the recovery process.

Many of the examples contained in this component are related to the impact that schizophrenia has had on ones' life, which participants described in phase two. For example, in the second phase of the recovery process, participants described how schizophrenia disrupts ones' life course and participation in valued social roles, especially their ability to work for pay. One of the ways this is addressed in this component is by identifying alternatives to work which provide other types of valued roles in which to participate. Participants described redefining ones' expectations for ones' life within the context of a disability and developing new hopes and dreams as important aspects of moving forward and conceptualizing a positive future.

A. Redefining expectations for life within the context of a disability (n=9, 20%).

Redefining goals and expectations is linked to phase two or recognizing the impact that a diagnosis of schizophrenia has on ones' life. A diagnosis of schizophrenia can disrupt a person's life through the direct experience of symptoms, through limited choices in housing, employment, and school because of discrimination, or through the different life choices that are made because of the experience of illness. After participants recognize how a diagnosis of schizophrenia impacted or disrupted their life, they are able to take

stock of their current situation and to redefine their current goals or set new goals based on this new understanding. This is an important aspect of recovery because it allows people to move forward by either taking into account the limitations imposed by a disability or by building on newly identified strengths and skills.

For some participants, redefining expectations for their life involved coming to terms with not being able to accomplish certain goals in life or attain certain dreams because of the limitations imposed by their psychiatric disability.

“Thinking that maybe there is a way.... And you know, something like this, where I'd work maybe six months out of the year at the most, and then all I would have to do is just hold it together for those six months and then, if I wanta get sick in the winter time, I have time to do that. It's not something I'll have to do every day for years and years and years.” (25-02-10)

“A good job, a wife, kids, money. It's a shame, I'll never get to complete that but as I said before, you got to start over sometimes....What I told my therapist, before I started coming to the meetings, I said ‘I know I can't be 100% again but if I'm able to get to the high 80s, I'll be happy.’ I would consider myself right now, because of my therapist and the group especially, I think I reached my goal. I think I'm about 85%. I am satisfied with that.” (30-02-02)

“I wanted to be able to support myself, to get off SSD. I realize now that's not going to happen unless some miracle drug comes out which I don't think will be for a while. And if it does, I don't know what I would do with myself because I identify myself as schizophrenic and living here in this apartment. I work at the library three hours a day, 9-12 Monday through Thursday and that's just right for me. It's not too much and it's not too little. So I've been lucky to find that, but I still had to struggle with was I ever going to get a Bachelor's degree and go on and do all that? Would I ever have kids and I've come to terms with those two things-no and no. I'm not gonna have any kids and I'm not gonna probably ever have a career that's full time. Strangely enough, it doesn't bother me. I just felt a release of negative energy when I gave up those aspirations.... It all depends on how bad our illness is and how realistic we are in accepting the illness.... I don't have all my goals fulfilled and everything, but I figure, you know, I don't have to do everything like modern women do. You know? And I can't anyway so I just accepted that.” (33-02-05)

“Before I got sick, I wanted to be a chief executive officer for a company so I

had high goals for myself. And SA kept reminding me that I had an illness. That maybe that dream wasn't realistic for me anymore. And maybe I had to start re-dreaming and start, start setting new goals and more practical to what I could actually accomplish rather than what I wanted to accomplish. I had to become more realistic. I had to become more down to earth and I had to look inside myself. ... You know, I got off the fast track and got really down to earth and didn't think about, I wanted to make a million dollars by the time I was 30. Now I've kinda forgotten about that. And I just enjoy life now. I told one person if I couldn't be chief executive officer, I wasn't gonna do anything. And just recently, that's when I was sick, just recently I'm saying to myself, hey, I'm gonna get out there and do more. So I think I'm coming around to another phase again." (35-01-00)

The role of developing new expectations for ones' self is supported by Koehler (1993) who acknowledges that in his own recovery process it is important for him to reduce his expectations, because he finds it improves his performance and increases his chance for success. For other participants, redefining expectations for their life involved learning to expect more from their life or career than they did previously.

"But had I never taken that first step, to admit I was schizophrenic and join the group, nothing would have developed, I would still be waitressing and wondering, you know? Because I thought I reached as far as I wanted to go, as far as career wise goes. I just wanted to continue helping others and helping myself." (08-01-02.1)

Redefining ones' expectations for ones' life through taking stock of ones' current situation and acknowledging both ones' limitations and talents allowed some participants to develop new goals, hopes, and dreams for their life.

B. Developing goals, hopes, and dreams (n=10, 22%).

Many of the goals, hopes, and dreams described by participants are the same as those expressed by the majority culture, including wanting to get married or having a partner, having a family, having a good place to live, having a job, going to school, and having a car. This is supported by what others have found - that people with schizophrenia are no different from people without schizophrenia in their needs for structure in life, for a decent standard of

living, for a role and identity, and for a reason to get out of bed in the morning (Bell, Lysaker, & Milstein, 1996). Some of the goals articulated by participants are focused on getting back what was lost when they became ill with schizophrenia and which were described earlier in phase two of the recovery process (e.g., loss of job, relationships). Being able to express and articulate goals and dreams for the future is a necessary step to eventually achieving ones' goals and it shows that the participant believes striving towards goals is possible. Ten participants described their goals, hopes, and dreams.

"I have a long life goal to be married and have a family, and have somewhere to live and transportation and a nice, steady job or two jobs, if I can manage my hours and my time....First, I gotta go to college to get a better job. I have to have a good quality brain to be able to study. If I don't have the brains to do the homework then I won't have the grades. So I'm just referring to that kind of goal." (02-02-11)

"I would like to get married when I'm capable of holding down a job. I want to be independent before I have anyone else sharing dependence. I want to be independent myself." (10-01-10)

"I'm learning how to dream and not look at my life... I'm learning how not to look at the terrible things that are happening right now. I'm learning how to dream and have hopes and aspirations. ...the dreams, the hope and dream is to get well one day and resume our former career, to start a new careers. To find a nice place to live. To own and operate a car. To have a family." (19-02-13)

"... making goals for myself. Even though I sometimes wouldn't meet those goals, it gave me something to look forward to. And I started changing, every six months, I started changing. ... I set some goals for this year. The first goal is to get me a car. My second goal is to go back to work and I'm going through a process of going to do that right now. I want to work in September and it looks like it's going to be in September, too. Just work part time and still keep my social security....When you set goals, if you don't make it, fine, start again. And if you do make it, good for you." (30-02-02)

Redefining ones' expectations and developing goals and dreams is a very important aspect of the recovery process. Davidson and Strauss (1992) describe a similar process, which involves "taking stock of [one's current] strengths and weaknesses" and "assessing possibilities

for change" (p. 134) as an integral part of the recovery process because it helps people to rediscover a functional sense of self. Doing this involves recognizing how schizophrenia has impacted ones' life and recognizing lost opportunities so that one can discover new ones (Lunt, 2000). It involves a degree of recognition of how schizophrenia has changed ones' attitudes and beliefs about ones' self, ones' values, and ones' requirements for a happy and contented life. In one person's account of their own recovery process, they emphasize the importance of rethinking ones' conceptions of success and happiness before and after becoming ill (Anonymous, 1989). Deegan (1993) also recognizes that mental illness can shatter ones' life and dreams, but that from the ruins one can build a new, possibly different life. Redefining ones' expectations allows people to re-evaluate their life, goals, values, and wishes in the aftermath of a diagnosis of schizophrenia and within the context of their perceived level of continued disability. It allows them to set realistic goals that they have a good chance of accomplishing and to take small steps towards accomplishing their larger life goals (Koehler, 1993). It does not have to mean a person lowers their expectations or settles for less in life. As Deegan (1993) states, "it is possible to live a whole and happy life and still have a psychiatric disability." (p. 10). It also involves reassessing ones' life and recognizing that ones' values, desires, and beliefs may have been changed by ones' experiences with schizophrenia and incorporating these changes into how one should move forward.

IV. Developing Strategies for Change (n=23, 50%)

The fourth component of phase three involves identifying specific areas of change within ones' life, identifying abilities and skills to utilize in creating positive change, and challenging and overcoming ones' fears and other impediments to creating the desired change. These are all important contributors to ones' ability to move beyond the illness

and to transform ones' self and life into something with value, meaning, and purpose. A total of 23 participants described one or both of these strategies of change.

A. Identifying specific areas of change (n=9, 20%).

Nine participants described how they identified areas of change and in many cases took action to implement the change in their life. Sometimes the impetus for change is feeling unhappy or discontented with one's current life situation or being told by others, such as a therapist, that the person needed to make a change.

"I didn't have a ride there. Then when I got my own car, I decided that I would go, make an effort to take myself and drive with my vehicle that I purchased, that I had bought. And I would make it like a regiment." (02-02-11)

"You know, I was looking to change my ways because I had very poor grooming skills. I mean, I'd take a shower every day but I didn't want to shave and stuff like that. I had a beard down to here....I didn't want to live my life the way I had lived it in the past and at that moment. I was very unhappy....I needed something to complete my life and I was looking for something at that time." (11-01-03)

"Well, well, I've taken this step a few times and I say, well, I say it because I wanta get more interested in praying and doing things that are spiritual and I think that that would help my life." (13-01-15)

"And I'm thinking, I'm here, at home. They didn't bother coming and talking to me. Seeing how things was or saying hi. I realized then that I had to do something to meet friends, do something to change my life." (30-02-02)

Identifying areas of change and taking action to create change is an important aspect of recovery because it indicates the presence of hope and the accompanying belief that change is possible. It also provides a direction and plan for implementing changes and allows a person to move forward by striving to create positive changes in their life. Once a person identifies areas of their life that they are discontented with or would like to change or improve, they must often overcome both physical and psychological barriers in order to implement those changes.

B. Overcoming fear and impediments (n=14, 30%).

Fourteen participants described how they had to push themselves physically and psychologically to overcome functional impairments, lethargy, fear, or anxiety in order to do something that they valued, to gain a particular skill, or to participate in an activity that was meaningful to them. When participants were able to overcome their fears and anxieties in one setting in order to reach a valued goal, they were encouraged to continue taking risks and challenging themselves in other ways. Challenging ones' self and overcoming both physical and psychological barriers to reaching ones' goals is an important aspect of recovery because it allows one to reach valued goals, develop self confidence and esteem, and puts one back in the drivers seat of ones' life.

Some participants described how they had to overcome a great deal of anxiety and fear when they first started attending or leading an SA group. Sometimes it was the support and encouragement of others and sometimes it was a desire for growth and change that led to the decision to face the fear.

“I was so nervous (about leading the group). I mean, I probably was shaking up a storm but I knew that this was what I wanted to do. That this was something that I had to do. For me and for anybody else who wanted me to help them, you know? So I just said OK.” (10-01-10)

“But anyways, I got to attend these classes and I thought it would be healthy for me just to be able to get up and, you know, go one step further from talking on a one on one to being able to talk in front of people. And that was a big step for me.” (11-01-03)

Although SA played a central role in some participants experiences, others described how participating in recreational or vocational programs or work or school settings helped them to face and overcome their fears and anxieties around making mistakes, not being good enough, or not having the skills or knowledge to succeed.

“And she said, “Yes, you can, here, I’ll show you how.” So she’s gotten me doing some projects and some art work and everything. And that fear, that subconscious fear, it’s all gone. It’s all gone.” (29-02-02)

“Well, the voices, the hallucinations. Nerves, everything. Because when I do the volunteer work, I get really nervous, you know.” (32-02-13)

“...get out and meet more people and tell them my story and tell them how hard it was for me to get started. I remember going down the halls of St. Joe’s and just crying because I was so confused. I wasn’t sure if I was on the right floor or not and I was a messenger at the time and one time a social worker came up to me and asked me if I was okay and I told her yes. And I was just going, get myself together, either in the chapel or else in the bathroom and then I was able to go ahead and do my job.” (35-01-00)

Once a person overcame the physical and psychological barriers to engaging in valued activities and started participating in more activities and settings, they began to identify abilities and skills that were either untapped prior to getting a diagnosis of schizophrenia or perhaps just dormant. Abilities and skills may also be identified prior to trying new things in order to give the person a direction or focus for implementing positive change.

C. Identifying abilities and skills (n=9, 20%).

Nine participants described how identifying new abilities and skills helped them to build self-confidence, identify areas of positive change, and provide direction to their lives. Tapping into one’s abilities and skills is an integral part of recovery because it opens up the possibility for change and helps to positively enhance ones’ sense of self.

Participants described SA’s integral role in providing opportunities to discover new abilities and skills, including ones’ ability to help others, ones’ ability to facilitate group discussion and interaction, and speak in front of groups of people.

“I feel more confident in leading groups now. Like I was in, I went to college and in seminars, I would, I was terrified. I never wanted to talk. The only thing that saved me was writing papers. I would have flunked every seminar

if it hadn't been for term papers. And leading the groups enabled me eventually to be talkative in small groups.” (21-01-00)

“Got me into volunteer work, raising funds for the center. I really enjoyed that. They saw qualities in me and talents and they helped me bring them to fruition.” (28-01-15)

“Not only that but A always gets me to read it if I am there because I am able to read, announce, and look at people all at the same time. I enjoy doing that for people. I am able to pronounce longer words than they are sometimes....Uh, I, there is always I can count on, they're giving me 100% carte blanche and it is not blaisy it is appreciated. Feeling that I am popular and you tell me that I am doing good and boy that is like gravy on the mashed potatoes.” (48-02-16)

Some participants described how the experience of having a mental illness enabled them to develop skills or hobbies that they might not have if they were just “normal” and to recognize and value those skills.

“That I can draw. And it's like I just picked it up. Never took a class. That I genuinely enjoy being around kids. ...Well, a lot of things. I can see a lot of significance into things. And if I can filter out what's valid and what's invalid, I feel that I have more insight than I might otherwise have if I was normal. ... But there are four things, no matter what I know I'll always be able to do and that's to draw and to write and to tell stories and to do scout craft, which is, you know, outdoorsman skills.... (01-02-11.1)

“Well, it (my illness) actually got me writing poetry. For which I've been published. I got some recognition. I've done poetry readings since my last child was born.” (34-02-05)

Still other participants described in more general terms how they recognize they have strengths and skills that are helpful and how this makes them feel.

“Though I have a mental illness. I have some strengths that I didn't know I had and stuff like that.” (12-01-03)

Identifying new abilities or skills can interact with how a person redefines the expectations for their life. Sometimes uncovering new abilities and skills helps one to redefine the expectations for their life, or sometimes redefining ones' expectations for ones' life forces a

person to uncover or develop new abilities and skills. In order for participants to develop new abilities or skills or to try and create change in their life, they often have to face and overcome fear and anxiety as well as other barriers to their success. Redefining ones' expectations and goals and developing strategies for change in the context of ones' perceived disability is important in moving beyond just managing and living with schizophrenia, to working towards accomplishing valued goals, as well as, contributing to positive beliefs about self.

In summary, phase three, the process of redefinition and transformation, involves changing ones' attitudes and beliefs about schizophrenia and ones' self, learning to live with schizophrenia by managing symptoms and seeking help, redefining ones' expectations and goals, and developing strategies for change - essentially learning to live life within the context of a disability. Learning to Live with Schizophrenia is another important component of phase three. This phase consists of both a cognitive component and an action-oriented component that involves participants' taking action to effectively cope with and manage their illness as well as developing strategies for change.

Cognitively, this phase requires a change in ones' attitudes and beliefs about schizophrenia to foster a sense of hopefulness about ones' chances for recovery and acceptance of the diagnosis and of ones' self with a diagnosis of schizophrenia. What acceptance of the illness means for a person's sense of self is important. The illness can either usurp a person's positive identity (Deegan, 1993), become a part of a person's identity in a meaningful way (Pettie & Triolo, 1999), or remain a separate entity - something to manage and control (Strauss, 1992). Deegan (1993) describes one of the potential negative outcomes of accepting a diagnosis of schizophrenia - the process of going from being a person to being an illness and how it is devaluing, dehumanizing, and

dangerous. She describes it as dangerous because once a person believes they are the illness, there is no longer a sense of self to defend or fight against the stigma of having an illness. Pettie & Triolo (1999) describe two ways that the relationship between ones' illness and self is negotiated with a positive outcome. One is to find positive meaning and purpose in having an illness (e.g., it has made me a stronger, better person) and to integrate it into ones' sense of self. The other is to personify the illness as an entity separate from ones' sense of self and to maintain positive identity and power and control over it by keeping it separate. Young and Ensing (1999) found that people tend to incorporate illness as only one aspect of a complex, multidimensional self which changes over time. Believing that schizophrenia is a biological illness is one way that people maintain distance from the illness. However, Hatfield (1996) warns that the recent organic theories of causation may have adverse effects if they lead people to believe that they are at the mercy of their biology. What one believes about schizophrenia can influence how a person chooses to situate the illness in relation to their self and how they choose to proceed through the recovery process.

Participants in this phase also used their new knowledge about schizophrenia and its associated problems to incorporate new ways of living with schizophrenia into their life, including managing ones' symptoms and seeking help. Participants described myriad strategies that they used to manage the symptoms and stigma associated with schizophrenia. Others have also found that individuals use a variety of strategies to manage their illness and symptoms (Breier & Strauss, 1983; Sullivan, 1994; Young & Ensing, 1999). Ones' skill and ability in managing the illness can influence how they understand their disability and chooses to redefine their expectations and goals for their

life, another important component of phase three. Redefining expectations and developing new goals does not necessarily mean that a person expects less from life or that they are precluded from achieving valued goals. It does mean, however, that the person recognizes their limitations and is trying to develop a strategy for change based on their current situation. Redefining one's goals and expectations and developing strategies for change are similar in some respects to what Davidson and Strauss (1992) call "taking stock of the self" (p. 136). Taking stock of the self involves identifying specific areas of change and strengths and limitations and then assessing the possibility for change. For some, it means they, at least temporarily, relinquish some of the goals and dreams that they held prior to becoming ill and instead focus on more immediate, easier to obtain goals. For others, it means recognizing that their values and desires have changed and that therefore a change in expectations and goals is appropriate. Hatfield (1996) describes how for some people with a diagnosis, reminding ones' self that life puts limitations of different types on all people, helps them to accept the limitations imposed by schizophrenia. Sometimes these changes result in enhancing well-being and improving ones' quality of life.

Phase 4: Enhanced Well-Being and Quality of Life (n=32, 69%)

Phase four of the recovery process consists of four components: (1) forming a positive sense of self, (2) developing a new way of approaching life, (3) accomplishing valued goals, and (4) finding meaning and purpose in life. This phase goes beyond accepting ones' self as someone with schizophrenia as described in phase three, to viewing one's self as a person of value and worth. The first two components involve positive changes about how one feels about ones' self and how they approach their life,

which contribute to enhanced well-being. The third component of phase four, accomplishing valued goals, is more illustrative of what is traditionally conceptualized as recovery and measured by traditional outcome studies. For example, Anthony (1993b) defines recovery in the field of psychiatric rehabilitation as "...[improving and maintaining] functioning in one or more of the major domains of life - work, housing, relationships, and recreation" (p. 15). Although some of the goals that are valued by participants are similar to the outcomes measured in more traditional outcome studies, the goals described in this study are identified and defined by the participants based on what is important to them and not pre-determined by professionals or researchers. The fourth component of this phase involves finding meaning or purpose in ones' life, which can also be an important contributor to well-being and what achievements a person values. Although well-being and quality of life are measured in traditional studies of outcome and functioning in schizophrenia, they are rarely measured by taking into account what is of value to the individual person or the process by which they achieve a state of well-being.

I. Forming a Positive Sense of Self (n=23, 50%)

One important component of recovery involves the formation or re-establishment of a positive sense of self. The need to form or re-establish a positive sense of self emanates from how schizophrenia has impacted a person's feelings about themselves, including feelings of shame and worthlessness, and a lack of participation in valued roles as demonstrated in phase two. Some participants described how forming a more positive sense of self began after they accepted the diagnosis of schizophrenia and figured out how to integrate it into their current identity. Forming a positive sense of self goes

beyond just accepting ones' self with a diagnosis of schizophrenia. It involves both accepting ones' self with a diagnosis and learning that one can still be a valued person through increased feelings of self-confidence and self-esteem and increased positive perceptions of self. Participants also reflected on the myriad ways that they have grown as a person or become stronger from their experiences related to having a diagnosis of schizophrenia, including increased caring and compassion for others. Overall, 23 participants formed a more positive sense of self by changing their beliefs and attitudes about themselves to not just include the diagnosis of schizophrenia, but to also acknowledge how they have grown and changed in positive ways.

A. Regaining a sense of value and worth (n=20, 43%)

Regaining a sense of value and worth is one aspect of forming a positive sense of self. Participants described a number of ways that they experienced a sense of value and worth, including increased self-confidence and esteem and recognition of ones' inner strength.

1. Gaining self-confidence and self-esteem (n=14, 30%). Fourteen participants described gaining self-confidence and self-esteem by identifying or using new skills or uncovering personal strengths.

“I feel a lot better since I was doing the SA groups. More confidence.” (06-01-04)

“Well, it's [participating in SA]made me feel better about myself and made me feel like I'm not alone.” (19-02-13)

“... to believe in myself more....I'm more confident.” (24-02-10)

“And it helps me out with my self-esteem because George will say well, L, you look pretty today. You know, and I try my best to keep myself well groomed and that. I used to have trouble with that....When I come out of group, I feel, you know like I could take the whole world on. Because it makes

me feel so good, you know?" (26-02-14)

"... I started helping with retreats and I helped organize retreats and they gave me some confidence because I was talking to people directly and my confidence was growing because of all the experiences I was having with SA." (35-01-00)

2. Identifying ones' inner strength (n=5, 11%). Five participants expressed having greater inner strength due to their experience of having a mental illness and the resulting adversity that they had to face.

"I admit that I, as a 22 year old woman am a lot stronger than any other 22 year old woman I have ever met... The things that I have now, and the way that I am now, I'm a very strong person." (10-01-10)

"I have inner strength that I never knew I had." (28-01-15)

"And it made me realize that if you're a strong person, you can go ahead and achieve whatever you need to achieve." (35-01-00)

"Helped me get stronger, function through other things, to move on....I've been through a lot of difficult times, but I never gave up. It was rough." (49-02-04)

Participants described how surviving difficult times made them stronger or made them realize that they are a lot stronger than they had previously assumed. Pettie and Triolo (1999) describe how people explain, make meaning, or cast their struggle in a positive light as part of the recovery process. This is an important aspect of the recovery process because it brings meaning to ones' experiences and can help integrate ones' illness into ones' identity.

3. Regaining a sense of value and worth (n=5, 11%). Five participants described regaining a sense of value and worth as an important aspect of the recovery process. This is in contrast to when they first received a diagnosis of schizophrenia in phase two and experienced feelings of worthlessness and devaluation because of the stigma attached to

the diagnosis. Oftentimes regaining a sense of value and worth is developed through a special relationship with someone or through participating in a valued role (Anthony, 1993; Deegan, 1988; 1996).

“... he helps me to learn that I have still value even though it's not in a job per se. It's value to the people here.” (05-01-11.1)

“One thing I like about him is he comes to me for questions and answers. He just doesn't answer them all by himself. He'll say well, what do you think? You know, and not a lot of people do that to me anymore. Makes me feel important.” (35-01-00)

“People are worth something no matter what their condition. And if you have a mental illness, that doesn't mean that you can't be productive or make life worthwhile.” (41-01-40)

“... Ann has made it clear that she counts on my point of view at times in order to shore up the others...I think, in every day is to prove to myself that I'm a worthwhile person.” (48-02-16)

Recognizing that one has value and worth, despite a diagnosis of schizophrenia and its implications, is an important component of forming a positive sense of self. Feeling that one is valued and worthwhile often involves forgiving ones' self and others for past mistakes or harms.

B. Forgiving ones' self and others (n=5, 11%)

Coming to terms with, and forgiving, how one has been treated by others, as well as how one has treated others, is described as a significant aspect of the recovery process for some participants. Coming to terms with how others have treated them and forgiving them is necessary in order move beyond the past and to live in the present and the future. Forgiving ones' self for past actions or thoughts that caused shame and embarrassment is also important to the recovery process, because it allows a person to move on. Five participants described how they were able to forgive themselves and others.

“I felt shameful...another failure upon a failure. I was able to release some of those feelings and you know, forgive myself and release everybody that has harmed me or injured me in anyway. So it was very beneficial for me...” (11-01-03)

“It makes me realize that what I've done may be wrong, but it's not unforgivable. I hope it's not anyway.” (14-02-11.1)

“That it really helps to relieve the burden if you can forgive yourself, especially yourself and others.” (20-01-00)

“She felt so bad for the way she treated me for many years because my parents never explained to her my illness. She didn't understand or relate to where I was coming from. So she said do you wonder why I was that way with you and therefore forgive me. So I wrote her a letter back and said I forgive you. That was best.” (49-02-04)

Forgiving ones' self and others in an important aspect of forming a more positive sense of self because it requires that a person adopt a more forgiving, accepting, and understanding stance towards themselves and others, which can facilitate the development of connections to other people and enable them to move forward with their lives.

C. Recognizing that one has grown as a result of their experience (n=12, 26%).

Recognizing that one has changed in positive ways from the experience of schizophrenia reflects one aspect of recovery. Twelve participants described how they feel that schizophrenia and the subsequent experiences associated with schizophrenia have made them grow and change and in essence, better people – more understanding, tolerant, and accepting of human suffering and differences.

“Before when I was a kid and not having any really bad symptoms, if I saw somebody who really looked, stood out, I might giggle like the rest of the kids. Now, I would have compassion for the person....I said that having a mental illness is something like an advanced course, a graduate course in humanity or something like that.” (07-01-05)

“It made me more human, too. Humane and more human because when I hear someone talk about their experiences, no matter how ugly, and believe me, with mental illness, it can get as ugly as you can imagine, you're dealing

with heaven and hell, and it made me really I have compassion and I have empathy. And I know how deep the pain goes.” (08-01-02.1)

“...I'm more tolerant of people....I'm more compassionate. I can sympathize a lot easier than what I could have before.” (11-01-03)

“I think it's helped me be more caring and have more of an open mind about people and what they're going through, you know? More compassion. Because you never know what people are going through until you really talk to them...I've become more compassionate.” (33-02-05)

“But it's just the compassion that they feel cause they know, like myself, that I feel it myself and I can see it in them, you know. ... I think I used to be too critical of others. I thought there wasn't anything that I couldn't do if I applied myself. And I would look at other people, think get up off your ass, you know. You can do it. What's the matter with you? If I can do it, you can do it. But it's making me, the sensitive side, we're not all the same. You know, we're all different. We all have different lives. We have a right to that different life and to judge other people.” (44-02-38)

Recognizing that one has developed in some positive ways, such as becoming more compassionate and understanding, helps one to bring meaning to their experience and to cast it in a positive light to enable them to move forward (Pettie & Triolo, 1999).

In summary, forming a more positive sense of self is an important aspect of the recovery process. Many authors have argued for the importance of identity or sense of self in recovery from both mental (e.g., Davidson & Strauss, 1992; Pettie & Triolo, 1999) and physical illness (e.g., Bury, 1982; Charmaz, 1983; 1987; 1995; Corbin & Strauss, 1987). Davidson and Strauss (1992) view the development of a functional sense of self as central to the process of improvement and Charmaz (1987) describes how people with chronic physical illness constantly struggle against adversity to maintain or obtain a valued identity. Developing a positive sense of self is a challenging proposition in light of the negative stereotypes of schizophrenia and the exclusion from valued social roles that most people face. However, developing a positive sense of self is clearly an

important component of the recovery process.

II. Developing a New Way of Approaching Life (n=16, 35%)

Sixteen participants described the ways that they approached life differently than before illness entered their lives.

A. Focus on things that can be changed (n=9, 20%).

Nine participants described how focusing on things that they can change helps them to move forward in life and maintain a positive outlook, because it prevents them from dwelling on negative, intractable problems or on past mistakes. This is an important aspect of the recovery process because it helps one to stop focusing on only trying to ameliorate the symptoms of the illness and its subsequent problems and to move beyond it to create positive changes and to pursue other interests and goals.

“I sort of just accept things I can't change.” (15-01-13)

“I choose to think the good things....perspective....” (23-01-00)

“Can't worry about things we can't change.” (28-01-15)

“...I have forgot my past. I'm more focused on my present and future now....I think the thing I learned from it especially is how to rebuild my whole life and make it positive instead of negative.” (30-02-02)

One of the specific ways that participants chose to focus on something that can be changed and on the positive side of a situation is by choosing to be well and trying to enhance wellness, instead of just eliminating the manifestations of illness.

B. Choosing to be well: Focus on health and healthy lifestyle (n=7, 15%).

Seven participants described how choosing to be well or focusing on their health is one of the important aspects of how they have changed their approach to life. Choosing to be well means no longer focusing on aspects of the illness that one may have no control over,

such as some of the symptoms. Instead it involves engaging in and reinforcing behaviors and attitudes, which enhance physical and mental well-being and affirm life. This is an important aspect of the recovery process because it builds on a person's pre-existing strengths and allows them to work towards positive change.

"... but to me the most important beliefs are, wanting to be well, having some power over your illness..." (08-01-02.1)

"We have choices that can help us to maintain a healthy lifestyle." (20-01-00)

"I choose to be well and that kind of stuff. We would all prefer to be well you know. It is a choice kind of, taking medication and doing what the doctor says. Work on your inner growth and stuff." (28-01-15)

"I do choose to be well and I want to be a happy..." (29-02-02)

Accepting schizophrenia as a life-long illness and also focusing on ways to enhance one's health or wellness are not incompatible. Instead this recognizes that health and illness exist on a continuum (Fabrega, 1979) and that health can manifest itself in many aspects of a person's life (e.g., physical health, mental health, spirituality, social relationships). Another way of approaching one's life that seems to enhance well-being is learning to value everyday life.

C. Learning to value everyday life (n=5, 11%).

Five participants described how experiencing schizophrenia and the losses that accompany it make them more appreciative and thankful for the things that life has to offer, including the small things.

"It taught me to count my blessings more than I used to." (03-02-11.1)

"... you learn to appreciate the small things in life. ... I stop to smell the roses. I appreciate the little things and I am satisfied with the little things in life." (23-01-00)

"I want to enjoy everyday of my life and I look forward to the future...I

realize now you've got to find some way to enjoy everyday and the future ..., just enjoy everyday of my life until my number comes up.” (30-02-02)

“... And I just enjoy life now.” (35-01-00)

Learning to value everyday life is an important component of recovery because it signifies that one has moved past some of the losses and traumas of schizophrenia to a new appreciation of life and a new way of approaching life.

Developing a new way of approaching or living ones' life is important to the recovery process. Deegan (1988) describes the essence of her recovery process as "...a way of approaching the day's challenges." (p. 15). This view of recovery focuses more on how you do things than on what you do. Included in how participants found new ways of doing things in their lives included, focusing on things that can be changed, focusing on wellness, and valuing everyday life. This new approach to living ones' life is one way to promote well-being. Another aspect of promoting well-being and quality of life is by accomplishing valued goals.

III. Accomplishing Valued Goals (n=11, 24%)

Eleven participants described the importance of accomplishing goals that hold value for them. Some of the most prevalent examples include having a home, working, returning to school, getting a car, having an intimate partner, developing leadership skills, or having a family. Accomplishing these goals greatly contributed to participants' perceived quality of life and their overall sense of well-being.

“I own my own house, I have 2 nice cars, I have a little boy who is just the most wonderful child I have ever met.” (10-01-10)

“So I gradually built myself up over the years, you know...about the days in college and how I felt. They introduced me as having a girlfriend and having a college degree which I completed.... This is what I have worked for all my life, to have something like this....You know, and it's not a mansion but hey,

it's home. I can put my feet up on the table if I want to, if Janie don't yell at me. I can do what I wanta do, you know? ...Honor Society. Proves I'm no dummy, you know? I think that's one thing that I wanted to prove to myself, that I could do something." (11-01-03)

"I'm better off than I used to be but at least I've got a car. I sort of felt helpless, you know. That's, by definition, an American's gotta have a car." (18-02-16)

"So I can say I have a degree in mental health. I have a masters in communication and I have a minor in business. So hopefully down the road where I wanta go is where all this has led me and everyone seems to think I would be good would be in the business end of mental health....And as time went on, I got insurance, with full time benefits and I was a full time employee in food service....That's when I was able to afford a new car so I went out and bought a little Ford Escort. And it was only \$6000 so... The manager of the food service liked me so she gave me full time hours even though I was part time." (35-01-00)

Being able to accomplish valued goals is an important component of recovery because it allows participants to develop a sense of normalcy, efficaciousness, independence, and self-confidence and esteem. These can all be important factors in forming a positive sense of self.

A final component of phase four involves finding meaning and purpose in ones' life.

IV. Finding Meaning and Purpose (n=16, 35%)

The fourth and final component of phase four consists of finding meaning and purpose in ones' life. Sixteen participants described how they found meaning and purpose in their life. For many, this occurs through participation in meaningful roles and activities.

For many participants, attending SA groups has provided them with the opportunity to be in the dual role of helpee and helper, which has provided a sense of purpose in their lives.

“It makes me feel like I've got something to give back to a system that's given to me. And it does definitely give me a purpose. I need the people there as much as they need me. It is kind of a mutual thing.” (05-01-11.1)

“Well, when I started leading the groups, then I began feeling better about myself. I think God made me schizophrenic to help people.” (06-01-04)

“I'm able to give them advice, they're able to give me advice... I'm not in it for the awards or anything. But occasionally somebody will say something I might happen to overhear in the smoke break. Or some people just might say spontaneously. Gee, I don't know what I'd do if I couldn't go to the group every week. That's worth more than all the plaques, you know. That's how I feel. I've got people I can share with, who have got me over humps... It's one of the few things I love in this life. I like helping people.” (07-01-05)

“I volunteer for the SA meetings and I feel really good about that. I give them all individual help. I devote all my spare time to these people and this program because that's the kind of person I want to be. I want to be the kind of person that can help that will help anybody. Somebody that will give up their own spare time to help others.” (10-01-10)

“Well, I got a lot of feedback from people, how it helped and I felt it was worthwhile. It made me feel needed. I felt like, that I was helping other people and I think that's what we're all here for. To reach out and help other people...But SA has given me a purpose to my life so it changed my life. It absolutely has changed my life.” (23-01-00)

“I feel that I'm doing something with my life that's worthwhile and I've always wanted to be somebody who did something for others as well as for myself.” (41-01-40)

For the above participants, helping others provided one of the fundamental ways that infused meaning and purpose into their life. For other participants, being involved in SA provided them with the opportunity to engage in meaningful activity, which contributed to the renewed sense of meaning and purpose in their life.

“We would spend a whole afternoon that way and all we would be doing would be putting letters into envelopes and sealing them and stamping them and getting ready to mail. And I felt that that was important to me because I felt that I was beginning to believe that SA was giving me a profitable direction for my life. Which it has. You know...If I didn't have SA to go on, it might be very likely that I would be in the hospital again. I'd be hospitalized. I need to work on my recovery from the illness and I do believe

that you need incentive to do that. You need some kind of motivation and SA gives me that.” (41-01-40)

Participants described how one of the ways that SA facilitates involvement in meaningful activity is by providing a variety of meaningful roles and tasks that require different levels of skill and confidence. This allows members to make meaningful contributions to the group regardless of their skills or confidence. For example, one member described how initially making the coffee was very important to him because it was a valuable contribution to the group and it was something that he could do to contribute to the group’s overall success.

“And SA was, really kinda saved my life in a sense because I didn't have any direction and so very early on, I was beginning to think of ways where I could make contribution and the first way I could make a contribution was very small, which was making coffee and cleaning up the tables afterwards....Say in '92, it was hard dragging myself every week to those meetings. I was not feeling well and I still felt a sense of responsibility to show up. Oftentimes though, I'd be so uplifted by something cool going on say at the hospital or say I would be uplifted that some, some agency or group was working somebody in the Pontiac group and I would feel uplifted and I would feel like I was doing something really worth while....It's given me worthwhile things to do. I guess that's really a big factor. Big factor is giving me things, something worthwhile to do with my life at times when I was very down.” (21-01-00)

Finding a greater purpose in life, either through meaningful roles or activities, is important to the recovery process because it encourages participants to focus on things beyond their own problems, helps them to develop self-confidence and esteem, and provides motivation or incentive to continue in their recovery process.

In summary, phase four of the recovery process involves components (meta-themes) that contribute to an enhanced sense of well-being and quality of life. The fourth phase of recovery, the process of enhancing well-being and quality of life, represents what is most often focused on in studies that examine the outcomes of schizophrenia.

Specifically, one component of this phase, accomplishing valued goals, is what is often used to define recovery. However, this is a very narrow view of recovery which does not take into account the internal changes which take place including developing a positive sense of self, a new way of approaching life, and finding meaning and purpose. Ralph et al. (1999) in their conceptual model of recovery have well-being and empowerment as their final stage of recovery, which encompasses some of the same components, including positive self-regard, compassion for others, participation in meaningful work, volunteer activities, or hobbies and stability in housing. Young and Ensing (1999) also describe the third or later phase of their recovery model as improving quality of life which consists of striving to attain an overall sense of well-being and reaching new potentials. This includes improving standard of living and increasing positive feelings about ones' self and life. Spaniol et al. (1999) identify finding new meaning and purpose as one component of the fourth phase of their proposed recovery model. These elements are similar to what was found in this study and are important aspects of the recovery process that are often invisible to traditional outcome measures because they describe a cognitive or internal change that is related to how one sees themselves and their life not just whether or not a person has achieved a specific level of functioning or achieved specific external goals. These are more about how one lives their life and views themselves than about what one has achieved.

Summary of Cross-Case Analysis

The intent of the cross-case analysis was to address the first research question, which asked how persons diagnosed with schizophrenia experience and describe recovery in the context of a mutual-help group, Schizophrenics Anonymous (SA).

As described by participants in this study, recovery is a complex and multifaceted concept, which can be characterized by four identifiable phases consisting of a total of 22 themes and 9 meta-themes. These phases were identified from the myriad ways that participants described the recovery process and were developed to capture the common processes at work across a number of themes. The phases included: (1) grief and mourning, (2) recognition and awareness, (3) redefinition and transformation, and (4) enhanced well-being and quality of life.

Although there have been only a few empirical investigations of the recovery process from the perspective of persons diagnosed with mental illness (e.g., Davidson and Strauss, 1992; Pettie & Triolo, 1999; Young & Ensing, 1999), there is an on-going discussion around different aspects of recovery in the literature (e.g., Anthony, 1993; Hatfield, 1994; Lefley, 1996; Ralph et al, 1999; Spaniol, et al, 1999) as well as a substantial number of personal accounts of mental illness and recovery (e.g., Anonymous, 1989; 1993; Deegan, 1993; Leete, 1987; Unizicker, 1989). In addition there is a growing literature on recovery based on models taken from physical illness (e.g., Bury, 1983; Charmaz, 1983; 1987; 1995; Corbin & Strauss, 1987) and addiction (e.g., Cain, 1995), which may be applicable to recovery from mental illness. These different models of recovery support the idea that recovery from illness and trauma consists of a number of different phases, stages, or components. Although recovery has traditionally been defined in the professional literature by measuring tangible outcomes, such as symptom remission, housing, work, and social relationships, this approach to measuring and understanding recovery clearly does not capture the diverse ways that people experience the process of recovery. The empirical finding that recovery consists of four

phases and that many of these phases are focused on the process of reflection and redefinition is significant because it provides empirical support for the theorized processes of recovery developed by researchers and those experiencing mental illness.

In addition to recognizing that recovery is a complex process, which consists of phases and meta-themes, it is important to understand how the different phases of recovery are related and how one proceeds through the phases over time. The within case analysis presented below allows us to further explore the recovery process over time and to look at how the phases, meta-themes, and themes are related.

Results and Discussion of Within-Case Analysis

The within case analysis was undertaken to address the second research question which was modified after completing the cross-case analysis to ask whether and how participants described movement through the identified phases of the recovery process. Therefore, the primary task of the within case analysis became to explore movement through the recovery process in relation to each person's unique situation and context.

The within-case analysis revealed that: (1) participants move through the different phases of the recovery process in an on-going or continuous manner with no clear or identifiable end point; (2) movement between the four phases is iterative with back and forth movement between the phases; and (3) the recovery process encompasses the whole person which can lead to simultaneously being in different phases for different aspects of ones' life. Please refer to Appendix G (p. 308-332) for all of the within-case summaries used in this analysis.

Recovery is On-Going or Continuous with No Clear or Identifiable End Point

The first characteristic of the recovery process identified in the within case analysis is that it is an on-going process that involves movement through multiple phases. Participants described being in different phases at different points in their life. All 15 participants who were identified as reaching phase 4 also described being in all of the other 3 phases at some point in their recovery process. The following 4 stories demonstrate that the recovery process is characterized by movement through multiple phases.

Lisa describes how it took her more than 7 years to realize and accept that she had a mental illness. After she would experience successes in school or work she would “still test the waters and go for a second opinion” because she did not believe that someone diagnosed with schizophrenia could achieve the things she was able to [phase 1 - denial]. Next she describes how being in therapy and trying to find out as much information as possible about schizophrenia [phase 3 - learning to live with schizophrenia] eventually brought her to SA. She describes her participation in SA as helpful because it helped her to realistically assess her situation and understand how schizophrenia had impacted her life [phase 2 - awareness and recognition of the impact of schizophrenia on life]. It also helped her to reassess her goal of being a CEO of a big company and settling for nothing less [phase 3 - redefining expectations and goals]. Later in her story she describes her recovery as really starting when she was able to maintain a full-time job and eventually buy a car with the money she saved [phase 4 - accomplishing valued goals]. Although Lisa at the time of the interview was doing very well by her own evaluation and had achieved many of her goals including being content at her job, getting married, and owning a home [phase 4 - accomplishing valued goals], she describes herself as “coming around to another phase again” in her recovery. This comment was made in reference to her desire to become involved doing some volunteer work with a mental health advocacy organization, which she saw as providing a renewed sense of meaning and purpose in her life [phase 4 - finding meaning and purpose].⁴ (35-01-00)

Matt describes how he did not accept that he had a mental illness [phase 1 - denial] until 1981, when he had “a big break and everything fell apart”. Although he was not hospitalized until 2 years later, he lost his job and knew that he would not be able to function at work, because of the symptoms he was experiencing [phase 2 - recognizing how schizophrenia manifests itself in ones' life]. It was four years later

⁴ The stories presented in this section are not quotes from the original interview, but are summaries or excerpts derived from the case summaries provided in Appendix G unless the text is enclosed in quotations. The information in brackets identifies the phase that is represented by the preceding text.

when he was in a day hospital, "feeling very, very bad" that he learned about SA and six years after he first accepted his diagnosis he started attending SA. As he was exposed to others with schizophrenia who were working full-time and in his words "making it", he started to believe that recovery was possible [phase 3 - change in attitudes or beliefs about schizophrenia and self]. It was also during this time that he started to seek ways to contribute to the group. "I was beginning to think of ways where I could make a contribution and the first way I could make a contribution was very small, which was making coffee and cleaning up the tables afterwards." Eventually, he was asked to work on creating the literature for the organization and to co-lead a SA group. In order to take on these roles and tasks, he had to overcome his fear of public speaking and failure [phase 3 - overcoming fears and impediments]. Participating in these activities has given him "meaningful things to do" and made him "feel like [he was] doing something really worthwhile [phase 4 - finding meaning and purpose]. During this time he became more involved at the organizational level of SA and started to feel out of touch with the actual purpose of SA and its role in helping people. So, at the time of the interview, Matt was in the process of again redefining his role within the SA organization in order to "return to some of [his] old idealism" [phase 4 - finding meaning and purpose] (21-01-00)

After struggling with symptoms for many years, Joel decided to commit suicide by overdosing on psychotropic medication [phase 1 - loss of hope and feelings of despair]. He was hospitalized and upon returning home he quit his job because of his awareness of how his illness was impacting his life [phase 2 - recognition of how schizophrenia manifests itself in ones' life]. Four years later and after being hospitalized numerous times, he describes returning home from one hospitalization and deciding that "...I don't care how bad it gets I don't care if I have to put duct tape on my mouth, I'm not going to say anything like that. If I have to sit in a chair with white knuckles, gripping it, I'm not going to give into the symptoms" [phase 3 - learning to live with schizophrenia]. He also describes how a couple of years later, he drove to Canada to get a new medication which was not yet approved in the United States, which took a tremendous amount of courage for him to overcome his anxieties and fears [phase 3 - overcoming fears and impediments] about driving across the border and navigating in an unknown town [phase 3- developing strategies for change]. He overcame these barriers and succeeded in obtaining the new medication. The new medication alleviated most of his symptoms and took away a lot of his shyness. The new medication in conjunction with facing and overcoming his shyness enabled him to eventually start attending a SA group. At the time of the interview, Joel described his involvement with his SA group as contributing significant meaning and purpose to his life as well as allowing him to accomplish one of his goals – to meet a girlfriend [phase 4 - finding meaning and purpose and accomplishing valued goals]. (07-01-05)

Joelle described herself as being 22 years old and having a young child when she first started having strange things happen to her. Eventually she had a "breakdown" and her mother called a local clinic and had her admitted. During her admission she refused medication and as soon as she was discharged she moved into

her own apartment with her son. She then spent about 12 years living in and out of psychosis and paranoia, trying to hold down jobs, care for her son, and trying to mask the symptoms of her illness [phase 1 - denial]. In her mid thirties she describes how she finally had to have answers. "So finally one day I just had to have, I guess I was ready to get well all the way, because I had to have answers." When she confirmed her diagnosis with her therapist she describes her reaction as "I jumped up in the room and said you better watch your mouth. You don't realize what you're saying...I am a person but, you know, what I really was saying is I'm not some weirdo." [phase 1 - anger at illness, self, world]. When she saw the diagnosis of schizophrenia on her physical form she describes how "then I got really upset and I looked in the yellow pages and I found an organization called Alliance for the Mentally Ill (AMI)...So I called them and told them my story ...I told them I'm a normal person but I've got this tag on me and how do I get it off? How do I tell them to get this schizophrenia word out of my records and stuff, and clarify this with my therapist." [phase 1 - denial]. It was during this call to AMI that she got the phone number for SA and eventually talked with a SA group leader. Joelle describes her first conversation with the leader as "And when I listened to her, I felt, you know, tears just started flowing down my face. I felt this big sense of relief. I felt like for the first time in my life, I didn't have to run, hide, or keep trying to mask symptoms or trying to show everybody I was normal." She felt she was able to face her illness and symptoms [phase 2 - recognizing how schizophrenia manifests itself in one's life] and that it was "the beginning of [her] life...I didn't have to hide anymore. I didn't have to suppress my own personality. [phase 3 - changing beliefs about self]. I could be whole [phase 3 - beliefs about self] and know that I could have a break and still recover and move on." [phase 3 - changing beliefs about the nature of schizophrenia]. This was the turning point in her life when she was able to move beyond denial and accept the illness. Participating in the SA group helped her to recognize her symptoms and how schizophrenia manifested itself in her life [phase 2- recognizing how schizophrenia manifests itself in ones' life] and how to tell the difference between reality and what was in her head [phase 3 - learning to live with schizophrenia]. Eventually, she became a group leader, which gave her a great sense of meaning and purpose [phase 4- finding meaning and purpose]. (08-01-00)

Lisa, Matt, Joel, and Joelle's stories capture how participants in this study described the recovery process as ongoing and continuous and involving movement between the 4 identified phases. Participants described the components in phase one, including anger, denial, and loss of hope, as how they initially responded to having a mental illness and also as how they reacted to the subsequent losses that they experienced as a consequence of mental illness. As described above, this phase can take a long time to move through. Participants described their tenure in this phase as a time of confusion

and darkness, because they are not ready to accept that they have a mental illness; they are not managing their symptoms effectively; and they know little about the illness. Participants denied their experiences and tried to show how normal they could be by covering up their symptoms and pretending that nothing was wrong. During this phase many participants experience numerous hospitalizations or other encounters with the mental health system. Joelle's story especially illustrates how long this phase can take to move through. After phase 1, all participants move at least briefly into phase 2 because it is necessary for them to, at a minimum, recognize that they are experiencing symptoms of schizophrenia (phase 2) in order to move onto phase 3. If participants do not recognize that the symptoms are impacting their life, they will have no reason to move into phase 3 and to accept and learn to live with schizophrenia or to accept help. As participants redefine and transform their lives, they start to redefine their goals and expectations and develop strategies for change that help to move them into phase 4.

This view of recovery, as an ongoing process, is supported by Anthony (1993) and Deegan (1988) who describe recovery as a way of living and approaching ones' life, instead of as an outcome to achieve. Recovery defined as an ongoing process is a framework within which to understand ones' growth, development, and setbacks following a diagnosis of schizophrenia. As Joelle stated "[I learned] that I could have a break and still recover and move on." At times the focus of the recovery process is primarily on illness or illness related matters, but as a person starts to cope with and control the illness the focus shifts to broader issues such as how to derive meaning and purpose from ones' life (Spaniol et al., 1999). It is clear that recovery is not a process of

returning to ones' premorbid functioning (Lefley, 1996), but is instead an on-going continuous process of growth, change, and adaptation (Hatfield, 1994).

Movement Between Phases is Iterative

Participants described moving back and forth between the phases as they faced new challenges or grew and changed in new ways. Even when a person reached phase 4, there may be movement back to earlier phases as the circumstances of their life unfold. One way that participants described moving back to earlier phases is when they returned to phase 2, when they became aware of and recognized new ways that having a diagnosis of schizophrenia impacted their life. Sometimes this led them back to phase 1 as they mourned and grieved over this additional loss.

Lisa described how she recently acknowledged an additional way that her mental illness may have impacted her life.

Although Lisa is married, owns a home, and works full-time and describes herself as happy and content [phase 4 - enhanced well being and quality of life], she also describes how in the last year since she got married she and her husband have been thinking about having children, and how this has made her recognize and acknowledge that it may not be possible for her to have a healthy baby [phase 2 - recognizing the impact schizophrenia has had on life]. (35-01-00)

Lisa also described how recent discrimination at work made her realize again, that no matter how much she achieves or how well she becomes, she is still treated differently by others and how that still makes her upset.

"They [co-workers] recently said you're the only person who is not supposed to have a key, when she found out I had a key to the office [phase 2 - recognizing how schizophrenia has increased social isolation and marginalization]. I don't know why she said that but that really hurt my feelings so today I'm gonna, when I go back into work, I'm gonna hand in my key and say here, here's the key back. I don't wanta be part of your cronies. I'm above that." (35-01-00)

Although this participant reached phase 4, she returned to a previous phase, recognition and awareness, as she realized how her diagnosis of schizophrenia interfered with how her coworkers treated her. However, there seems to be a new added maturity or understanding to dealing with this recognition. For example, the anger and hurt felt in relation to discrimination on the job is directed towards those who are treating her unfairly, not at herself or her illness. It is important to note that as people revisit different phases in the recovery process they may have an enhanced level of self-knowledge, maturity, and hope gained through their experience of living with the illness and their journey of recovery.

Similarly to how Davidson and Strauss (1992) conceptualized the dynamic movement back and forth between the four different aspects of recovery that they identified, the delineation of these four phases does not indicate that a person moves in an orderly fashion from one to the next or that a person is engaged in one phase at a time. In Weingarten's (1994) narrative of the challenges of recovery, he describes how he delivered a talk titled "Nine steps to my recovery from mental illness" (p. 369). However, after a series of events occurred in his life that challenged the notion that he was "recovered", he re-titled his paper, which appeared in the journal, *Psychiatry* in 1994, "The ongoing process of recovery". Orrin (1994) in her personal narrative describes relapse as part of her recovery and not as a failure. If recovery is viewed as a non-linear, iterative process, then relapses are viewed as part of the process, which allows a person to accept the relapse as part of the process of change and growth and to move more easily forward. This view of relapse and iterative movement between the phases reflects the

nature of life and mental illness and demonstrates that as the challenges of life surface, one may find they need to revisit different phases of the recovery process.

Recovery Process Encompasses the Whole Person

As described by participants, the recovery process encompasses all facets of their life. It is not solely about addressing the symptoms of the illness, figuring out the right treatment plan, or taking the right medication. Recovery involves emotions, beliefs and attitudes, ones' relationship to other people and ones' self, participation in valued roles, redefining ones' life and accomplishing valued goals. This means that in the course of ones' life, a person may simultaneously experience different phases for different aspects of their life.

Mary captures how a person can simultaneously experience different phases in different areas of ones' life.

Mary was hospitalized in the past because cut herself with razor blades to alleviate the sensation that bugs were under her skin. Although she still feels the bugs crawling under her skin, she now knows not to use razor blades to cut them out because then she will have to go to the hospital again. She describes herself as "having enough control at this point ...I make a decision to not cut." [phase 3 - learning to live with schizophrenia]. Mary also expresses pain and anguish during the interview by crying and stating "I hate this illness" over losing her job that she held for seventeen years [phase 1 - anger at illness, self, and world]. However, later in the interview she describes how leading her SA group has given her a sense of purpose in her life because she is giving back "to a system that has helped me so much." [phase 4 - finding meaning and purpose]. (05-01-11)

Mary's story captures how it is possible to simultaneously experience different phases of the recovery process. This is important, because it means a person's recovery can not be measured by how a person is doing in just one domain - such as work, or managing one's symptoms.

Summary of Within-Case Analysis

The within-case analysis explored how participants move through the recovery process over time. Based on these findings the recovery process can be broadly characterized in three ways: (1) recovery is a continuous and on-going process with no identifiable end point, (2) movement through the phases of the recovery process is iterative involving back and forth movement, and (3) recovery encompasses all aspects of a person's life which means that a person may be simultaneously involved in different phases of the recovery process for different aspects of their life.

Because people move through the recovery process in a variety of different ways depending on their individual experiences and contexts, recovery is best described as a highly unique and individualized process. Fisher (1996) after reflecting on his personal journey of recovery concludes that there are certain principles or values which continually emerge from people's stories, but that each person's journey of recovery is uniquely their own. Hatfield (1996) also describes each person's recovery journey as unique but that what is important is how people choose to define mental illness and the place they see it playing in their lives. How one experiences their illness and their recovery is also influenced by the natural course and history of the illness, including ceilings, moratoriums, and change points (Strauss, Hafez, Lieberman, & Harding, 1985). One's background, life experiences, and experiences with the mental health system can also influence how they proceed through the recovery process.

MEETING THE CRITERIA OF TRUSTWORTHINESS AND AUTHENTICITY

In a qualitative study, the criteria for validity and reliability are replaced by the criteria of trustworthiness including: (1) credibility, (2) transferability, (3) dependability,

and (4) confirmability, as described by Lincoln and Guba (1986).

The first criterion, credibility, is defined as the match between the participants' realities and the realities represented in the research conclusions (Lincoln & Guba, 1989). This study addressed this criterion in several ways. First, the author's prolonged engagement in the setting as a research assistant on the larger evaluation project permitted attendance at numerous organizational meetings and different SA groups, and allowed contact to be maintained with SA groups and leaders over a period of two and a half years. Another technique used to ensure credibility is the "member check". A member check was carried out using insiders (SA participants) and outsiders to the organization (knowledgeable peers) in validating the interpretations of the data. Specifically, several experienced, long-term SA leaders were asked to validate the cross-case and within-case interpretations and results by first having them talk about their personal experience with recovery and then by presenting to them the specific interpretations and findings of this study. Overall, there was a high degree of convergence between the leaders own experience of recovery, what they had observed as others' experience of recovery, and the interpretations and findings of this study. However, there were four issues that emerged from this process, which were not adequately captured in this study.

First, even though participants could eventually view recovery as a more holistic process, work or employment still holds significant power in many participants' lives. According to the leaders, societal expectations around work put pressure on some, especially men, to work. If they are unable to work, then their feelings of value and worth and self-esteem and confidence is greatly diminished. The second issue that

emerged during the process was that the role of spirituality was underrepresented in the recovery process as presented in this study. Perhaps, this is because it was not identified as a distinct aspect of the recovery process, but instead was an underlying part of many of the other components that participants talked about. For example, participants might regain a sense of value and worth because they believe that all people are valued and worthwhile in God's eye, which would be captured as a regained sense of value and self worth and *not* spirituality. Another underrepresented aspect of the recovery process as identified by the leaders who took part in this process was self-care. The leaders described how it is important to just be able to get out of bed to attend a meeting, to take a shower, put on clean clothes, or shave. These self-care events can constitute some of the small steps or goals that start to give a person a sense of achievement and accomplishment in their life, as well as help them to form a more positive sense of self. The final issue that emerged from this process was that the recovery process is really more of a stage-like process than was evident in the stories. Often in the individual stories, it was clear that people progressed from phase 1 to 4, but it was not clear how they moved through the middle phases. The leaders felt that people at least needed to recognize how schizophrenia had manifested itself in their lives (phase 2) before they could conceive of moving into phase 3 and accepting the illness and recognizing the need for help. This probably did not emerge as clearly from the stories because they were retrospective and some were not told in a linear manner. Overall, the member check process confirmed the credibility of the interpretations and findings of this study, which according to Guba and Lincoln (1989) is the most important technique for establishing credibility.

The second criterion used to assess trustworthiness is transferability.

Transferability ensures that the conclusions drawn from this study are only transferred to other appropriate contexts. This was addressed by allowing the participants to provide rich descriptions of their particular social and individual contexts, as well as by providing a rich description of the mutual-help setting in which this study is situated. A context would be deemed appropriate to transfer these findings to, if it was similar to the social, individual, and setting contexts of the cases included in the study.

The third criteria of trustworthiness is dependability and confirmability. These criteria were addressed by keeping a detailed record of all of the empirical data and all of the data analysis techniques and decisions that were used in this study. An independent auditor was used to examine both the data sources and the data analysis and interpretation processes and to validate the appropriateness of the inquiry process. The use of NU*DIST, a qualitative software program, will greatly aid in this task by facilitating organized record keeping of all data reduction, analysis, and interpretation decisions and tasks.

Not only did this study meet the criteria for trustworthiness, but it also employed the criteria for authenticity proposed by Lincoln and Guba (1989). Authenticity ensures that participants' constructions of the phenomenon have been collected and represented accurately. The criterion for authenticity that is applied in this study is fairness. Fairness has been addressed by soliciting participation from all SA members within the state of Michigan, and by using a sampling technique that includes participants with different experiences in SA.

Employing the criteria of trustworthiness and authenticity, as detailed by Lincoln

and Guba (1989), has ensured that the interpretations and conclusions drawn from participants' stories can be verified and confirmed by other individuals. In addition, use of these criteria helps to bolster confidence in the conclusions of this study.

IMPLICATIONS AND CONCLUSIONS

This is one of the first empirical explorations of recovery that maintains a commitment to understanding recovery from the perspective of those experiencing it within a context that encourages its participants to develop experientially-based definitions of recovery. The findings of this study demonstrate that recovery in this context consists of four phases (Grief and Mourning, Awareness and Recognition, Redefinition and Transformation, and Enhancing Well-Being and Quality of Life) and can be characterized as an on-going process with no clear or identifiable end point. This definition of recovery, as an on-going process that consists of phases, is very different from traditional definitions or understandings of recovery that focus solely on outcomes or symptom remission. Adoption of this alternative view of recovery has implications for the following: (1) changing the attitudes and beliefs held by professionals, individuals diagnosed with schizophrenia, and their family members about schizophrenia and recovery, (2) developing programs and services which promote recovery, (3) studying schizophrenia and recovery in ways that better capture the actual lived experience of recovery, and (4) creating new social policies that recognize and facilitate the recovery process.

Changing Attitudes and Beliefs about Schizophrenia and Recovery

Traditionally in the realm of psychiatry and mental health services, a diagnosis of schizophrenia is associated with a deteriorating course, a poor prognosis, and little hope

for recovery (Harding et al., 1992; 1997). These beliefs have been adopted by the general population and are reflected in stereotypes and discriminatory practices (Wahl, 1998). They are also adopted by those who are diagnosed with schizophrenia to produce a sense of hopelessness and despair (Deegan, 1988; 1993; Houghton, 1982; Lovejoy, 1984; Unzicker, 1989; Weingarten, 1994). The findings of this study present a view of schizophrenia and recovery that differs from these traditional beliefs in three important ways.

First, the results of this study demonstrate that recovery from schizophrenia is possible no matter what definition of recovery you use – the more traditional definition or the more inclusive definition developed by this study. Although this study reveals that the process of recovery is broader than the traditional definition of recovery (e.g., outcomes in domains such as work or school or symptom remission), it is important to note that even using the traditional definition of recovery there is evidence for recovery in the stories of participants who are working full-time, own their own homes, have intimate relationships, and are caring for family members. These types of outcomes are the kinds of indicators or standards that are usually used by traditional mental health settings, professionals, and researchers when thinking about whether someone has recovered from schizophrenia. However, evidence for recovery is also found in the stories of participants who have not achieved these traditional concrete outcomes, but who have made more subtle cognitive changes such as developing a more positive sense of self and finding meaning and purpose in one's life. Although these aspects of recovery may not be evident and visible from the outside these individuals are also in the process of recovery,

even though it may not look like it based on the traditional definitions of recovery that only take into account outcomes.

The second way the findings of this study diverge from previously held beliefs about recovery is by demonstrating that previous conceptualizations of recovery are too narrow to capture the process of what people actually experience in their search for a better, happier, more fulfilling life. How recovery has been traditionally measured only captures a small part of the entire process. Essentially it captures that part of the process (e.g., experience of symptoms, participation in work, level of independence) that is the most objective, easily measured, and quantified. However, this ignores the majority of the process which is not immediately visible on the outside (e.g., changing attitudes about schizophrenia) and which may be more subjective and grounded in each individual's values, beliefs, and experiences (e.g., finding meaning and purpose in one's life).

The third finding of this study shows that recovery from schizophrenia is not that different from recovery from other types of losses or traumatic events. While there are some components of the recovery process that are unique to the problems associated with a diagnosis of schizophrenia, there are also some components which are similar to the components of recovery from other illnesses or traumatic events. For example, in phase two, many of the elements – learning to live with schizophrenia and accepting a diagnosis of schizophrenia, are very illness specific because they are directly related to how one experiences schizophrenia and the associated stigma. However, also in phase two there are elements which are less focused on illness specific issues and more focused on how to move forward from such an event by redefining one's life and developing new hopes and dreams. Anthony (1993) describes recovery as transcending the illness and disability

fields and as a truly unifying human experience because all people experience catastrophes (e.g., death of a loved one, divorce, physical illness) from which they must recover. In order to normalize the experience of illness, loss, and trauma experienced by many people diagnosed with schizophrenia it is important to recognize how their experience is similar to the experiences of others who have experienced life altering events.

Adopting attitudes about schizophrenia and recovery that reflect that recovery is possible, that it is a process that occurs over time with both internal and external changes, and that is not unlike recovery from other illnesses and events will help to facilitate changes in the way we think about people with schizophrenia and try to assist them in their recovery. Specifically, adopting this definition will have implications for how we design contexts for recovery, how we study and measure recovery, and how we develop policies (specifically the Social Security system and public health insurance programs). Adopting a new definition of schizophrenia and recovery lays the foundation for creating changes in how we conceptualize contexts for recovery, research studies, and social policies that have the ability to facilitate or deter the recovery process.

Changing the Way we Conceptualize Contexts to Promote Recovery

Changing attitudes and beliefs about schizophrenia to include the belief that recovery is possible, as well as to understand recovery as an on-going process that consists of multiple phases, can change the way we conceptualize different contexts to promote recovery. The adoption of this view of recovery highlights the need for contexts that promote an accurate sense of optimism and hope, understand and recognize the

multiple phases, and identify services and natural supports that can support people at different phases.

Optimism and hope

Personal narratives written by individuals with schizophrenia discuss how current beliefs about schizophrenia leave patients and their families without hope (Chamberlin, 1979; Lovejoy, 1984). One way that hopelessness is conveyed is through language that reflects negative and pessimistic beliefs about schizophrenia and recovery (Spaniol and Cattaneo, 1997). A more positive view of schizophrenia, including the belief that recovery from schizophrenia is possible, will help to create a sense of hope and optimism, which Deegan (1993) has identified as one of the cornerstones of recovery. If schizophrenia is conceptualized to include recovery as something that is attainable, then having a diagnosis of schizophrenia will not be viewed as so devastating or stigmatizing. One way to do this is to make sure that there are hopeful messages being sent at the individual, contextual, and societal level.

At the individual level, it is important for mental health professionals and family members to believe in recovery and convey that belief to the person with schizophrenia. At the setting level, it is important to develop contexts that have a culture or expectation of recovery that is reflected in opportunities for growth beyond just dealing with the symptoms of the mental illness. At the societal level, it is important to send messages, through media campaigns and the inclusion of people with mental illness in the public sphere, which show people with mental illness in all of their humanity including positive, optimistic, and hopeful images. Although it is extremely important to convey a sense of hope and optimism, it is also important to present a balanced view of the struggles and

difficulties that many people will face in their recovery process. This is why it is especially important to ensure that people with mental illness are treated and seen in their totality, in order to challenge the stereotypes that still abound in our society. To the extent that people change their beliefs about schizophrenia and recovery, we might develop less stigmatizing and pessimistic views of people, which might in and of itself decrease some of the secondary consequences of the illness and provide greater access to all settings.

Recognition of Multiple phases

In order to develop contexts that facilitate and support people in their recovery it is necessary to recognize that recovery is a process with multiple phases that encompass all aspects of a person's life. Any context that is trying to promote recovery needs to take into account the myriad needs of people in different phases of the recovery process and also understand where each individual is in their own recovery process in order to provide the most appropriate supports. Designing programs to address multiple phases of the recovery process recognizes that people move back and forth between phases and that a broad range of services and opportunities are essential to provide opportunities for growth or forward movement as well as to support a person who returns to an earlier phase. Recognizing that recovery from schizophrenia encompasses all aspects of a person's life encourages a holistic approach to service delivery and recognizes the need for contexts to view the person holistically and address all aspects of a person's life. This does not mean that all programs need to be all things to all people, but that there should be a wide array of contexts that are well enough connected to facilitate movement between them. For example, if a person is in phase 1 and they are denying that they have

an illness, it would be helpful for them to have access to a setting, such as a mutual-help group or other peer led setting, to get to know others who have a diagnosis of schizophrenia and who are living successfully with their illness (e.g., have a job, stayed out of the hospital for a long time). This might make a diagnosis of schizophrenia more palatable and might help the person to accept it. However, later in the process the same individual may also need assistance finding a job, which may be better addressed by a vocational rehabilitation agency. However, if the vocational rehabilitation agency does not believe recovery from schizophrenia is possible or that people with schizophrenia have little chance of holding down a job, they are unlikely to invest much time or effort into securing employment for that person. In addition, if the vocational rehabilitation agency does not have an awareness of the different phases of recovery and a person comes to them while still in denial of having a problem, then the person may not be successful in their job placement and this reinforces the belief that people with schizophrenia can not take the stress of working. If the vocational rehabilitation agency had an understanding of the different phases of recovery, they would help the person secure the necessary supports in order to accept their illness and start managing it before seeking work. This would increase the person's chance for success and decrease the chance that the person's failure will contribute to the negative stereotypes of schizophrenia and the person's own sense of failure. Therefore, understanding that recovery is a non-linear process with multiple phases is essential for developing contexts that allow for the back and forth movement through the process as well as recognition of the different supports that are needed in each phase.

Identifying Natural Supports and Peers.

There are several types of settings or ways to promote recovery by connecting individuals with mental illness to others who have had similar experiences. These can include: (1) mutual-help groups, (2) drop-in centers, (3) warm-lines, (4) buddy systems, or (5) published accounts of mental illness and recovery. All of these are ways to connect people who have a diagnosis of schizophrenia to a peer or peers who have had similar experiences and who can provide strategies for living with the illness, support, hope, and a sense of belonging.

Mutual-help groups

Mutual-help groups are one type of setting that help to promote recovery by addressing some of the less tangible and less visible aspects of the recovery process. For example, they can help people redefine the problem as less stigmatizing (Steinman & Traunstein, 1976) by providing a normative narrative community that provides an alternate understanding of the problem (Cain, 1991; Humphreys, 1993; Rappaport, 1993; Rappaport & Simkins, 1991) and by providing specific ideologies about the problem and its solution (Antze, 1965). This often includes the belief that recovery is possible for all people (Walker & Davis, 1995). They can also instill hope by providing role models who are living successfully with the problem (Powell, 1975).

By changing ones' understanding of schizophrenia and recovery and by providing role models mutual-help groups can restore a sense of hope and help one to accept a diagnosis of schizophrenia, both components of phase 3. They also provide opportunities to engage in valued activities and social roles (Levine, 1988; Reissman, 1965), which may contribute to a person being able to identify skills and abilities or find meaning and

purpose again in their life. Mutual-help groups also help restore a sense of value and worth through helping others or being in the helper role instead of just a helpee role (Arntson & Dodge, 1987), which is one component of phase 4. Again, no single context can be expected to be all things to all people all the time, but mutual-help groups illustrate many of the setting characteristics which are important to promoting recovery including: role models, beliefs about schizophrenia that include recovery, more holistic understandings of recovery that incorporate people's actual lived experience, opportunities to participate in meaningful roles, and the sharing of stories and experiences.

Drop-in Centers

Drop-in centers are peer-operated settings, which were developed to provide people with mental illness a place to conjugate, meet others with mental illness, talk, hang out, or just have a warm place to go during the day or in the evening. Although drop-in centers have no specified program of recovery or structure to the setting, they do provide a place for people to go and get to know others with mental illness. They are also peer-operated settings, so like mutual-help groups they have the possibility to develop definitions or understandings of recovery that are not based on professional definitions. However, unlike mutual-help groups they do not have a formal mechanism for conveying or developing these definitions of recovery (i.e. the community narrative). Drop-in centers recognize the need for people to move through the earlier phases of recovery, such as grief and mourning and awareness and recognition, and how having the opportunity to talk informally with others who have experienced similar things helps to

facilitate this process. Drop-in centers can also provide role models or people who are living successfully with the illness, which helps to instill a sense of hope.

Warm-lines

Warm lines were also developed and operated by people diagnosed with mental illness. They were developed to provide a way for others with mental illness to talk with a peer and someone who really understands their situation over the telephone. Warm lines are not considered a crisis services, but are instead a way for people to get support from a peer in times of need. Similar to drop-in centers, warm lines recognize the benefits of talking with a peer about one's experiences and feelings and how this can facilitate the recovery process.

Buddy systems

Buddy systems have been developed in some areas to help transition people from the hospital to the community. They connect people who are being discharged or who are recently discharged from the hospital with a peer who is living successfully in the community and who can act as a support person, a friend, and an advocate. This type of service recognizes that people who are leaving the hospital need to learn to live with schizophrenia (phase 3) and that peers who are successfully living in the community have valuable expertise to share. It also recognizes the value of providing a person early on with a role model who is living successfully in the community

Published Accounts of Schizophrenia and Recovery

Published accounts of schizophrenia and recovery can provide people with other's narratives of recovery without face-to-face contact. These accounts can provide a sense of hope and a sense of connection to others. Personal accounts are often written by

people at all different points in their recovery and this can help people to locate their own experience along the continuum. As more and more accounts of mental illness and recovery are published, recovery seems less like a deviation from the norm and more like what we should learn to expect.

Implications for Research

Another implication of adopting an understanding of recovery as an on-going process, consisting of multiple phases, is that we need to change the way that we study and measure recovery. First, we need to measure recovery in such a way as to capture the process and progress through the various phases. This means measuring beliefs and attitudes about how one feels about their diagnosis of schizophrenia and its impact on their life. It means measuring ones' beliefs about self and schizophrenia and understanding how one lives with schizophrenia. It means measuring how and whether one has redefined their expectations and goals and whether or not they have developed strategies for change. Finally, it involves measuring achievements, well-being and quality of life, more traditional indicators of recovery from schizophrenia, in a manner that reflects the goals and aspirations of the individual. It also means that we need to employ a variety of methods that are suited to capturing an on-going process and taking into account a person's context. These include methods which capture process and take into account the person's own subjective understanding of their life. Conceptualizing recovery as an on-going process consisting of phases will encourage the development of measures and the use of methods that are better suited to capture the subtleties of the process including the four phases instead of just focusing on outcomes such as work, symptom alleviation, and living independence.

Social Policies

Finally, adopting this new understanding of recovery has implications for how Social Security and Medicare and Medicaid benefits should be structured. It is important to address these two systems, because it is clear that people with psychiatric disabilities desire to work, but are often deterred by the prospect of losing access to financial support and health benefits.

Currently, the Social Security system has no mechanism to support people who are able to successfully return to work for a period, but who may experience future episodes of prolonged disability. The current system does not accommodate many people's intermittent need for support in periods of increased disability. Although a person can reapply for benefits, there is a chance they will no longer be considered disabled or at a minimum there will be a significant time lag before they are reinstated. This can have very negative consequences including homelessness, increased symptoms, and/or hospitalization. For many, these consequences, understandably, deter their willingness to work.

The threat of losing public health insurance benefits (e.g., Medicare or Medicaid) without having access to private health insurance is also a significant barrier to returning to work. Most people with schizophrenia depend on Medicare or Medicaid to pay for their medications and mental health treatments. Without this support they would not receive needed treatments and interventions. Changes such as buying into Medicare or Medicaid to cover medical expenses, while they remained uninsured from other sources, such as what is occurring in Oregon, Vermont, Massachusetts, and Michigan, or if it was

easier to reinstate once it was terminated, would make significant differences in the lives of people with schizophrenia.

The current structure of Social Security and Medicare and Medicaid is a significant barrier for people with schizophrenia who wish to return to work. If these systems took into account the nature of schizophrenia and recovery, including the experience of relapses and setbacks, perhaps a more flexible and accommodating system could be developed that would encourage persons diagnosed with schizophrenia to return to work in periods of health knowing that if they become ill they will not be penalized.

In summary, understanding recovery as an on-going process will allow us to see potential in all people and to recognize that people who appear to not make progress may in fact just be in the early phases of recovery that can take so long to move through. This will help us to maintain hope for them as well as instill hope in them that things will get better. This view of recovery as an on-going process also reduces the tendency to see things in an either/or fashion and to make judgments about who is recovered and who is not. Adopting an understanding of recovery as an on-going, longitudinal process consisting of multiple phases has broad implications for our beliefs and attitudes about schizophrenia, for reducing stigma and discrimination, for developing contexts to promote recovery, for how we do research, and for social policies. Understanding recovery as a unique and individualized process also reminds us to remain open minded and flexible in our understanding of how each individual moves through the recovery process and not get stuck in adopting another rigid and limiting view of recovery. Finally, adopting an understanding of recovery, which is grounded in the lived experience

of schizophrenia and recovery recognizes and acknowledges the importance of the person in their own recovery process and their expertise gained through lived experience.

Influence of SA on Participant's Stories of Recovery

It is important to note that participants' experience of recovery was shaped by their participation in SA. SA participants who experienced all four phases of recovery and who had more complete stories of mental illness and recovery (those participants included in the within-case analysis) had greater involvement in SA over time and were more likely to be leaders than members.

SA was related to individuals' stories of recovery by encouraging participants to develop and tell a coherent story of their recovery and by encouraging the adoption of SA's 6 steps of recovery into participants' understanding of their own recovery. An important part of participation in mutual-help groups is that members are encouraged to think about, tell, and develop their stories in an evolving way. As described by participants, the recovery process involves an iterative process of making sense of one's past and current experiences, integrating them into an understanding of one's self and illness, and assigning meaning to them in order to arrive at a new understanding of one's life. Within the context of mutual-help, the telling of stories and the use of personal narratives to convey understanding about the problem and its solution, are viewed as a mechanism to assist people in rebuilding a personal meaning system for understanding their lives (Arntson & Dodge, 1987) and for constructing a new understanding of one's self and identity (Cain, 1991).

In addition to encouraging participants to develop a personal story of recovery, SA provides a community narrative about recovery, that assists members in reshaping

their personal narratives. There are a number of ways that SA's community narrative, which is based on the program philosophy and the six steps for recovery appears to have been adopted by participants for use in the recovery process. Often times the specific ideologies' adopted by mutual-help groups help to counteract negative societal beliefs or attitudes that are shared by members of a group and viewed as detrimental to their cause (Antze, 1979). SA's community narrative, which encompasses specific ideologies or beliefs about the nature of schizophrenia, including that it is a no-fault biological illness, it is life-long, and recovery is possible, were all evident in the stories of participants. For example, participants described how they used to blame themselves or their parents for the illness until SA taught them that it is a no fault illness caused by a chemical imbalance in the brain. These beliefs help to counter negative societal beliefs or attitudes that are shared by participants, their parents, and professionals. Often times it is this change in participants' beliefs that facilitates their ability to accept a diagnosis of schizophrenia and to forgive themselves and others for past mistakes.

SA's community narrative is also structured around the six steps of recovery, which are used as tools inside and outside the group to facilitate the recovery process. The six steps of recovery are evident in several components of the recovery process as described by participants. For example, the step "I choose...I choose to be well. I take full responsibility for my choices and realize that the choices I make directly influence the quality of my days" is reflected in participants' descriptions of how they have decided to take power and control of their life and to make choices to be well or to focus on wellness. Another step that is prominently reflected in participants' descriptions and experiences of the recovery process is the step "I surrender...I admit I need help. I can't

do it alone.” This step is evident in phase two of the recovery process when participants are learning to live with schizophrenia and one way they do this is by accepting help.

The adoption of SA’s community is facilitated by the presence of role models in the group or organization. The presence of role models helps to reinforce and validate the community narrative by demonstrating that schizophrenia is a life-long illness, but that recovery is possible. Role models and other group members help to promote and develop the community narrative by sharing their individual stories. Sharing of individual stories helps members to generate their own narrative for their own life (Arntson & Dodge, 1987). This helps members to feel so not alone, accepted, and understood. It also helps members to learn from each other's stories and to develop their own understanding of schizophrenia and recovery based on the community narrative and their individual experiences and beliefs.

SA is a setting that provides a community narrative based on the lived experiences of people with schizophrenia. Other contexts, not based on experiential knowledge, may produce different or no understandings of recovery, depending on their belief system. For example, traditional mental health settings may espouse the belief that schizophrenia is a chronic illness with a poor prognosis and little chance of recovery. Not only does this create hopelessness, but it leaves very little chance for developing a narrative of recovery. The understanding and experience of recovery, including both the content and the order of the phases of recovery, in Schizophrenics Anonymous may be different from what would be found in traditional settings or even in some other types of peer run settings depending on their philosophy and beliefs around recovery. Some of the findings may be universal and generalizable to other settings, but some may be

idiosyncratic and emanate from SA's specific community narrative. The finding that significantly more participants who were included in the within-case analysis (i.e. participants who experienced all 4 phases of recovery and who had more complete stories) were affiliated with SA groups based in the community, versus a group in a mental health setting such as a clubhouse, drop-in center or community mental health center, may support this point. SA groups based in the community may be more likely to adhere to the principles of a peer-run setting and to maintain the SA philosophy and belief system. Therefore, the generalizability of these findings to other individuals with schizophrenia is unknown. For individuals who have access to accurate information about schizophrenia and other individuals who share their illness, their experience of recovery is likely to share many of the components of recovery identified by this study. This is certainly supported by the similarity between these findings and the findings of other researchers (e.g., Davidson & Strauss, 1992; Young & Ensing, 1999) and the personal narratives written by individuals diagnosed with mental illness (e.g., Deegan, 1993; Leete, 1989; 1994; Lovejoy, 1994). These findings are less likely to be generalizable to individuals who are isolated with their illness and exposed primarily to traditional professional and societal views of schizophrenia and recovery.

Limitations and Boundaries

The purpose of this study is to describe and understand the process of recovery from the perspective of individuals with schizophrenia within a mutual-help setting. This study does not attempt to examine what recovery means to all people, or what recovery means within other settings, such as mental health settings or psychiatric hospitals. The participants in this study have chosen both to participate in a voluntary mutual-help group

that values the process of recovery and to participate in this study. Therefore, it would be inappropriate to generalize these findings to other individuals, especially those who are participating in settings on an involuntary basis, such as people committed to psychiatric institutions or in mandatory treatment programs.

This study is based on a secondary analysis, which may limit the depth of the exploration of recovery. A study with a primary focus on the recovery process may have elicited a more in-depth understanding of the phenomenon. However, the primary purpose of the larger evaluation study is to understand participants' experiences in SA, an organization whose goal is to promote recovery from schizophrenia. Therefore, although recovery is not directly asked about in the interview protocol, it is a salient and meaningful experience to many SA members.

Participants in this study were also asked to tell the story of their mental illness, which involved recalling and discussing life events that happened many years ago. Although the accurateness of a person's recollection of both details and time can be questioned, the purpose of this study was to understand how each person described and experienced the recovery process, which may be best captured in a person's ability to reflect back on past experiences and draw meaning from them.

Finally, my biases must be taken into account because they helped shape the decisions that I made in designing and carrying out this study, including what research questions were asked, what questions were asked during the interviews, and how I choose to understand the data. Although, considerable precautions were taken as described in the section on authenticity and trustworthiness, it seems that someone else might have chosen to do this study in a different manner. Nonetheless, the precautions used to test

the conclusions from this study give me confidence that the results presented here could be of considerable use to individuals with schizophrenia, people and programs interested in promoting recovery, and social systems that interface with individuals diagnosed with schizophrenia.

Because of some of the limitations of this study and the narrow focus of the questions there are some important questions that need to be addressed in the future. These questions include: (1) what are some of the catalysts or events that trigger either forward or backward movement through the recovery process, (2) what things can facilitate faster progression through phase one Grief and Mourning, (3) what is the effect of context on one's understanding of the recovery process and do different settings produce different understandings of recovery, and (4) what does a person need at each phase in order to facilitate their movement to the next phase.

In spite of these limitations the data from this study provide strong support for the conclusion that recovery from schizophrenia is an ongoing process with multiple phases. It also demonstrates that people are active participants in their own recovery, even when we do not see visible changes. If we adopt this view of recovery it will enable people with schizophrenia to maintain a sense of hopefulness and optimism and for others to do the same.

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UNDERSTANDING RECOVERY FROM SCHIZOPHRENIA IN A MUTUAL-HELP
SETTING

VOLUME II

By

Katie Weaver Randall

A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

A MASTER OF ARTS

Department of Psychology

2000

APPENDICES

APPENDIX A

APPENDIX A

Consent to Contact and Interview Consent Forms

Schizophrenics Anonymous Study Consent to Contact

Dear SA Member:

As part of our effort to understand the experience of participating in Schizophrenics Anonymous we are interested in conducting interviews with SA members. These interviews will be arranged with a member of the Michigan State University (MSU) research team and will involve questions regarding your living situation, employment and social activities, history of mental illness and treatments received, life satisfaction, and participation in SA. These interviews will be approximately 1 ½ to 2 hours in length and will be audiotaped. Those who participate will be reimbursed \$10 for their time.

Unfortunately, due to limited time and resources, we will not be able to interview all members of SA. Instead, we will randomly select a group of SA members to interview. If you would be willing to participate in an interview, please complete the information requested below.

Voluntary Participation Your participation in this study is voluntary. You may choose not to fill out this form. There are no penalties to you or your group if you choose not to participate. You may also choose to withdraw from our study at anytime without penalty.

Confidential Participation The MSU research team will use data collection and data reporting procedures that will ensure that your participation in the study will be kept confidential. Personal identities of the participants in this study will not be recorded on data records and will not be reported in any research reports. Instead, ID #'s will be used. All information about SA members (including this form) will be stored in locked facilities at MSU.

By completing this form and returning it to a member of the MSU research team, you indicate your voluntary agreement to participate in an interview. If you have any further questions about this study, please call Dr. Deborah Salem or Dr. Thomas Reischl at Michigan State University at (517) 353-5015.

Name _____ Gender _____
Phone # _____ Age _____
Best time to reach _____ SA Group _____
Date of 1st SA meeting _____
Signature _____ Date _____

Schizophrenics Anonymous Study Consent Form

Established SA Group Leaders

Purpose of the Study

Some of the primary questions of this study are: “How does SA develop new group leaders?” and “How does SA engage new members?” To address these questions, the research team at Michigan State University (MSU) will be collecting information from a variety of sources. The sources include interviews and observations with employees of the Mental Health Association in Michigan (MHAM) and with organizational leaders from Schizophrenics Anonymous (SA) and with SA group leaders in regions where SA groups have already been established and with SA group leaders in regions where new SA groups are being established.

Procedures

Interviews with New SA Group Leaders in Established SA Regions. New SA leaders will be invited to participate in one 60-90 minute interview during their first year as a group leader. These interviews will focus on progress and problems with starting and maintaining the SA groups and the impact of the weekly meetings on group members. These interviews will also cover the leaders’ living situation and psychiatric service use. These interviews will be audiotaped. At the completion of this interview, the group leader will receive \$10.

Interviews with Experienced SA Group Leaders in Established SA Regions. Experienced SA leaders will be invited to participate in one 60-90 minute interview. These interviews will focus on progress and problems with starting and maintaining the SA groups and the impact of the weekly meetings on group members. These interviews will also cover the leaders’ living situation and psychiatric service use. These interviews will be audiotaped. At the completion of this interview, the group leader will receive \$10.

Voluntary Participation

Your participation in this study is voluntary. You may choose to not participate in any part of this study. You may choose to not participate in this study at all. There are no penalties to you or your organization should you choose not to participate in any or all of the data collection activities described on this consent form. During an interview, if you wish to stop for any reason, the interview will end.

Confidential Participation

The research team at Michigan State University will use data collection and data reporting procedures that will protect the confidentiality of your participation in this study. Personal identities of the participants in this study will not be recorded on data records and will not be reported in any research reports. Instead, ID codes will be

recorded on all interview forms and only pseudonyms or identified roles (e.g., group leader) will be used for reporting the results of this study.

Potential Risks and Benefits

There are very few risks from participating in this study. Interviews will require your time, but these procedures can be done at your convenience. The observations of organizational events require no extra time. The interviews will be of reasonable length--no more than 90 minutes. Interviews will end early if the participant becomes tired or wishes to end the interview for any reason.

Since identifying information such as the person's gender, age, and the group leader role may be recorded and reported, there is a chance that you could be identified in the research reports. There is little risk that you could be personally identified by anyone outside the MHAM or SA organizations. The risk of personal identification, however, is reduced because the research team will only use ID numbers, pseudonyms, or role designations in data records and in reports. And all data records will be stored in locked facilities at MSU.

The potential benefits to participating in this study include having an opportunity to reflect on one's participation in the organizational expansion efforts of Schizophrenics Anonymous. Participation in the study will also help ensure that your experience related to SA's expansion will be more accurately recorded and interpreted. The agencies involved in this study could also benefit from helping the MSU research team because the reports on expansion efforts of SA could help guide future expansion efforts.

Consent to Participate

By providing your name, address, telephone number, and signature below, you show (a) your complete understanding of the information in this consent form and (b) your voluntary consent to participate in the research activities described in this consent form.

Print Your Name: _____ Telephone #: _____

Print Your Address: _____

Your Signature: _____ Date: _____

Witness Signature: _____ Date: _____

Schizophrenics Anonymous Study Consent Form

New SA Group Leaders

Purpose of the Study

Some of the primary questions of this study are: “How does SA develop new group leaders?” and “How does SA engage new members?” To address these questions, the research team at Michigan State University (MSU) will be collecting information from a variety of sources. The sources include interviews and observations with employees of the Mental Health Association in Michigan (MHAM) and with organizational leaders from Schizophrenics Anonymous (SA) and with SA group leaders.

Procedures

Telephone Interviews with New SA Group Leaders. Members of the MSU research team will conduct weekly telephone interviews with SA group leaders involved in the SA expansion effort in Central Michigan. The weekly telephone interview will focus on recording attendance at the most recent SA meeting(s) and other issues related to the maintenance of the SA group.

Face-to-Face Interviews with New SA Group Leaders. Roughly 3-4 weeks after a new group leader begins leading a new SA group, they will be invited to participate in a 60-90 minute interview. New group leaders will also be invited to participate in similar follow-up interviews roughly 6 months and 12 months after a new group begins. These interviews will focus on progress and problems with starting and maintaining the SA groups and the impact of the weekly meetings on group members. These interviews will also cover the leaders’ living situation and psychiatric service use. These interviews will be audiotaped. At the completion of each interview, you will receive \$10 for your assistance.

Voluntary Participation

Your participation in this study is voluntary. You may choose to not participate in any part of this study. You may choose to not participate in this study at all. There are no penalties to you or your organization should you choose not to participate in any or all of the data collection activities described on this consent form. During an interview, if you wish to stop for any reason, the interview will end.

Confidential Participation

The research team at Michigan State University will use data collection and data reporting procedures that will protect the confidentiality of your participation in this study. Personal identities of the participants in this study will not be recorded on data records and will not be reported in any

research reports. Instead, ID codes will be recorded on all interview forms and only pseudonyms or identified roles (e.g., group leader) will be used for reporting the results of this study.

Potential Risks and Benefits

There are very few risks from participating in this study. Interviews will require your time, but these procedures can be done at your convenience. The observations of organizational events require no extra time. The interviews will be of reasonable length--no more than 90 minutes. Interviews will end early if the participant becomes tired or wishes to end the interview for any reason.

Since identifying information such as the person's gender, age, and the group leader role may be recorded and reported, there is a chance that you could be identified in the research reports. There is little risk that you could be personally identified by anyone outside the MHAM or SA organizations. The risk of personal identification, however, is reduced because the research team will only use ID numbers, pseudonyms, or role designations in data records and in reports. And all data records will be stored in locked facilities at MSU.

The potential benefits to participating in this study include having an opportunity to reflect on one's participation in the organizational expansion efforts of Schizophrenics Anonymous. Participation in the study will also help ensure that your experience related to SA's expansion will be more accurately recorded and interpreted. The agencies involved in this study could also benefit from helping the MSU research team because the reports on expansion efforts of SA could help guide future expansion efforts.

Consent to Participate

By providing your name, address, telephone number, and signature below, you show (a) your complete understanding of the information in this consent form and (b) your voluntary consent to participate in the research activities described in this consent form.

Print Your Name: _____ Telephone #: _____

Print Your Address: _____

Your Signature: _____ Date: _____

Witness Signature: _____ Date: _____

New Member Interviews

Purpose of the Study

The research team at Michigan State University is conducting a study to learn about how participation in SA groups affects the group members. The research team is especially interested in learning about (a) why members become involved in the groups and (b) how participation in SA is related to changes in members' life situations and self-understanding.

Procedures

Each member will be invited to participate in three interviews. If the member agrees, the first interview will occur two or three weeks after the member joins the SA group. The second interview will occur six months after the first interview and the third interview will occur 12 months after the first interview. The research team would like the members in this study to participate in all three interviews even if they are no longer active members of SA at the time of the follow-up interviews.

Each interview will probably take about 60 to 90 minutes. The interviews include questions about the member's living situation, employment and community activities, experiences with psychiatric services, understandings of their mental illness, social activities, life satisfaction, and participation in SA. When the interview is finished, the participant will receive a \$10 reimbursement for their time.

Voluntary Participation

Your participation in this study is voluntary. You may choose to not participate in any part of this study. For example, you may choose not to answer any question in the interview. You may choose to not participate in this study at all. There are no penalties to you or to SA if you choose not to participate in this study. During an interview, if you wish to stop for any reason, the interview will end.

Confidential Participation

The research team at Michigan State University will use data collection and data reporting procedures that will protect the confidentiality of your participation in this study. Personal identities of the participants in this study will not be recorded on data records and will not be reported in any research reports. Instead, ID codes will be recorded on all interview forms and only pseudonyms or identified roles (e.g., group leader) will be used for reporting the results of this study.

Potential Risks and Benefits

There are very few risks from participating in this study. Interviews will require your time, but they can be done at your convenience. The interviews will be of

reasonable length--no more than 90 minutes. Interviews will end early if the participant becomes tired or wishes to end the interview for any reason.

Since identifying information such as the person's gender, age, and the group role may be recorded and reported, there is a chance that you could be identified in the research reports. There is little risk, however, that you could be personally identified by anyone outside the SA organization. The risk of personal identification, however, is reduced because the research team will only use ID numbers, pseudonyms, or role designations in data records and in reports. And all data records will be stored in locked facilities at MSU.

The potential benefits to participating in this study include having an opportunity to reflect on one's participation in the Schizophrenics Anonymous groups. Participation in the study will also help ensure that your experience in the group will be more accurately recorded and interpreted.

Procedures for Contacting You

When the research team contacts you to arrange for the interviews, procedures will be used to protect the confidentiality of your involvement in SA. For example, any letters sent to you will not include reference to SA on the outside envelope and we will not mention SA if we need to leave messages for you.

To help the research team know the best way to contact you if you move or change your telephone number, it would be very helpful if you would provide names, addresses, and phone numbers of two people who would know how to contact you in the future:

Contact Person: _____

Address: _____

Telephone: _____

Consent to Participate

By providing your name, address, telephone number, and signature below, you show (a) your complete understanding of the information in this consent form and (b) your voluntary consent to participate in the research activities described in this consent form.

Print Your Name: _____ Telephone #: _____

Print Your Address: _____

Your Signature: _____

Date: _____

Witness Signature: _____

Date: _____

APPENDIX B

APPENDIX B

Interview Protocols

MEMBER INTERVIEW

1. Date _____
2. Member ID _____
3. Interviewer ID _____
4. SA Group ID _____

Before beginning interview:

- a) Discuss confidentiality.
- b) Go over and sign consent form.

Directions to interviewer:

Allow member to “tell their story”, as they touch on the areas outlined in prompts, check each one. When they are done with their story, ask them any prompt questions which they have not yet discussed.

SA INVOLVEMENT

I would like to begin our interview with a discussion of your experiences in Schizophrenic's Anonymous. I am interested to hear your views about SA as an organization, as well as your own personal involvement in SA and how this has influenced you.

5. First, I would like to hear the story of your involvement in SA. I would appreciate it if you could go back to the beginning, when you first heard about SA and tell me the story of how you became involved.

- ___ Who told you about SA? Had you heard about SA before?
- ___ When did you attend your first meeting? Why did you think it would be helpful? How did you feel on your way to the meeting?
- ___ What were your first thoughts/impressions of SA? How did you feel at the meeting? Did you talk? What did you think of the leader? Did they greet you? After the meeting did you share the experience with anyone?
- ___ Basic chronological flow of involvement.
- ___ What was a typical meeting like? (Structure, what kinds of things would people talk about?)
- ___ Why do you think you have stayed involved?
- ___ Have you ever attended any other SA meetings?

6. Have you been involved in any SA activities outside of attending your group?
☐ retreat
☐ social events

7. What have you liked the most about your experience in SA? What about being in SA has been the most helpful to you? What would you say you have learned from being in SA?
☐ support
☐ friendship
☐ information about schizophrenia
☐ six steps
☐ spiritual component

8. Have there been things about being a member that have been difficult or less satisfying?

9. *Referent Power*
 Do you feel that you have a lot in common with other SA members or leaders? If yes, what are the most important things you have in common? How is this helpful in a self help group like SA?

10. *Experiential Knowledge*
 a) In what ways are other SA members and leaders best able to help you? What types of things can they best help you with?
☐ support
☐ expertise/technical information

10. b) What types of things do you feel that they are least able to help you with? What types of things might you seek someone else's help with? Who else would you turn to?
☐ support
☐ expertise/technical information

11. Now, I would like you describe SA for me. For example, if you were telling a potential member about SA what would you tell them?
☐ Why should someone join?
☐ Philosophy/important beliefs of SA.
☐ Are there similarities and/or differences between SA and traditional mental health services?

12. Has there been a person or experience you have had with traditional mental health services that has been helpful? Who? How? Why?

13. Is there anything else about your involvement in SA that you would like to mention?

PERSONAL STORY

Now, I am going to ask you some general questions about what living with a mental illness has been like for you.

14. First, could you tell me the story of when you first realized that you had a mental illness.

___ Identify things that have been most difficult (symptoms, interpersonally), summarize and ask how this has effected their life and how they have coped with it.

___ If they haven't mentioned SA ask if SA has helped them cope and how it has helped.

15. Would you say there are ways that your mental illness has impacted how people treat you or interfered with other things in your life? Would you tell me about that?

16. Are there ways that your mental illness has helped you grow as a person or learn things about yourself? Would you tell me about that?

SOCIAL SUPPORT

Now I would like to find out about what your social life is like and who you consider to be your social supports.

17. Can you tell me who are the most important people in your life, what your relationships are like with them, and what sorts of things you do with them?
18. Overall, how happy or satisfied are you with your current social life and social supports?
1. not at all satisfied
 2. a little satisfied
 3. somewhat satisfied
 4. mostly satisfied
 5. extremely satisfied
19. Can you tell me who helps you when you really need help or when you are upset about something? What type of help or assistance do they provide?
20. Overall, how happy or satisfied are you with your current relationships?

1. not at all satisfied
2. a little satisfied
3. somewhat satisfied
4. mostly satisfied
5. extremely satisfied

Now that you have told me about your social life and your relationships with other people, I would like to know if there is anything that you wish was different about these things.

21. Is there anything that you would like to be different about your relationships or social life?
- ____ more or less contact with other people
- ____ relationships that you don't have now that you wish to have

DEMOGRAPHICS

Up to this point in the interview I have been asking you very open ended questions. Now I would like to continue by asking you some structured questions about yourself and your background.

22. Gender
1. male
 2. female
23. How old are you? _____ years
24. Date of birth ____/____/____
25. What's the last grade that you completed in school?
1. elementary school
 2. some high school
 3. high school graduate
 4. some college
 5. associates degree
 6. bachelors degree
 7. graduate degree (Please specify) _____
26. Do you think of yourself as belonging to any organized religion?
1. no
 2. Catholic
 3. Jewish
 4. Protestant
 5. Other _____

27. Are you or have you ever been married?
1. never married
 2. currently married (Please specify how many times ____)
 3. legally separated
 4. divorced
 5. widowed

28. Do you have any children?
1. no
 2. yes

If yes go to 29.

If no go to 30.

29. How many children? _____

30. Are your parents living?
1. no
 2. one parent living (Please specify which one _____)
 3. both parents living

31. Ethnic background
1. Asian
 2. African-American
 3. Hispanic
 4. Native American
 5. White
 6. Other _____

COMMUNITY ADJUSTMENT

Now I'd like to ask you some questions about your current living situation.

32. a) Where are you currently living? What kind of living situation is it? (code below)
- b) INDEPENDENT:
1. independent house or apartment
 2. with family or friends
 3. boarding house (pay for room in house, no staff)
 4. single room occupancy hotel (pay for room in hotel)
- SUPERVISED:
5. supervised apartments (independent apt., staff available)
 6. group home (shared home, staff available)
 7. adult foster care (with foster parents)
 8. hospital (long hospitalization/no current residence)

- 9. homeless (on the streets)
- 10. homeless shelter or program
- 11. other (specify)

33. How long have you lived there? _____ months
34. Who do you live with? _____
If roommate probe as to whether or not a romantic relationship?
35. Overall, how happy or satisfied are you with your current living situation? (Use card)
- 1. not at all satisfied
 - 2. a little satisfied
 - 3. somewhat satisfied
 - 4. mostly satisfied
 - 5. extremely satisfied

Now I would like to ask you some questions about whether you are currently involved in any work, volunteer, or school situation.

36. First, are you currently working for pay?
- 1. no
 - 2. yes

If yes go to 37.
If no go to 39.

37. a) What is your job? Describe in detail (duties, how long there) (code below)
b) Indicate type of employment:
- 1. competitive employment- paid job obtained on open market
 - 2. transitional employment- paid job obtained through training program
 - 3. sheltered employment- paid job, long term, controlled environment

38. How many hours per week do you work? _____

39. Are you currently volunteering anywhere?
- 1. no
 - 2. yes

If yes go to 40.
If no go to 41 if working for pay or 44 if not working for pay.

40. Where are you volunteering? Describe in detail (duties, how long there).

If not working for pay go to 40.
If working for pay go to 44.

41. a) Can you tell me why you aren't working for pay at this time? (code below)
- b) Indicate reason person is not working
1. can't find a job
 2. physically disabled
 3. psychologically disabled
 4. retired
 5. homemaker
 6. student
 7. other (Please specify _____)
42. When did you last work? or, Have you ever worked?
Number of months since last job _____
43. Are you currently looking for work?
1. no
 2. yes
44. How do you support yourself financially?
Or, if currently working: Do you have any other sources of financial support outside of your earned income? (Circle all that apply)
1. earned income (savings)
 2. social security benefits (SSA) or supplemental security income (SSI)
 3. social security disability income (SSDI)
 4. armed service related disability income
 5. social welfare benefits (welfare, AFDC, food stamps)
 6. retirement, investment, savings
 7. rent supplements (HUD, public living programs)
 8. family and spouse contribution
 9. other (specify)
45. To what extent do your financial resources provide for your basic needs? Do you have enough money for the essentials (rent, food, clothing)? Overall, how satisfied are you with your financial situation? (Use card)
1. not at all satisfied
 2. a little satisfied
 3. somewhat satisfied
 4. mostly satisfied
 5. extremely satisfied
46. Are you in school or some kind of training program?
1. no
 2. yes

If yes go to 47.

If no go to 50.

- 47. Are you in school/training program full time or part time?
 - 1. full-time
 - 2. part-time
- 48. Are you working towards a degree?
 - 1. no
 - 2. yes
- 49. Where are you attending school/training program and what are you taking?
- 50. Overall, how happy or satisfied are you with your work/volunteer/school/training program situation? (Use card)
 - 1. not at all satisfied
 - 2. a little satisfied
 - 3. somewhat satisfied
 - 4. mostly satisfied
 - 5. extremely satisfied

Now I would like to ask about some of your social activities and what you do with your time.

- 51. What (else) do you do during the day?
 - 1. formal day programming within mental health system
 - 2. drop in center or Clubhouse
 - 3. hangs out (no structured activity)
 - 4. other (specify)
- 52. Can you describe a typical day?
- 53. Are you involved in any regularly scheduled activities? What are they?
How often do you participate in them?
- 54. Have you attended any other self-help groups?
 - 1. no
 - 2. yes

If yes go to 55.

If no go to 56

- 55. What group? How often did you attend?
- 56. Do you attend religious services?
 - 1. no
 - 2. yes

57. Overall, how happy or satisfied are you with the way that you spend your time?
(Use card)
1. not at all satisfied
 2. a little satisfied
 3. somewhat satisfied
 4. mostly satisfied
 5. extremely satisfied

PSYCHIATRIC HISTORY

Now I would like to ask you some questions about your mental health history.

58. Have you ever been hospitalized for psychiatric reasons?
0. no
 1. yes

If yes go to 59.

If no go to 62.

59. How many times (in life)? _____
60. a) Where was your first hospitalization? _____
b) When was your first hospitalization? ____/____/____
61. a) Where was your last hospitalization? _____
b) When was your last hospitalization? ____/____/____
62. Are you taking any psychiatric medication?
1. no
 2. yes

If yes go to 63.

If no go to 66.

63. <u>Name</u>	64. <u>Dosage (mg/day)</u>	65. <u>Purpose</u>
a	_____	_____
b	_____	_____
c	_____	_____
d	_____	_____
e	_____	_____

f _____

g _____

66. Do you know what your psychiatric diagnosis is?

67. Who diagnosed you?

68. Do you agree with that diagnosis?

1. no
2. yes

If yes go to 70.

If no go to 69.

69. Why not?

70. Are you currently involved in any outpatient or day treatment?

1. no
2. yes

If yes go to 71.

If no go to 75.

71. What type of treatment? Where do you go? Who do you see? (Circle all that apply)

1. individual and/or group therapy (specify type of therapist)
2. medication management
3. day programming (voc. rehab., recreational activities, day hosp., etc.)
4. case management
5. other

72. How often do you see this person?

1. daily
2. 2-4 times a week
3. once a week
4. about once every 2 weeks
5. about once a month
6. less than once a month

73. Treatment

74. Frequency code

a _____

b _____

c _____

75. Have you ever had a problem with drug or alcohol abuse?

1. no
2. yes

If yes go to 76.

If no go to 77.

76. Can you tell me about this?

77. Did you ever seek treatment for your drug/alcohol abuse?

1. no
2. yes

78. Overall, how happy or satisfied are you with your mental health treatment? (Use card)

1. not at all satisfied
2. a little satisfied
3. somewhat satisfied
4. mostly satisfied
5. extremely satisfied

FUTURE

To wrap up the interview I would like to ask you a couple of questions about the future.

79. Could you tell me in general how you think things will go for you in the future?

- ___ Are you hopeful
___ Any short or long term goals

80. Is there anything that I didn't ask you that you think is important or that you would like to tell me about?

To end interview:

- 1. Remind member about confidentiality.**
- 2. Provide payment and have leader sign payment voucher.**

LEADER INTERVIEW

1. Date _____
2. Leader ID _____
3. Interviewer ID _____
4. SA Group ID _____

Before beginning interview:

- a) **Discuss confidentiality.**
- b) **Go over and sign consent form.**

Directions to interviewer:

Allow leader to “tell their story”, as they touch on the areas outlined in prompts, check each one. When they are done with their story, ask them any prompt questions which they have not yet discussed.

SA INVOLVEMENT

I would like to begin our interview with a discussion of your experiences in Schizophrenic's Anonymous. I am interested to hear your views about SA as an organization, as well as your own personal involvement in SA and how this has influenced you.

5. First, I would like to hear the story of your involvement in SA. I would appreciate it if you could go back to the beginning, when you first heard about SA and tell me the story of how you became involved.

___ Who told you about SA? Had you heard about SA before?

___ When did you attend your first meeting? Why did you think it would be helpful? How did you feel on your way to the meeting?

___ What were your first thoughts/impressions of SA? How did you feel at the meeting? Did you talk? What did you think about the leader? Did they greet you? After the meeting, did you share the experience with anyone?

___ Basic chronological flow of involvement.

___ What was a typical meeting like? (Structure, what kinds of things would people talk about?)

___ Why do you think you have stayed involved?

___ Have you ever attended any other SA meetings?

6. Now I would like to focus on the story of how you became a leader. Can you tell me about that?

___ Who first approached you about becoming a leader?

___ Why was it something you thought you wanted to do?

- ☐ When did you lead your first group?
 - ☐ How did it go?
 - ☐ Did you start a new group or take over an existing group.
 - ☐ Chronology/history of group.
 - ☐ What is a typical meeting like? (Structure, do people help to problem solve, talk about symptoms, examples).
 - ☐ Things that have helped the group.
 - ☐ Things that have made it difficult for the group.
 - ☐ What do you think you have gotten out of being a leader? Has is changed the way you view yourself?
7. Have you been involved in any SA activities outside of running your group?
- ☐ retreat
 - ☐ social events
8. Can you tell me if you have had any interactions with other SA leaders, the central leadership of SA, Joanne, Eric (from the MHA)?
- ☐ supportive
 - ☐ provided materials
 - ☐ know/don't know who these people are
9. What have you liked the most about your experience in SA? What about being in SA has been the most helpful to you? What would you say you have learned from being in SA?
- ☐ support
 - ☐ friendship
 - ☐ information about schizophrenia
 - ☐ six steps
 - ☐ spiritual component
10. Have there been things about being a member or leader that have been difficult or less satisfying?
11. *Referent Power*
Do you feel that you have a lot in common with other SA members or leaders? If yes, what are the most important things you have in common? How is this helpful in a self help group like SA?
12. *Experiential Knowledge*
a) In what ways are other SA members and leaders best able to help you? What types of things can they best help you with? *What is the most important thing SA has helped you with? Example.*
- ☐ support
 - ☐ expertise/technical information

12. b) What types of things do you feel that they are least able to help you with? What types of things might you seek someone else's help with? Who else would you turn to?
___ support
___ expertise/technical information
13. Now, I would like you describe SA for me. For example, if you were telling a potential member about SA what would you tell them?

___ Why should someone join?
___ Philosophy/important beliefs of SA.
___ Are there similarities and/or differences between SA and traditional mental health services?
14. Has there been a person or experience you have had with traditional mental health services that has been helpful? Who? How? Why?
15. Is there anything else about your involvement in SA that you would like to mention?

PERSONAL STORY

Now, I am going to ask you some general questions about what living with a mental illness has been like for you.

16. First, could you tell me the story of when you first realized that you had a mental illness.

___ Identify things that have been most difficult (symptoms, interpersonally), summarize, and ask how this has effected their life and how they have coped with it.
___ If they haven't mentioned SA ask if SA has helped them cope and how it has helped.
17. Would you say there are ways that your mental illness has impacted how people treat you or interfered with other things in your life? Would you tell me about that?
18. Are there ways that your mental illness has helped you grow as a person or learn things about yourself? Would you tell me about that?

SOCIAL SUPPORT

Now I would like to find out about what your social life is like and who you consider to be your social supports.

19. Can you tell me who are the most important people in your life, what your relationships are like with them, and what sorts of things do you do with them?
20. Overall, how happy or satisfied are you with your current social life and social supports?
(Use Card)
 1. not at all satisfied
 2. a little satisfied
 3. somewhat satisfied
 4. mostly satisfied
 5. extremely satisfied
21. Can you tell me who helps you when you really need help or when you are upset about something? What type of help or assistance do they provide?
22. Overall, how happy or satisfied are you with your current relationships?
(Use Card)
 1. not at all satisfied
 2. a little satisfied
 3. somewhat satisfied
 4. mostly satisfied
 5. extremely satisfied

Now that you have told me about your social life and your relationships with other people, I would like to know if there is anything that you wish was different about these things.

23. Is there anything that you would like to be different about your relationships or social life?
____ more or less contact with other people
____ relationships that you don't have now that you wish to have

DEMOGRAPHICS

Up to this point in the interview I have been asking you very open ended questions. Now I would like to continue by asking you some structured questions about yourself and your background.

24. Gender
 1. male
 2. female
25. How old are you? _____ years

26. Date of birth ____ / ____ / ____
27. What's the last grade that you completed in school?
1. elementary school
 2. some high school
 3. high school graduate
 4. some college
 5. associates degree
 6. bachelors degree
 7. graduate degree (Please specify)_____
28. Do you think of yourself as belonging to any organized religion?
1. no
 2. Catholic
 3. Jewish
 4. Protestant
 5. Other _____
29. Are you or have you ever been married?
1. never married
 2. currently married (Please specify how many times ____)
 3. legally separated
 4. divorced
 5. widowed
30. Do you have any children?
1. no
 2. yes

If yes go to 31.

If no go to 32.

31. How many children?_____
32. Are your parents living?
1. no
 2. one parent living (Please specify which one _____)
 3. both parents living
33. Ethnic background
1. Asian
 2. African-American
 3. Hispanic
 4. Native American
 5. White
 6. Other _____

COMMUNITY ADJUSTMENT

Now I'd like to ask you some questions about your current living situation.

34. a) Where are you currently living? What kind of living situation is it? (code below)
- b) INDEPENDENT:
1. independent house or apartment
 2. with family or friends
 3. boarding house (pay for room in house, no staff)
 4. single room occupancy hotel (pay for room in hotel)
- SUPERVISED:
5. supervised apartments (independent apt., staff available)
 6. group home (shared home, staff available)
 7. adult foster care (with foster parents)
 8. hospital (long hospitalization/no current residence)
 9. homeless (on the streets)
 10. homeless shelter or program
 11. other (specify)
35. How long have you lived there? _____ months
36. Who do you live with? _____
If roommate probe as to whether or not a romantic relationship?
37. Overall, how happy or satisfied are you with your current living situation? (Use card)
1. not at all satisfied
 2. a little satisfied
 3. somewhat satisfied
 4. mostly satisfied
 5. extremely satisfied

Now I would like to ask you some questions about whether you are currently involved in any work, volunteer, or school situation.

38. First, are you currently working for pay?
1. no
 2. yes

If yes go to 39.

If no go to 41.

39. a) What is your job? Describe in detail (duties, how long there) (code below)

b) Indicate type of employment:

1. competitive employment- paid job obtained on open market
2. transitional employment- paid job obtained through training program
3. sheltered employment- paid job, long term, controlled environment

40. How many hours per week do you work? _____

41. Are you currently volunteering anywhere?

1. no
2. yes

If yes go to 42.

If no go to 43.

42. Where are you volunteering? Describe in detail (duties, how long there).

If not working for pay go to 43.

If working for pay go to 46.

43. a) Can you tell me why you aren't working for pay at this time? (code below)

b) Indicate reason person is not working

1. can't find a job
2. physically disabled
3. psychologically disabled
4. retired
5. homemaker
6. student
7. other (Please specify _____)

44. When did you last work? or, Have you ever worked?

Number of months since last job _____

45. Are you currently looking for work?

1. no
2. yes

46. How do you support yourself financially?

Or, if currently working: Do you have any other sources of financial support outside of your earned income? (Circle all that apply)

1. earned income (savings)
2. social security benefits (SSA) or supplemental security income (SSI)
3. social security disability income (SSDI)
4. armed service related disability income
5. social welfare benefits (welfare, AFDC, food stamps)

6. retirement, investment, savings
7. rent supplements (HUD, public living programs)
8. family and spouse contribution
9. other (specify)

47. To what extent do your financial resources provide for your basic needs? Do you have enough money for the essentials (rent, food, clothing)? Overall, how satisfied are you with your financial situation? (Use card)
1. not at all satisfied
 2. a little satisfied
 3. somewhat satisfied
 4. mostly satisfied
 5. extremely satisfied
48. Are you in school or some kind of training program?
1. no
 2. yes

If yes go to 49.

If no go to 52.

49. Are you in school/training program full time or part time?
1. full-time
 2. part-time
50. Are you working towards a degree?
1. no
 2. yes
51. Where are you attending school/training program and what are you taking?
52. Overall, how happy or satisfied are you with your work/volunteer/school/training program situation? (Use card)
1. not at all satisfied
 2. a little satisfied
 3. somewhat satisfied
 4. mostly satisfied
 5. extremely satisfied

Now I would like to ask about some of your social activities and what you do with your time.

53. What (else) do you do during the day?
1. formal day programming within mental health system
 2. drop in center or Clubhouse
 3. hangs out (no structured activity)

4. other (specify)

54. Can you describe a typical day?
55. Are you involved in any regularly scheduled activities? What are they?
How often do you participate in them?
56. Have you attended any other self-help groups?
1. no
2. yes

If yes go to 57.

If no go to 58.

57. What group? How often did you attend? How was this group similar/different from SA?
58. Do you attend religious services?
1. no
2. yes
59. Overall, how happy or satisfied are you with the way that you spend your time?
(Use card)
1. not at all satisfied
2. a little satisfied
3. somewhat satisfied
4. mostly satisfied
5. extremely satisfied

PSYCHIATRIC HISTORY

Now I would like to ask you some questions about your mental health history.

60. Have you ever been hospitalized for psychiatric reasons?
0. no
1. yes

If yes go to 61.

If no go to 64.

61. How many times (in life)? _____
62. a) Where was your first hospitalization? _____
b) When was your first hospitalization? ____ / ____ / ____
63. a) Where was your last hospitalization? _____

b) When was your last hospitalization? ____/____/____

64. Are you taking any psychiatric medication?

1. no
2. yes

If yes go to 65.

If no go to 68.

65. Name

66. Dosage (mg/day)

67. Purpose

a _____

b _____

c _____

d _____

e _____

f _____

g _____

68. Do you know what your psychiatric diagnosis is?

69. Who diagnosed you?

70. Do you agree with that diagnosis?

1. no
2. yes

If yes go to 72.

If no go to 71.

71. Why not?

72. Are you currently involved in any outpatient or day treatment?

1. no
2. yes

If yes go to 73.

If no go to 77.

73. What type of treatment? Where do you go? Who do you see? (Circle all that apply)

1. individual and/or group therapy (specify type of therapist)
2. medication management
3. day programming (voc. rehab., recreational activities, day hosp., etc.)
4. case management
5. other

74. How often do you see this person?

1. daily
2. 2-4 times a week
3. once a week
4. about once every 2 weeks
5. about once a month
6. less than once a month

75. Treatment

76. Frequency code

a _____

b _____

c _____

77. Have you ever had a problem with drug or alcohol abuse?

1. no
2. yes

If yes go to 78.

If no go to 79.

78. Can you tell me about this?

79. Did you ever seek treatment for your drug/alcohol abuse?

1. no
2. yes

80. Overall, how happy or satisfied are you with your mental health treatment? (Use card)

1. not at all satisfied
2. a little satisfied
3. somewhat satisfied
4. mostly satisfied
5. extremely satisfied

FUTURE

To wrap up the interview I would like to ask you a couple of questions about the future.

81. Could you tell me in general how you think things will go for you in the future?
____ Are you hopeful
____ Any short or long term goals
82. Is there anything that I didn't ask you that you think is important or that you would like to tell me about?

To end interview:

- 1. Remind leader about confidentiality.**
- 2. Provide payment and have leader sign payment voucher.**

APPENDIX C

APPENDIX C

Coding Scheme Iterations

CODING SCHEME VERSION 3

I. Impact of mental illness

A. On perceptions of self & life

1. Loss of hope and dreams
2. Loss of identity, sense of self – Who am I?
3. Stigma, shame, and feelings of worthlessness

B. On how others treat you

1. Treated with kid gloves
2. Loss of valued roles (e.g., work, student, family member, productive member of society)
3. Discrimination

C. Symptoms

II. Antecedents to Recovery

A. Interpersonal

1. Realizing someone cares (e.g., Professional, SA member, partner)
2. Being needed, depended on by others
3. Feeling not alone – developing hope through meeting others with schizophrenia whom have made it
4. Social Comparison – things could be better, things could be worse

B. Intrapsychic

1. Feelings of anger, loss, mourning (Grief Process)
2. Discontented with life – status quo no longer bearable or acceptable

C. Environmental or situational

1. Have basic needs met (e.g., housing, food, meds)
2. Sense of belonging - Find a place to belong (e.g., drop in center, SA)

III. Experience of Recovery

- A. Personal background characteristics and experiences shape individuals' experience of recovery (Research Question #2)
 - 1. Upbringing & opportunities before illness
 - 2. Goals & aspirations before illness
 - 3. Accomplishments before becoming ill
 - a) Good – something to get back to
 - b) Bad – something to mourn, can never measure up or return to previous activities
- B. Gaining insight and understanding of schizophrenia
 - 1. Recognizing symptoms
 - 2. Cyclical nature of illness – setbacks not end of the world
 - 3. Learning about medications and side effects
- C. Change in Attitudes or Beliefs
 - 1. Acceptance & forgiveness of self and others with schizophrenia
 - 2. Illness does not define you
 - 3. Not alone – Sense of belonging
 - 4. Belief in higher power
 - 5. Want to improve life
 - 6. Think improvement/recovery is possible
 - 7. Appreciate life and the small things
 - 8. Feel valued and worthy
- D. Building a foundation
 - 1. Accept help - Recognize interdependence – Can't do alone
 - 2. Know self - Identify needs and limitations/strengths & vulnerabilities
 - 3. Change Expectations – expect more, less, or different
 - 4. Role of medication
- E. Agency
 - 1. Take control of Life
 - 2. Take responsibility for decisions
 - 3. Actively fight/control/cope with symptoms of illness
 - 4. Act in spite of anxiety/fear

F. Outcome

1. Finding a meaning/purpose in life
 - a) Helping Others
2. More compassionate
3. Discover skills/abilities not previously identified
4. Accomplish valued goals
5. Challenge self and grow

CODING SCHEME VERSION 5

I. Change in Attitude or Beliefs

For many participants recovery involves changing their attitudes or beliefs about themselves, their illness, and their relationships' to others and the world. Changing attitudes and beliefs contributes to a sense of hope which is essential to recovery.

A. Beliefs About Self

1. *Acceptance and Forgiveness of Self.*
2. *Schizophrenia's Role in Identity and Sense of Self*

B. Beliefs about Others & Relationships with Others

1. *Acceptance and Forgiveness of Others*
3. *Sense of Belonging*

C. Beliefs about the World

1. *Belief in Higher Power*

D. Beliefs about Illness

1. *Believe Change or Recovery is Possible*
2. *Focus on Positive and Things that can be Changed*

II. Understanding Schizophrenia

Recovery involved participants' gaining a fuller understanding of the symptoms and nature of schizophrenia as well as the impact it has had on their life. How participants understand schizophrenia is influenced by SA through the sharing of stories and information about medication, stigma, and discrimination. SA also provides a context for social comparison, which allows participants to realize that there are people who are doing better with the illness and doing worse. This provides participants with

hope that things can change.

A. Nature of Schizophrenia

- 1. Recognizing Symptoms*
- 2. Cyclical Nature*
- 3. Continuum of Levels of Functioning*

B. Role of Treatment and Mental Health Services

- 1. Role of Medications and Understanding Side Effects*
- 2. Using the Hospital*

C. How Schizophrenia has Impacted Life

- 1. Stigma and Discrimination*
- 4. Feelings about Self*
- 5. Feelings of Shame*
- 6. Treated Differently by Significant Others*

III. Being Open to Change

Some Participants described a process of opening themselves up for the possibility of change. This involved accepting help and suggestions from professionals and peers and accepting that recovery cannot be done alone. Recovery also involves knowing one's limitations and needs as well as one's strengths and skills so changes are compatible with a person's capacity and needs are addressed through securing appropriate support and resources. Another important component of setting oneself up for change is changing one's expectations either to expect more or to expect less depending on the persons' own history and expectations.

A. Accepting Help (recognizing interdependence) – can't do it alone

1. *From Professionals*

2. *From Peers*

B. *Knowing One's Needs, Limitations, and Vulnerabilities*

C. *Identifying One's Strengths and Skills*

D. *Changing Expectations*

1. *Expecting More*

2. *Expecting Less*

IV. Taking Control

Taking control of different aspects of one's life is important for recovery. Part of this involves knowing what you have control over and what is outside your control and focusing your energy on those things more likely to be within your control. Becoming an active agent in one's psychiatric and medical care is an important aspect of recovery. Not only does it result in better treatment but also in a sense of self-efficacy and empowerment.

A. *Take Control of Life*

B. *Actively Fight, Control, or Cope with Symptoms of Illness*

C. *Take Action in Spite of Fear and Anxiety*

D. *Being Assertive with Doctors and Other Care Providers*

V. Positive Changes and Accomplishments In Life

Making positive changes and accomplishing things that we value are important to recovery and to an overall sense of happiness.

A. *Finding Meaning and Purpose in One's Life.*

1. *Through helping others*

- 3. *Through discovering new skills or abilities*
- B. *Trying New Things, Taking Risks & Challenging Self*
- C. *Accomplishing Valued Goals.*
 - 1. *Returning to school,*
 - 2. *Buying a home*
 - 3. *Having an intimate relationship*
 - 4. *Making friends.*
- D. *More Compassionate*

CODING SCHEME 8

I. RECOGNITION AND AWARENESS

A. Understanding Impact of Schizophrenia on Life:

1. Direct experience of symptoms
2. Disrupts normal life course
3. Loss of job
4. Interferes with self-sufficiency
5. Impairs or disrupts identity
6. Treated and viewed differently by others
7. Feelings of loneliness, isolation, and social marginalization
8. Feelings of shame, low self-esteem, and worthlessness

B. Reactions to How Schizophrenia Has Impacted Life

1. Loss of hope, feelings of despair
2. Denial
3. Anger at illness, self, world

II. REDEFINITION AND TRANSFORMATION

A. Change in Attitudes or Beliefs about Schizophrenia and Self

1. Beliefs about the Nature of Schizophrenia
 - a. Overcoming stereotypes
 - b. Schizophrenia is here to stay
 - c. Learning to accept setbacks and relapses
 - d. Schizophrenia is a no fault illness
 - e. Recovery is possible
2. Beliefs about Self
 - a. That one is not alone in their illness or experience
 - b. Accepting the diagnosis of schizophrenia
 - c. Accepting ones' self
 - d. Gaining power and control over life
 - e. Learning to value everyday life and all things

B. Learning to Live with Schizophrenia

1. Managing symptoms and illness
2. Recognizing need for help

C. *Moving Forward:*

1. Focusing on positive
2. Choosing to be well
3. Identifying areas of change
4. Overcoming fear
5. Identifying strengths and skills
6. Redefining expectations for life within the context of a disability
7. Developing goals, hopes, and dreams

III. *ACHIEVING VALUED GOALS AND OUTCOMES*

A. *Accomplishing Valued Goals:*

B. *Forming a Positive Sense of Self:*

1. Gaining self-confidence and self-esteem
2. Identifying ones' inner strength
3. Regaining a sense of value and worth
4. Forgiving ones' self and others
5. Becoming more compassionate, accepting, and tolerant of others

C. *Finding Meaning and Purpose*

FINAL VERSION OF CODING SCHEME

<u>PHASES OF THE RECOVERY PROCESS</u>			
Phase 1 - Mourning and Grief	Phase 2 –Recognition and Awareness	Phase 3 –Redefinition and Transformation	Phase 4 – Enhanced Well-being and Quality of Life
<u>I. Mourning and Grief</u> <u>A. Loss of Hope and Feelings of Despair</u> <u>B. Denial</u> <u>C. Anger at Illness, Self, and World</u>	<u>I. Recognition and Awareness</u> <u>A. Recognizing how schizophrenia manifests itself in ones' life</u> <u>B. Recognizing how schizophrenia disrupts "normal" life course and participation in age appropriate roles</u> <u>C. Recognizing how schizophrenia has increased social isolation and marginalization</u> <u>D. Recognizing how schizophrenia has disrupted ones' sense of self</u>	<u>I. Change in Attitudes or Beliefs About Schizophrenia and Self:</u> <u>A. Beliefs about the nature of schizophrenia</u> <u>B. Beliefs about self</u> <u>II. Learning to Live with Schizophrenia:</u> <u>A. Managing symptoms and illness</u> <u>B. Recognizing need for help</u> <u>III. Redefining Expectations and Goals:</u> <u>A. Redefining expectations for life within the context of a disability</u> <u>B. Developing goals, hopes, and dreams</u> <u>IV. Developing Strategies for Change:</u> <u>A. Identifying areas of specific change</u> <u>B. Overcoming fear and impediments</u> <u>C. Identifying abilities and skills</u>	<u>I. Forming a Positive Sense of Self:</u> <u>A. Regaining sense of value and worth</u> <u>B. Forgiving ones' self and others</u> <u>C. Recognizing that one has grown</u> <u>II. Developing a New Way of Approaching Life:</u> <u>A. Focusing on the positive</u> <u>B. Choosing to be well</u> <u>C. Learning to value everyday</u> <u>III. Accomplishing Valued Goals</u> <u>IV. Finding Meaning and Purpose</u>

APPENDIX D

APPENDIX D

Preliminary Themes and Sub-themes of Recovery
Used to identify "recovery" and "non-recovery" cases listed in Appendix C

Different Aspects of the Recovery Process

Main Theme	Sub-Theme
Acceptance of self, illness, and disability	Acceptance of others who have schizophrenia Acceptance of self as similar to others with schizophrenia Acceptance of symptoms Acceptance of limitations caused by illness
Changing one's attitudes and beliefs	
Discovery of hope	Through role models Through caring professionals
Insight and understanding of own illness process	Relapses not a failure Not a linear process
Outcomes	Job Place to live Relationships and social support
Recognition of oppression of individuals with mental illness	Working to change the system Working to fight stigma and discrimination Working to raise consciousness of others with mental illness
Redefining goals and expectations for life	Assess strengths and weaknesses Assess possibility for change
Rediscovering meaning and purpose in life	Through activities Through relationships Through religion/spirituality
Rediscovering or remaking one's sense of self	Through new identities Through new attitudes about mental illness Through discovery of new competencies
Regaining value and worth	
Seeking information and resources	Schizophrenia Medication Services Learning what others do to cope
Taking control of one's mental illness and life	Way one uses services Way one manages symptoms and environment
Use of the word "recovery"	What it means How it is used
Wanting to help others	Save from suffering (See previous self in others who are less far along in recovery and

	want to save them some of the pain) Wanting to give back to others Working to change the system Working to fight stigma
What people are recovering from	Loss of valued roles and activities Stigma and discrimination Loss of family support Loss of aspirations

APPENDIX E

APPENDIX E

Evidence of Recovery Count of number of cases that include discussion of recovery

Recovery Present	Member	Leader	Category 1 2 - 6 months	Category 2 6 months – 2 yrs	Category 3 2 years or more
Yes	19	15	10	7	17
No	10	2	4	4	4
Total	29	17	14	11	21

Recovery Present	Group ID Number												
	00	02	03	04	05	10	11	13	14	15	16	38	40
Yes	4	4	1	4	3	3	5	2	2	1	0	3	1
No	0	0	1	0	0	1	1	1	1	1	2	4	1
Total	4	4	2	4	3	4	6	3	3	2	2	7	2

Examples of Recovery by Main Theme (see Appendix B)

Acceptance of self, illness, and disability

"I realize you have to live with it [schizophrenia]...this [attending SA] is a great way to find out how you can take advantage of it." (01-02-11)

"[SA] helped me change, it helped me not be ashamed about having a mental illness..." (12-01-03)

"...[after struggling with schizophrenia for years] I chose to accept it. I'm better, I am getting better." (36-02-39)

You know, at least I can admit in group what is wrong [schizophrenia]." (26-02-14)

"I look at my schizophrenia as a blessing in disguise. I'm a better person for it..." (23-01-00)

"...I think it is so important to accept it [schizophrenia] as a challenge." (23-01-00)

"I see schizophrenia as a challenge....It's been tough the last couple of weeks, years, but I'm sure it's gonna get better." (32-02-13)

"...beginning to be able to accept myself...put the disease in perspective." (08-01-02)

"...to forgive myself was the most important step." (11-01-03)

"...[other people have to accept my schizophrenia] acceptance of who I am or they're not worth having as friends." (45-02-38)

"...It is an illness, it's like having cancer or something. It's not that your bad or anything." (28-01-15)

"...It [being around others with schizophrenia] has helped me to accept my disability." (32-02-13)

"Once I saw myself behaving in their behaviors, I started to realize that hey here I am, saying they're sick and I'm doing it myself" (02-02-11)

"...I felt there was nothing wrong with me,...not a disability, I could function just fine...and then I met other people that seemed like that they could function just like the way I did, the only thing is that they had a mental illness...so I just learned, learned that there are people just like me that feel like they're just fine with a mental illness. (22-02-02)

"...then I thought to accept myself I've gotta accept these people because...it is how people see me." (44-02-38)

Changing one's attitudes and beliefs

"I look at life totally differently." (23-01-00)

Discovery of Hope

"I'm learning how to dream and not look at my life... I'm learning how not to look at the terrible things that are happening to me right now. I'm learning how to dream and have hopes and aspirations." (19-02-13)

"...[realize] that you can still go on with your life." (23-01-00)

"When I first became ill, I was very ill and I was going to Pontiac and what helped me was I saw people who were worse than me and it helped me get better...cause I felt hopeless at first. You know, then I felt more hopeful." (32-02-13)

"... hearing about them [other SA members] getting better encourages me to keep doing better because it can be done...you know when somebody says that they've gone back to work, that's something that's so encouraging for me. One day I'll be able to handle a job." (10-01-10)

"[In response to hearing the founder of SA speak]...it made me think that I might have a pretty rough road ahead of me. But it also gave me hope that you know, it's not impossible to overcome something like this which is something I'm still struggling with but there are a lot of people who seem to get by okay. Every now and then, they may

have a few set backs, but I guess that's something I'm gonna have to expect." (25-02-10)

Insight and Understanding of Illness Process

"I have my ups and downs, you know, there's been some better breakthroughs." (12-01-03)

"...normal for most people to have good days and bad days." (45-02-38)

"[important in recovery]...meds and SA...and the steps and the fellowship and leading a low-key life you can maintain." (20-01-00)

"...learn that there are varying degrees of illness and a set back doesn't mean that you're not successful." (20-01-00)

Outcomes

"...we were interested in how to apply those 6 steps [6 steps of recovery] that would make it easier to get those things that they wanted [housing, job]." (21-01-00)

"...the hope and dreams to get well one day and resume our former career...to find a nice place to live, to own a car, to have a family. " (19-02-13)

Recognition of oppression of individuals with mental illness

"I wanted to do something to fight the stigma." (23-01-00)

"...I was wondering why those people didn't wanta fight for their independence and so I kinda made that my theme...I told [him] I want to do something more. I'd like to get out and meet more people and tell them my story and tell them how hard it was for me to get started." (35-01-00)

Redefining goals and expectations for life

"...that's something I'm working on, is to expect more from my life, and from my creator and keep things going." (03-02-11)

"[What did you learn from SA?]...I can get better someday and go out and work in the community." (04-02-11)

"...success has a lot of different meanings." (20-01-00)

"...[When struggling in school] felt like maybe just go to SA and recover....Felt a release of negative energy when I gave up those aspirations [full-time career]." (33-02-05)

"...I made goals for myself [in the SA group]. Even though sometimes I wouldn't meet

those goals, it gave me something to look forward to." (30-02-02)

Rediscovering meaning and purpose in life

"...[after leading an SA group] I would feel uplifted and I would feel like I was doing something really worthwhile." (21-01-00)

"It [SA] gave me something worthwhile when I was very down." (21-01-00)

"...[I was] beginning to think of ways I could make a contribution...making coffee...cleaning up the table." (21-01-00)

"SA has given me a purpose in my life so it changed my life. I think when you stop focusing on yourself and your own problems and you start reaching out and when you look at your blessings and how grateful." (23-01-00)

"...[SA] gives me a sense of purpose. It makes me feel like I've got something to give back...I need the people there as much as they need me." (05-01-11)

Rediscovery or remaking one's sense of self

"...sometimes you discover things [skills and abilities] about yourself that you really didn't know." (09-01-14)

"I have some strengths that I didn't even know I had..." (12-01-03)

"...[after getting sick] it was like starting all over again....And outside staying the same but the insides all burned out so the medication they give you is more or less rebuilding that inside. It will never be the same again but you do the best you can with it...you could tell that even in my mind. I tried to hold, I was trying to hold onto my old life but I felt it slipping away. (30-02-02)

"...[attending SA] gave me a chance to come together with who I was, where I was at the time, and how I wanted to go....I set some goals and by listening to other people I began piecing my life back together and understand what schizophrenia was." (35-01-00)

"And I started changing, every six months, I started changing. I knew I was getting used to it. It was like a new world was, a lease for a new life...and I slowly started changing over time." (30-02-02)

"It [SA] has brought out a lot of talent in me. Things I thought I couldn't do." (29-02-02)

Regaining value and worth

"I see their strengths [other SA members] and I grow from that...I look at people like my therapist...by being confident in me...he helps me to learn I still have value." (05-01-11)

Seeking information and resources

"...[education is important] because you can't expect people to take responsibility for their illness if they aren't educated about it." (23-01-00)

"Intellectually I'm not ignorant anymore. I have more understanding. Especially people with illness." (29-02-02)

"Understand why some medications work and others don't." (35-01-00)

Taking control of one's mental illness and life

"...the most important beliefs [about recovery] are wanting to be well, having some power over your illness and empowering yourself over your illness." (08-01-02)

"I was looking to change my ways..." (11-01-03)

"...believe you have a choice...don't be the victim all the time...there's such freedom to be in charge of your life....the most [that helped me in recovery] was when I realized I had a choice. In all my years I thought I was a victim of this illness." (23-01-00)

"...[SA provides] an opportunity to take the initiative to heal yourself...step out and overcome your difficulties regardless of your discomfort, the suffering, the headaches, the failures, and the set backs." (41-01-40)

"...[when introduced to the 6 steps of recovery] I could see the things I have been trying to work on without those words." (39-02-38)

"...I do need help and I choose to be well and I want to be a happy person." (29-02-02)

Use of the word "recovery"

"...I am on the road to recovery right now." (10-01-10)

"Recovery does not mean you have to have a full time job. It's recovery to your potential with your limitations...there's a possibility out there, but there's a handicap and a challenge to

overcome but you have limitations. Just like somebody in a wheelchair...you know, any other disability." (23-01-00)

"Well, I was in therapy and I was just starting my recovery routine. I call it a routine." (35-01-00)

Wanting to help others

"I wanted to help the less fortunate mentally ill because I know what it's like to be so bad and so sick and I knew what it was like to be well." (23-01-00)

What people are recovering from

"We've had very deep emotional pain...seen our lives disrupted...lost relationships...had a sense of promise disrupted."

Examples from cases where recovery does not emerge:

"I just, I don't think I'll ever be normal, really a normal person. I'm just scared I'm never gonna get married or anything. I'm never gonna be successful. I've always been a nerd, the outsider." (18-02-16)

"I really don't think I am schizophrenic...I do believe I have a mental illness but I really don't, not sure exactly what it is, or if it is anything." (18-02-16)

"I don't really have anything positive to say of where I've improved. And so I can't say that I have a lot." (31-02-10)

"I can't say it is helpful [to come to the meetings] but I come because I feel that just participating is better than staying at home...you're better off coming here." (31-02-10)

"Feeling there's no hope for me." (25-02-10)

APPENDIX F

APPENDIX F

All Data in Support of the Eight Meta-Themes

Note: Text was bolded in order to more easily identify which part of the quotation was directly related to the identified theme. The other non-bolded text provides context for the quotation to help the reader better understand the meaning of the text.

Phase 1: Mourning and Grief (N=12, 26%)

A. Loss of hope or feelings of despair (N=5, 11%).

"Anyways, so I got discharged and for about a year, I didn't even feel like doing anything....In spring of '81 I began to consider suicide. Then finally, things were getting worse and worse. The whole thing with the typewriters getting loud again and stuff. Then in October of '81, I took like 72 Navane." (07-01-05)⁵

"I was thinking suicide but nobody knew that. My self esteem was very, very low because I was very, very skinny. You know, guys would pick on me. The girls were starting to, you know, develop boobs and all that and I thought I didn't fit in. You know. I felt ugly. I said well, I wanted to give up" (12-01-03)

"I made a suicide attempt while my wife was divorcing me." (14-02-11.1)

"I just think I'm different. I just, I don't think I'll ever be a normal, really a normal person. I'm just scared I'm never gonna get married or anything. I'm never gonna be successful. I've always been the nerd and the outsider." (18-02-16)

"Well, I was, like I said, I was really glad to know other people that were like myself. When I saw some of the lower functioning people, it kinda made me think is this what I'm gonna be like some day? But overall, it was pretty positive (involvement in SA).... I don't believe that it ever could get better....I've attempted (suicide) four times since I got sick. I guess feeling that there's no hope for me. And I know, I know one or two people, yeah, two as a matter of fact, in the group, that make about as much money as the average person does in a year and all the rest of them either live in group homes or on disability. A lot of that, feeling like my life may have to stay horrible. I mean, just for the rest of my life. Knowing that each day could be something different....Well, I don't know. It's

⁵ This is the interview identification number, which can be used to trace this information back to the original interview, or it can be used to link this quotation with the quote provided in the crosscase results and discussion section.

made me really wonder if I should stay on this earth or if I should just go lay in front of a moving train. Because I had a lot of fear every day that my life may never get any better and the only thing that's gonna happen is that I'm gonna get older, older, and pretty soon I'll have to worry about physical health problems and you know, my parents are gonna die and, you know, really, I wonder how am I gonna survive." (25-02-10)

B. Anger at illness, world, & self (N=4, 9%).

"It's hard sometimes, you know. When you have to look back, it was ugly. This is an ugly illness. I gotta tell you, I hate it. I hate every day of it. I want my job back.... I had a loss. It's been a loss for a long time....I'm not good at anything anymore. I hate this illness. I hate it." (05-01-11.1)

"Just that I get short of temper. I never get angry. I feel angry all the time." (14-02-11.1)

"... the fact that I may have to live with something wrong in my life just really, makes me really pissed off, I guess." (25-02-10)

"Which my mind is not too bad now. But I still can't go out and work and do this and do that. Sometimes it makes me mad." (28-01-15)

C. Denial of illness (N=6, 13%).

"I like to think that I'm not really mentally ill because I feel I was justified in, justified in behaving out of, out of sinc with the community because there was something going on in my life at that time that really represented a strange and biological magic, you know. Black magic, sort of like." (02-02-11)

"I didn't accept it at first. I began partially accepting it in spring of 1988. I had been hospitalized 3 times, each time I had gone off my medications before being hospitalized. **I don't believe in it,** but I needed to start taking my meds." (03-02-11.1)

"Actually, I don't think I have schizophrenia....I don't know. I really don't think I'm a schizophrenic. I do believe I have mental illness but I really don't, not sure exactly what it is, or if it's anything." (18-02-16)

"... I learned that I might not have. I might have just had an emotional breakdown at the time." (24-02-10)

"But it's, I attend some of the meetings, you know. But I'm not like them. I don't go to a psychiatrist. I don't take psychotropic medicine because I'm not mentally deranged." (40-02-38)

"I don't know. I don't think I ever had any. YOU DON'T THINK YOU HAVE A MENTAL ILLNESS? No. I go to seminars in the hospital but other than that I turn out being normal." (47-02-40)

Phase 2: Recognition and Awareness (N=33, 72%)

I. Recognition and Awareness

A. Recognizing how schizophrenia manifests itself in ones' life (N=10, 22%)

"Well, I think when it comes down to the day to day experiencing of voices that I hear, they're my voices and the delusions that I have are my delusions. And because they're delusions, even though I can call them delusions, since they are delusions, I can't, part of me really can't call them a delusion because if I can, if I can entirely call it a delusion, I wouldn't have schizophrenia. I'm thoroughly convinced of the things that I'm thinking....But I have a hard time sometimes being able to discern between what's a good idea and what's crazy." (01-02-11.1)

"You've probably become aware some of my thought processes. They don't work too well. All the past, the concentration is gone, memory is gone. And the thoughts are brutal. That sums up how I feel." (14-02-11.1)

"I have a hard time concentrating. I know a lot of chess tricks but my concentration isn't the best. But I'm better than most people." (18-02-16)

"I think I was always a little bit off beat but I don't think L.. my mind will skip around more than it did before. Can't concentrate sometimes, what do they call it? Loose association, associations that don't exist sometimes.... From the get go, we've all been hit with this diagnosis. We've all had these symptoms. Almost all of us have been hospitalized. Almost all of us are on these medications, we all see psychiatrists. We've all had very deep emotional pain....Just craziness. Hallucinatory stuff and depression. Anxieties that I never, to the extent I never felt before. I was always uptight, I think, worrisome type. But it just kept multiplying." (21-01-00)"

"That's something else about the illness. I'm not really able to communicate with people the way I used to. A lot of the time, I find myself stumbling over words and just not having the right thing to say. That's really difficult...because it happens a lot." (25-02-10)

"You feel sort of a like a social outcast. Not, I don't feel a stigma, not because of the stigma of the illness, I don't feel that. It's in myself....I experience things that other people don't, most people don't....If I get,

start getting real active, I have to keep it kind of low key because if I start getting real active, I start getting like manic. I start going real fast and then you run into a brick wall and crash. You know. I have to stay low key. I have to keep myself calm and I need a lot of quiet, a lot of quiet. But then too much quiet... you have to interact, you know, to keep yourself going.” (28-01-15)

“Well, the constant issue I had with my delusions. I'll bring that in a lot because I constantly have delusions. It may not seem that way but when I'm at work, I can be in the stacks of books, straightening or whatever, and I'll be laughing. Not, out loud, ha ha ha, like that. Just kind of chuckling to myself and smiling and I think that looks kinda weird.” (33-02-05)

“Now, if I don't go singing it all the time and like grinning all the time, but there's something on my mind that made me grin. Because I'm grinning all the time” (36-02-04)

“But it's the ups and downs. You know, even with the medication, Katie, I still feel I gotta fight it, you know. Who am I? Who am I? This withdrawn, I don't want nobody around person or am I this real manic, I love everybody and I wanta be with you and let's go, go, go. Let's do it, do it, do it. Let's have fun, fun. Who am I? You know. And hoping this lithium is putting me somewhere in the middle. I'm not having the real lows or the real highs. You know. But I'm still not right. I don't feel like I'm still right, you know.” (44-02-38)

“...voices and I was seeing hallucinations at work and I tried to, you know, go home. I'm not feeling good. You know, stuff like that...But they usually came when I was alone but towards the end, before I went, you know, on that three-year thing, it was like they were just constant. You know, I couldn't do nothing about it if I was in a group, you know, 1000 people at a concert, it wouldn't make a difference.” (45-02-38)

B. Recognizing how schizophrenia disrupts normal life course and participation in age appropriate roles (N=19, 41%).

“It's hard sometimes, you know. When you have to look back, it was ugly. This is an ugly illness. I gotta tell you, I hate it. I hate every day of it. I want my job back....I had a loss. It's been a loss for a long time.” (05-01-11.1)

“I can't work or I start cracking up.” (07-01-05)

“I think that if I was a normal person I would be in college, partying, hanging out with my friends, probably living with my mother, mooching off her. So I think that I'm quite a different person because of my illness and the things that I have been through.” (10-01-10)

"I felt shameful because I wasn't able to go through boot camp in the right amount of time. I wasn't able to complete schooling.... It's just like now you're another failure upon a failure. I was able to release some of those feelings and you know, forgive myself and release everybody that has harmed me or injured me in anyway. So it was very beneficial for me." Oh, yeah. It's definitely taking me longer. LONGER TO ACCOMPLISH THINGS? Well, I should have been 22 and out of school. Now I'm gonna be probably 42 before I accomplish school. I'll probably never ever work in a work place using what I know. It's just for my own goals and my own satisfaction that I wanta go back to school." (11-01-03)⁶

"... they didn't have a job for me because I was mentally ill. You know, that was discrimination but I just didn't seek getting help.... I'll probably never ever work in a work place using what I know." (11-01-03)

"But talking to my parents, they suggested that I just stay on disability and work these menial part time jobs to earn extra money because at least I have that safety net. You know, and to get back on disability, they make it so tough to get back on it, then I would have went out there and tried to find a full time job. But I don't have any interest in doing that. Because they make it so darn tough to get back on. And I don't want to be homeless and lose this." (11-01-03)

"Yeah. It's kept me from working. Even makes me lazy, the work that I have to do....I can't drive a car. There are a lot of little, a lot of little things. A lot of little things that's all. They're insignificant....I hate to say it but she (mom) cleans my house sometimes." (14-02-11.1)

"It's kept me from working. Even makes me lazy, the work that I have to do. I don't know." (14-02-11.1)

"Well, it's made me unemployable. So it's hard to support myself." (19-02-13)

"Most of us had a sense of promise that got disrupted. Most of us, there is kind of a pariah thing..., my life was wiped out in a sense. The tract of my life was kind of just, things have never been the same as they were in 1980. 1981, I had, this past Saturday we had a reunion with all the gang both from high school and college. And you know, I'm different from them. They have normal lives. I don't have any of the vestiges of a normal life. I say, that's exaggerating but... exaggerating to... Well, I don't have a professional job. I don't have the prospects of marriage. I don't have

⁶ Some themes were identified more than once in a single participants interview. All the identified themes are listed, but they are only counted once in the final count and frequencies that are presented with each theme.

the prospects of having children. I drive around in an eight year old car that is always on the verge of malfunctioning. I lived in a, kind of a young professional's apartment arrangement prior to that and now I'm living in a subsidized apartment. I lived on my salary from work where now I, you know, the biggest part of my income is social security. I had health insurance from my work. Now I am on Medicare probably Medicaid now. I have a certain degree, I had a certain degree of regard... I was regarded and now generally, generally when I walk into situations, **I have stigma** I am making it sound really dramatic but there was a... I could walk into social situations in 1980 with a relative ease whereas I know right away that even if I do, you know, fix myself up that there'll be an element of stigma once the word gets out about my mental illness. Hard to deal with that." (21-01-00)

"Trouble keeping a job." (22-02-02)

"Not enough respect from friends. My mental illness **has prevented me from** going to school for auto mechanics, being able to play the drums in a band, and **having a steady job**. I wouldn't tell anyone. I thought I could deal with it." (24-02-10)

"I will say though that they (family) invite me to a lot of things with them. But you know, it's, I have this thing about facing the world the way that I am right now. I'm so dissatisfied with myself that I just, I don't want anyone to see me this way. **I just think that I should be more successful and you know, have a babe on my arm and a car of my own to drive and things like that. You know, go there like a regular human being, not like a child that's being taken somewhere by his parents.** And you know, that's the way it always, you know, has felt the few times that I've went places with them so I try not to do that." (25-02-10).

"Well, we take medication. We all take medication. **We don't work.** We know how to deal with day to day not knowing we're going to have a job. And we're all on some type of public assistance, dealing with Medicaid and all this stuff. We're all seeing our doctors." (28-01-15)

"We all take medications. We're all struggling to live day to day. **Most of us don't work. It's hard Most of us, are living with our families, or alone. We haven't been married. We've been in and out of the hospital a lot. ...I feel like I've lost about ten years. I wasn't able to get married. I've been engaged quite a few times but it's interfered with that. My job, being able to hold a job, it's terrible....You know, instead of living with people my own age, you know, doing things people my age do and having a nice car or being married or a nice career, you know, that's what I had planned.** A career and children. Well, I'm glad I never had children. That would be devastating to them. You know. I don't know if I'd have hurt them or not." (28-01-15)

“And we're all on some type of public assistance, dealing with Medicaid and all this stuff....I have to live, I'm always on edge that they're gonna drop me. SS, you know, I'm on SSD, on Medicaid, you know, constant worries me. I'm at the mercy of the state, you know, and how they are going to vote in Congress and instead of being independent and holding a job and having a life.” (28-01-15)

“But due to the illness and not having my medication, other than helping others I would say my whole life, my career is gone. “(29-02-02)

“And it was just, you could tell that even in my mind, I was trying to hold onto my old life but I felt it slipping away....I had my whole life planned out. And it was a disappointing feeling because I felt myself getting ill. When I first realized, I was loading garbage and I kept going around in circles, thinking that one day I'd run into somebody. I don't know why I was having these thoughts but I do now because it's part of my schizophrenia just beginning, but it hadn't hit me hard enough yet. I thought somebody was gonna help me get into the National Football League and play football. And I was going to make good money and get away from the world for a while. ...A good job, a wife, kids, money. It's a shame, I'll never get to complete that but as I said before, you got to start over sometimes....I think what people don't realize it that it's a disability like a lot of things. ...I still wish, that my two friends K and T, the ones I told you about the marriage deal. I wish I could still talk to them. Different times I'm tempted to go to their house. But, I've got to realize, too, they're living a different life that I can't live no more. There will always be, like getting drunk at night, partying with them. Talking is hard because they don't want to hear it when it comes to my illness. Social security, they wouldn't understand.” (30-02-02)

“But the hardest part was going back to work again to face the workers again....The management, not all of them but just a few, one did, would ask me you're not going to bring in a gun next time, are you? I just laughed about it but I, you know, it was disturbing because they had a lot of shootings at the post office and stuff like that. And I got really defensive but I just let it go in one ear and out the other. It [medication] affects the work, too. I wasn't as quick. I worked at a steady pace but I wasn't as quick as I used to be and they didn't like that. A lot of drivers were trying to make me move quicker. And it was just, you could tell that even in my mind, I was trying to hold onto my old life but I felt it slipping away. That's how people were treating me. ...Like I told the group, before I got fired, I knew eventually it was going to end because I was getting really stressed out. And even the weekends were gone, because like I said, I took my medication during the weekend and that knocked me out like that. My weekend was here and gone before I knew it.” (30-02-02)

“Feeling way, way out of the mainstream.” (34-02-05)

“...loss of status in jobs. And maybe the ability not to have a baby, or to have a healthy baby. And just **lost dreams.**” (35-01-00)

“**The loss of status in jobs.**...Oh, when I went on medical leave and came back, they were all calling me names and stuff, you know. So my manager, he'd tell them to treat me with respect and not make any comments about mental illness or anything. And that was taken care of. **And I think it stopped me from getting a promotion at work.** They recently said you're the only person whose not supposed to have a key, when she found out I had a key to the office. I don't know why she said that but that really hurt my feelings so today I'm gonna, when I go back into work, I'm gonna hand in my key and say here, here's the key back. I don't wanta be part of your cronies. I'm above that. Because I guess they've had some stuff missing or stolen or something. And I've only had the key for a week” (35-01-00)

“And I don't, you know. Exceptional is what I was, being number one like that. Of course, then 2 seconds later, you know, you can be at the other end of the, the other end of the, you know, feeling the other guy, whatever. So that's why I always know who I am and what I won't do.” (37-02-04)

“... it keeps me from holding a good job and I don't draw much. I only draw \$485 a month. And I've got section 8 so that's the only reason I can pay my rent. . **I'm a nurse and I don't think that I could take the mental strain of being a nurse. ...not able to drive any more.** I used to drive. I'm not able anymore. Because I got a fear of driving. And I have to **depend on people** to take me. Mary picks me up to come to volunteer every day. And I have to have somebody take me to the doctor. And take me to the grocery store.” (38-01-38)

“Yeah, **it interfered with my job.** I got to the point, you know, this last series, this last three years, I haven't been able to work. And like before I went in the hospital, I worked for my dad as a secretary and, you know, these voices and I was seeing hallucinations at work and I tried to, you know, go home. I'm not feeling good. You know, stuff like that. But they usually came when I was alone but towards the end, before I went, you know, on that three year thing, it was like they were just constant.” (45-02-38)

“Oh, definitely....interfered with working.” (48-02-16)

“So it's not others that I'm finding more or less too much resentment or unhappiness with. Once again, it's my own ill health. **I almost feel like everybody kinda goes through some changes between birth and adolescence and adulthood. And it's like mine's taking up by illness and suffering.**” (48-02-16)

C. Recognizing how schizophrenia has increased social isolation and marginalization (N=27, 59%).

“My family treats me with kid gloves. Or used to. They don't so much anymore.” (05-01-11.1)

“So I was able to accept my myself as a whole person not long after that and in fact, I remember, it was a few months after I joined, I asked my brother in law to drive me to group and he said well, how are you going to get home? Because my car had broken down. And I said oh, one of the people there will give me a ride. And he goes well, where are you going? I said Schizophrenic Anonymous group meeting. He said oh, my God, you be careful who you ask for a ride home from, you know? And I laughed. When I got there, I told the group and the whole group burst into laughter. Because they know what it's like, you know, what people feel about us. And we know that when we're sick, we're sick, you know? And that anything can happen....I've been able to play the role of a professional in a lot of the work I've done over the years with Liberties, and opening up the shelter and working with a lot of agencies that really didn't even care that I had been mentally ill, there were times when people tried to remind me that I was mentally ill, to intimidate me, and it had no power over me, you know? Or they tried to diminish me because I had this other thing attached to me. But SA has taught me that, I always say it's part of my medical history. It's not me at all.” (08-01-02.1)

“That we are people, we have souls, we have feelings, and for us not to be treated like trash and pushed aside. That there are ways of helping us, and I wish that people would wake up and get these programs started and start doing more for us because we can be helped. That is what people don't understand, it's like from the very beginning, the first people to be burned in the fires were schizophrenic people. In Hitler's ovens, that was the first people to be burned. Like they weren't even people, like they were dogs. Not even dogs, it was like they were rocks, just throw them in the fire. It's almost still continuing that way.” (10-01-10)

“You know, because I felt I was all alone. I felt isolated and that's a terrible feeling, you know. You feel like you're shut out from the world. All of a sudden the people at the VA said my God, you're schizophrenic, and I'm going my God, what the hell is that? I just went through a terrible ordeal... I lost some really good friends. I grew up with these guys and I've known them since I was probably either 8 or 9. We used to caddie together.” (11-01-03)

“...get paid anything by these employers, because they didn't have a job for

me because I was mentally ill. You know, that was discrimination but I just didn't seek getting help.” (11-01-03)

“Well, **I felt isolated.** I was severely withdrawn. I felt I didn't fit in with people. I was severely depressed....Like I said, I felt, for many years, isolated. No one understood what I was going through. I didn't have any social outlet.” (12-01-03)

“Well, it put a **strain on my relationships with my family.** Really, they give me all the support I can expect though. My family, they support me pretty well. My mother, she doesn't cope with it at all. She can cope with it, my problems.... Well, that would be my brothers and my sister. And my daughter. My nephews and nieces. My immediate family anyway.... Well, what about them? It just, they try to be as friendly as they can. Understanding, try to understand it and I don't know if they do. This is difficult, this is very difficult.” (14-02-11.1)

“I hate to say it but **she (mom) cleans my house sometimes.**” (14-02-11.1)

“Just being able to have a **normal social life.** I am such a wierdo.” (18-02-16)

“Well, I wish that I was more approachable so I could make friends more easily. I wish I had better social skills so I could make **friends** more easily.” (19-02-13)

“Most of us, there is **kind of a pariah thing that we've all experienced,** well, I say all, most of us do. We have some members who look and behave and seem absolutely normal but **as soon as the word schizophrenia gets introduced to a relationship, things alter pretty quickly.** So a lot of us have a choice of keeping entirely to ourselves or.... how do I put it. People looking, people gape at you, it is like you are a Martian. I don't remember ever having, you know, in a normal situation, I don't remember ever having a really awkward social situation where it seems like I'm in awkward social situations all the time.” (21-01-00)

“...was in the hospital, I didn't talk about my schizophrenia to other patients. I was ashamed. I didn't want them to know my diagnosis. **Because I felt they'd be fearful of me and I've heard other people say that, too....There has been some stigma at work.** I was treated nicer after I went public, less gossip, there was some jealousy because of the awards. It helped for people to know me at work. To know that I am not violent, etc. I still don't recommend that people go public, don't use the S word. People at work would do things like call my girlfriend if they thought my eyes looked weird. They would do that instead of asking me directly....**Around my mother I can't get angry because if I get angry she thinks I'm getting sick.** It's not always the illness,

we have the same emotions and needs as everybody else.” (23-01-00)

“I felt, I know what it's like to **feel alone** and misunderstood and the stigma and so on. And ashamed. I was ashamed for 14 years.” (23-01-00)

“**Not enough respect from friends.**” (24-02-10)

“I mean, I'm still, I really haven't come too far, I don't think, since then. And I wish I could say, yeah, a lot has changed but unfortunately it hasn't.... You know, **go there like a regular human being, not like a child that's being taken somewhere by his parents. And you know, that's the way it always, you know, has felt the few times that I've went places with them so I try not to do that....The fact that most of us really have really overprotective parents. That I think in a lot of ways hurts us.** Me included.... Well, I don't really hear too many people complaining that their parents are overprotective. It's just like, it's just that, you know, they say, you know, things like how involved their parents are with their lives. And like one guy saying that he needs, he needs money from his parents because he lives on his own. But his parents wanta enforce all these rules on him. You know, he has to stop smoking pot and get rid of all his credit cards and things like that. And basically they wanta run his life. And I've known other members who have parents that are just like that. One guy couldn't go out of the house after 9:00 and he was 35 years old... but when I got the illness he kinda just, I guess, you know, stopped hanging around with me.... But yeah, after I was diagnosed, I guess word was out that I was a freak so nobody wanted anything to do with me. ... They're (parents) very overprotective. ... There really is nobody who's that important in my life. And I miss it a lot. I'm extremely lonely. (25-02-10)

“**They are very, very careful with me. They act like I'm porcelain and if I fall I would break.**” (26-02-14)

“Well, it's, **sometimes it scares people. You know, it scares people.** They always say something like - Do you have a counselor there you can talk to, you know. And so they get kind of, they either back away from you or they try, you know. But you can tell that you are intimidating them. They back away or something.... Why are they frightened?... Anything different, you know, out of the ordinary. We have a couple in our church that are very involved in the Alliance for the Mentally Ill. Their son is mentally ill. We have a few mentally ill in the church and they talk to me about it and how he'll talk out during the sermon, you know. He's not terribly inappropriate. A lot of churches, like the charismatic churches, they do talk out, you know. Amen or something like that or say something. Our church doesn't do that. But he does, you know, and they talk about it and it makes me mad. They talk to me about him, you know. Because he's an individual and he has his way of doing

his things and they accepted him into the church and I don't think they should be talking about it. Oh, did you hear him, you know. He talked out during the sermon. They're good people. They don't mean but I said well that's Bob, you know. He's all right. He's not doing anything. Yeah, but you know, that kind of upsets me. You gotta understand. He's very active in the church. He's doing very well. He doesn't take medication. He won't take it. He has a job, just bought a house.” (28-01-15)

“Consider it ignorant of me, but I was ignorant because I didn't know anything. **I thought I would shunned so I never put it on an application or anything. So I was afraid to even tell anyone.** Now, I'm not. Now I'm more open minded. I wouldn't be afraid to tell somebody.” (29-02-02)

“I was a sanitation worker and I didn't want to lose my job. So I went back to work and people were asking me are you on medication still? **And so there were always a lot of questions and a lot of people didn't trust me no more. I told them I just had a nervous breakdown and nothing more. But the hardest part was going back to work again to face the workers again. The management, not all of them but just a few, one did, would ask me you're not going to bring in a gun next time, are you?** I just laughed about it but I, you know, it was disturbing because they had a lot of shootings at the post office and stuff like that. And I got really defensive but I just let it go in one ear and out the other. ...I think I lost all my friends because my mental illness scares them. Because of movies, TV, people get intimidated by you. I think what people don't realize it that it's a disability like a lot of things.” (30-02-02)

“My mother wouldn't allow me not to, to drop off. I would say she's very firmly wanting me at these meetings and so I, it's very difficult. Like once I didn't feel like coming and so my father and I just went off and went to Big Boys and went to Elizabeth Park. But frequently, **my mother would not hear of my not coming.**” (31-02-10)

“I was paranoid and that didn't help, you know. **People were scared of me because I was mentally ill, you know. ...It's hard to make friends because people find out you're ill and they're scared of you.** Like my girl friends at the post office and then she learned about my illness and was mad at me, you know....They try to treat me like a baby, you know....Just that I'm, **talk down to me, you know.**” (32-02-13)

“We always spend time in his apartment or my apartment, watching TV. We are very, very close and that's what makes it hard for my mom because **she doesn't want me to get stressed out. That's why she won't let Steve come over because she feels... One time we broke up and she feels that he was the cause of it all so now she says I don't want him over because I don't want you to get stressed out.**” (33-02-05)

“Because I did get 2 Ds, I think I got one E, two Ds or something like that in a couple courses I was taking **and one of the instructors asked me what I was doing here because he found out I was schizophrenic....**as far as meeting people with the same illness that understand my illness. I can talk about my illness without worrying about chasing people away, you know, scaring people away. ...I want to get feedback and tell people, you know, and connect with reality somehow. The best place to do it is over at the SA meetings and the social groups afterwards because people who don't have the illness don't really, they shy away from you and they don't really... I'm not saying you don't, but most other people don't understand what it's like to have schizophrenia. ...I think if it (having schizophrenia) leaks out, if I let it leak out that I have an illness, they don't understand. They don't understand so they kind of back away. I've gotten used to that and I'm learning to not talk about my illness so much....We always spend time in his apartment or my apartment, watching TV. We are very, very close and that's what makes it hard for my mom because she doesn't want me to get stressed out. That's why she won't let LZ come over because she feels... One time we broke up and she feels that he was the cause of it all so now she says I don't want him over because I don't want you to get stressed out.” (33-02-05)

“**Because my husband is always pointing out to me, well, if you are moving strangely people think something's wrong with you.** They're staring at you....It has to do with my tardive dyskinesia, which is one of the reasons I chew gum a lot. It helps because it gives the impression that, oh, she's chewing gum. That's why her face is moving.” (34-02-05)

“**Loneliness, I guess. Feeling way, way out of the mainstream.**” (34-02-05)

“Oh, when I went on medical leave and came back, **they were all calling me names and stuff, you know.** So my manager, he'd tell them to treat me with respect and not make any comments about mental illness or anything. And that was taken care of. **And I think it stopped me from getting a promotion at work. They recently said you're the only person whose not supposed to have a key, when she found out I had a key to the office.** I don't know why she said that but that really hurt my feelings....” (35-01-00)

“As far as being treated, **I feel like my family treats me differently.** Like sometimes I feel as if, my one sister told me, well, we just don't have anything in common. And another sister praised me for doing all the things that I've done and accomplished even though I have an illness, you know. And so each one of them, I have seven sisters and one brother. Each one of them treat me a little bit differently. The only one that treats me as normal is my youngest sister, Carol. She doesn't have a bias or stigma or anything like that. She helped write a book for a company so, on mental illness and I think that's why she's so much better with it than the rest of them. She's educated towards it. I think the more you're educated, the easier it is to get along with somebody. I

think there should be a lot of family education programs out there.” (35-01-00)

“Well, my dad likes to golf... I golf with him. **My mom is over-defensive on me.** She's the one who is afraid. She cares too much.” (37-02-04)

“And I took driver's training at \$30 a half hour. And I had about four or five lessons. Then I applied for a driver's license and I took, I passed the driver's test, passed the paper test and I got my license. But I had no car to drive. **My mother had the car. And she would not let me drive alone. She had to be in the car with me all the time. So it was not long after that that I was in the hospital again, depression, and, let's see.**” (41-01-40)

“They don't understand that you're manic depressive. They don't understand it. Homosexual or what's the other one, alcoholic, oh, yeah. Well, she's got a drinking problem. You know, they'll understand that but this isn't, this is taboo. **You know, you're gonna get, you're shut, might shoot the whole damn building up or something, you know, so I just, I know who my friends are. I've been here (apartment building) five years.**” (44-02-38)

“And sometimes it has a little bit of fear. Sometimes you meet somebody who doesn't have a mental illness and they know nothing about it and nothing what you've been through, you're kinda afraid to tell them **because they might not wanta be, continue friend with you because they're afraid you might, you know, go crazy on them. And you know, they kinda judge you, judge you like a book sometimes. They say don't judge a book by its cover but I feel with a mental illness, I think a lot of mentally ill people get judged and some of them aren't, a lot of them aren't treated fairly because there's a lot of very intelligent mentally ill people. And people think because they're mentally ill you're not, you know, you don't have a brain.**” (45-02-38)

“**Interfered with relationships,** interfered with a happy home life, interfered with working. Even interfered with the idea that I can just pop outside for a minute and talk to somebody. That's...they're all big deals to me.” (48-02-16)

“I've been through a lot of difficult times, but I never gave up. It was rough. Oh, there were times when I would cry, I'd get emotional. **My mom shielded my illness from my family because she was worried about what they'd think.** She was worried that they might be judgmental, judge, you know what I mean. Less tolerant, that stuff. **So she thought it was in my best interest to shield it but she was always there for me. But there were times when I wanted to figure out and solve some problems on my own, and she was hard to tell at that time.** But then I did manage to solve some things myself. I learned to get quicker, learned to face my peers better. ...I used to ask frequently as a child to people do you like me? Am I your friend? I used to read people by their looks and paranoia but I don't do that frequently any more. I just need more time to grow and see the difference. **And since my**

mom wasn't around there anymore, I had a chance to grow out of it. She was in the way, didn't always work because I became even more confused and mixed up, you know. I don't do that today anymore. I don't, I'm not gonna worry about what others think and say and when with friends, do you like me, etc you know. I wrote that in my journal. I don't do that frequently anymore so I shared that with my family and they also read my journal and they were pleased.” (49-02-04)

D. Recognizing how schizophrenia has disrupted ones' sense of self (N=5).

“So it's not so much a shameful thing like I can so easily think.” (03-02-11.1)

“... I was thinking of suicide until I met other people who, first of all, who would accept me as a person because that's what I had to have. I wanted to find some identity. I didn't know what my identity was....You've gotta teach the person so they have some deep beliefs about what they're experiencing. So they can help themselves, you know? I was just left alone like in the mess for all those years as far as I was concerned. What is wrong with me? What am I? How evil am I? And what am I all about, you know? And then every time I heard I was a good person, I had potential, I didn't believe it because I also knew that I was mentally ill. I was crazy. I didn't think mentally ill. I thought I was insane, you know? So then I'd think, well, maybe I'm a mad scientist, you know? But I couldn't give myself credit for anything because I always had the insanity to attach to it. I wanted some distance, some power over it. Some way to help myself. (08-01-02.1)

“Why was I this way and how come and is there anybody else? You know, it was just really strange. Like maybe I was an alien or something, you know? So it helped me get down to earth because I was out there alone with this illness that all these other people were telling me it was schizophrenia. I read about it in books but I've never seen anybody in real life with schizophrenia. So I was quite confused. I didn't know why I was the way I was and plus, the doctors didn't really give me that much information about it....So I think that I'm quite a different person because of my illness and the things that I have been through.” (10-01-10)

“It was just so hard. I just always wished that there was something that I could go to, or somewhere that I could go to where people were going to tell me that it's OK to be the way I am. That it's not a bad thing because as far as I was concerned, my mom was ashamed of it. She couldn't even say the word schizophrenia. And you know, like my fathers, they just didn't even pay any attention to it and so I had nobody to relate to, nobody to talk to about anything except for the psychiatrists and therapists that I saw.” (10-01-10)

“I felt shameful because I wasn't able to go through boot camp in the right amount of time. I wasn't able to complete schooling. It's just like now you're another failure upon a failure. I was able to release some of those feelings and you know, forgive myself and release everybody that has harmed me or injured me in anyway. So it was very beneficial for me.” (11-01-03)

“Gosh, I don't know. My reputation suffered plenty. A lot of people think I'm a very cruel man.....” (14-02-11.1)

“You know, I really felt miserable. Failure, shame, stupid things like that.” (18-02-16)

“...stigma and so on. And ashamed. I was ashamed for 14 years. And I was never ashamed to go to the hospital but I was ashamed I had schizophrenia. I told my psychiatrist I don't want that on Blue Cross forms. I don't want nobody to know. And that was just in '84. So the miraculous growth. Now I don't give a damn who knows cause I know who I am. And there's nothing to be ashamed of, although I was ashamed, you know. But if it weren't for the professional help, Katie, I wouldn't be around today.Lots of times we don't talk about that. When I was in the hospital, I didn't talk about my schizophrenia. To other patients, I was ashamed. I didn't want them to know my diagnosis. Because I felt they'd be fearful of me and I've heard other people say that, too. But we talked in general about problems and things like that but not voices or delusions... because there were patients in there that were just depressed, not that it's just depressed, but you know what I mean. And they were mixed in. And then in my last experience, most of them were alcohol abuse and drug abuse and I didn't talk about my schizophrenia. Even in the hospital I experienced that stigma. Not from the nurses but from the other patients.” (23-01-00)

“I will say though that they (family) invite me to a lot of things with them. But you know, it's, I have this thing about facing the world the way that I am right now. I'm so dissatisfied with myself that I just, I don't want anyone to see me this way. I just think that I should be more successful and you know, have a babe on my arm and a car of my own to drive and things like that. You know, go there like a regular human being, not like a child that's being taken somewhere by his parents. And you know, that's the way it always, you know, has felt the few times that I've went places with them so I try not to do that.” (25-02-10)

“Like the outside is all just the same, but the inside is all burned out...And it was just, you could tell that even in my mind, I was trying to hold onto my old life but I felt it slipping away.” (30-02-02)

“That was really hard. And it took a long time. Like I said, even though after seven years, I still tested the waters and went for a second opinion. And it was lonely. It was scary. **I felt like a failure. I felt like I had to start my life all over again. I felt like I had damaged my reputation.** (Interrupted by K) Because of the illness, you know, making me really do wacky things. I was embarrassed.” (35-01-00)

“**And it gave me a chance to come together with who I was,** where I was at that time, and where I wanted to go. I had to set some goals and by listening to all the other people, I was able to start piecing together my life again, and understand what schizophrenia was. Understand what appropriate behavior was. Understand why some medications did work and some medications didn't work for some people. I found out that I had friends there who had the same problems that I had and I could talk openly and freely about my condition without feeling stigmatized.” (35-01-00)

“... I still feel I gotta fight it, you know. **Who am I? Who am I? This withdrawn, I don't want nobody around person or am I this real manic, I love everybody and I wanta be with you and let's go, go, go. Let's do it, do it, do it.** Let's have fun, fun. Who am I? You know. And hoping this lithium is putting me somewhere in the middle. I'm not having the real lows or the real highs. You know. But I'm still not right. I don't feel like I'm still right, you know.” (44-02-38)

Phase 3: Redefinition and Transformation (N=38, 83%)

I. Change in attitudes or beliefs about schizophrenia & self (N=30, 65%)

A. Beliefs about the Nature of Schizophrenia (N=25, 69%)

“That we are people, we have souls, we have feelings, and for us not to be treated like trash and pushed aside. **That there are ways of helping us, and I wish that people would wake up and get these programs started and start doing more for us because we can be helped.** That is what people don't understand, it's like from the very beginning, the first people to be burned in the fires were schizophrenic people. In Hitler's ovens, that was the first people to be burned. Like they weren't even people, like they were dogs. Not even dogs, it was like they were rocks, just throw them in the fire. It's almost still continuing that way.” (10-01-10)

a) Overcoming stereotypes – forming positive images of people with schizophrenia (N=12, 26%).

“**Saying that that's, schizophrenia is so big. So diverse is a good way to describe it. It's like each of us are our own little sort of race and**

subculture....Well, if they've got schizophrenia, they've got to realize that it isn't going to go away. And you've gotta live with. And other people have to live with them. And this is a great way to find out how you can make an advantage of it.” (01-02-11.1)

“You've gotta teach the person so they have some deep beliefs about what they're experiencing. So they can help themselves, you know? I was just left alone like in the mess for all those years as far as I was concerned. What is wrong with me? What am I? How evil am I? And what am I all about, you know? And then every time I heard I was a good person, I had potential, I didn't believe it because I also knew that I was mentally ill. I was crazy. I didn't think mentally ill. I thought I was insane, you know? So then I'd think, well, maybe I'm a mad scientist, you know? But I couldn't give myself credit for anything because I always had the insanity to attach to it. I wanted some distance, some power over it. Some way to help myself....I knew I had been mentally ill but a schizophrenic, I thought I remember everything, **I'm smart, I'm, you know, I thought I can't be schizophrenic because schizophrenics to me are in a daze and it said in the books that you couldn't love.** It said that if you were a schizophrenic that they used to have companions for schizophrenics because the people didn't want to take a risk....I figured there was no career that would welcome me, especially nursing, I thought that was totally out of the question. I gave that up in my 20s, not to pursue that anymore because once they found out, you know, once it happened it would be over with. I think that's why a lot of us lose our self-esteem, there's nothing to look forward to anymore. I think one thing SA does is show that there's lots of stuff and by collecting the news media articles about people who've been successful and finding doctors who have had mental illness.” (08-01-02.1)

“**[WHAT KINDS OF THINGS DO THEY BEST HELP YOU WITH?]** Probably relating and also hearing about them getting better encourages me to keep doing better because it can be done. That sort of thing. You know, when somebody says they've gone back to work, that's something that's just so encouraging for me. That one day I'll be able to hold down a job.” (10-01-10)

“... I was very nervous because, you know, **even though I was schizophrenic, I still had that fear that, you know, how people that don't have schizophrenia have fear against schizophrenics, like they're crazy and they're going to attack you and you know, all these wild stories. So I myself was scared of that. So I was really nervous. [SO YOU DIDN'T KNOW ANYONE?]** I saw all these smiling faces when I went in and everybody was just like normal and nobody even looked like they would be schizophrenic, you know? And that was very reassuring, too.” (10-01-10)

“...productive life even if you are mentally ill. **Edgar Allen Poe, Van Gough, Michelangelo names all these people. I almost think it's sort of**

that mental illness is sort of the genius gene. Sort of breaks you some from the average people who have very bigoted views. I even notice, sort of notice it with my dad. I mean, some, on some things, no amount of logic can get through to him.” (18-02-16)

“But she was holding a full time job. She had been through the hospital thing. She was taking her meds. She was seeing her psychiatrist. The whole, you know, a big portion of the experience that people that have this illness, in a big way she had experience and she was making it.” (21-01-00)

“So I didn't really think there was anything wrong with me. Then I met other people that seemed like that they could function just like the way I did, the only thing is that they had a mental illness just like I did and they took medications to prevent them from having another episode just like me. So I just learned that there are people just like me that feel like they're just fine.” (22-02-02)

“[SO TELL ME ABOUT SEEING JV SPEAK. WHAT WAS THAT LIKE FOR YOU? WHAT DID YOU THINK?] Well, I had recently been diagnosed and it really made me think that I might have a pretty rough road ahead of me. But it also gave me hope that, you know, it's not impossible to overcome something like this. Which is something that I'm still struggling with, but there are people who seem to get by okay.” (25-02-10)

“Yeah, it might sound silly, but anyways, if someone had said, oh, **I want you to meet my friend who has schizophrenia, I would get scared and say no. Now I would say, Oh, I would be more than happy to meet them, please bring them over. Let's have coffee together. Let's get together. You see? See the change there? I'm open minded now about it whereas my mind was closed to that before.”** (29-02-02)

“Well, I guess the thing would be that, you know, they are proof that you can stay well even though you have schizophrenia.” (39-02-38)

“It's just that I personally feel that I found some people that, you know, are more like my level. You know, they're pretty good people. **Boy, I tell you, some of them are pretty high functioning, too. Well, there's something about the Schizophrenics Anonymous in '90, they looked like pretty scary people to me. These people do not look scary. They certainly aren't sick or nothing. And they kinda look kinda healthy to me. You know, I think, you know, considering their problem, they're healthy looking, you know.”** (39-02-38)

“...there have been a lot of surprising, worthwhile people, outstanding people who have had schizophrenia, like Abraham Lincoln was supposed to have been schizophrenic....Edison was eccentric. People are worth something no

matter what their condition. And if you have a mental illness that doesn't mean that you can't be productive or make life worthwhile. While there is life there is hope." (41-01-40)

"And I really admire that, the organization that she has, the control. **You know. It still surprises me that she's schizophrenic. I can't believe it. I can't believe it because she seems so knowledgeable and thoughtful and wears a lot of hats. She wears a lot of hats....Well, at first I felt I don't belong here (at the drop in center). I mean, these people are bizarre but there are some they're like street people maybe. But they are, there's different degrees of their illnesses that I feel some, for instance, Sara, is above me. I mean, and there are some that I'm not saying beneath me. I'm just saying maybe like I'm in the middle. I'm not that, I thought well, I'm not necessarily but in my mind, I'm too good for these people. I mean, I don't belong here.** Like going to the bar and sitting and just sitting there and drinking coke while they're drinking beer. That's, you know, I'm saying that's my comparison. I don't belong here. These people are schizophrenics for God's sakes. They might kill me, you know. You know, I don't want, I don't want to get in an argument with them. **But my impression of, I was shocked because they seem very normal. I mean, there's one guy that's, he's going to college. He told me he's on the dean's list and he had a speech impediment and he... I can't see no...**" (44-02-38)

"Uh, we did get a notation once that was quite interesting about this man who was working for his English degree in college, got sick, worked his illness until he became a hospital administrator and it is known that he has this disease. And nobody is making excuses and the man is doing great. It, so things like that, we get things that give us hope." (48-02-16)

b) Learning that schizophrenia is here to stay (N=6, 13%).

"Well, if they've got schizophrenia, **they've got to realize that it isn't going to go away.** And you've gotta live with. And other people have to live with them." (01-02-11.1)

"It's a **life long thing.**" (6-01-04)

"That's how I am coping with it, manic depression, and you know, **you're not ever, get cured of.** Which is what my doctor was saying. An example is that someone that takes blood pressure medicine or what's that other one? When they take insulin? Diabetes. They say when you have diabetes, that will probably **stay with you for the rest of your life.** So with your manic depression, you might take medication. You might take it for the rest of your life and I really don't want to. But then the doctor was telling me that I probably would take it for the rest of my life. That's the part about it I don't, I don't know it to be true. Because I want to someday not take medicine. Just not

be able to just take medicine.” (36-02-04)

“And so well, this is, **this is a long term illness**, you know. They didn't know about schizophrenia back then.” (41-01-40)

“Just that's the way it goes, I guess. You know, you **can't say okay, I want it to go away**. But you can get it to a point where you can function semi, you know, good. I mean, it's normal for somebody to have good days and bad days...” (45-02-38)

“**No getting around this problem**, but we work at it.” (48-02-16)

c) Learning to accept set backs & relapses (N=5, 11%).

“I was saying that was a beginning of my life when I understood. I didn't have to hide anymore. I didn't have to more or less suppress my own personality. **I could be whole and know that I could have a break and still recover and move on.**” (08-01-02.1)

“I'm not always stable, I have **ups and downs** during the year.” (09-01-14)

“...there are varying degrees of illness and that we're not alone. **And a set back doesn't mean that you're not successful** and success has a lot of different meanings.” (20-01-00)

“Well, I had recently been diagnosed and it really made me think that I might have a pretty rough road ahead of me. But it also gave me hope that, you know, it's not impossible to overcome something like this. Which is something that I'm still struggling with but there are people who seem to get by okay. **Every now and then, they may have a few setbacks but I guess that's something I'm gonna have to expect.**” (25-02-10)

“And even though I did **have one setback after I got my masters**, I thought well, I have my masters degree and I'm working full time. I'm leading a group. I wonder if I really have schizophrenia. So I went for a second opinion at the University of Michigan and they took me off all my medication.” (35-01-00)

d) Understanding that schizophrenia is a no fault illness (N=7, 15%).

“But SA has taught me that, **I always say it's part of my medical history. It's not me at all....Now you can kind of put that aside and say OK, this is what it is, it's a disease, but it's not me. It's something that affects me, but it's not me, you know?** So it's almost like you gain your identity through joining.” (08-01-02.1)

“Because you know, as another thing that was brought up, a person in SA, I

won't mention her name because I don't think you're interviewing her but she thought it was just demons in her head because of religion. And I said no. It's not the devil. You know, and she first felt worse about herself. You know how religion... religion can really mess up a lot of people, you know. That condemnation of a soul, of a person, and their self esteem. **But I said no, it's a chemical imbalance in the brain.** It's not these spirits that are demons like they preach on so I do voice that in my opinion. Because it only gets you into trouble. ...Somebody might say, well, it's all my mother's fault. **What I would say to them is I thought it was, too. I blamed my mother for years. But my mother did the best she could and I realize that this is a no-fault illness. It's not my mother's fault and it's not my fault. It just is....**And I tell them I always thought of my illness as devastating and as a defeat and now, like step number one, I admit I need help. I can't do it alone. And I accept it as a challenge. And what do you do with challenges? You overcome them. And that's what I tried to do with the steps, put it in a positive mode. You know, positive. And try and end every meeting with a positive feeling....That's what I notice about people, when they start coming to SA for a while. They start feeling better about themselves. They didn't have this terrible ashamed feeling of the most terrible illness in the world, schizophrenia. It just didn't seem so overwhelming. You know what I mean? More accepting, like diabetes. ...I'm not such a bad person, you know, that's what they were saying to themselves. It's a no-fault illness, too. A lot of them thought it was a weakness of character, like I did. I just, why did I have this weakness of character and I couldn't overcome this terrible sickness.” (23-01-00)

“They emphasize that the **illness is a, it's like having cancer or something.** It's not that you're bad or anything. **It's a chemical imbalance.**” (28-01-15)

“I went there several times and I was so upset. Oh, my God, I was describing this to Mary and Mary says they do this. I said Mary, I will never go back there again because he had me so scared and I don't think this has nothing to do with Satan. **It's an illness, it's a physical thing, it's brain chemistry** and I will never go back to him again. I was insulted, humiliated. It hurt....And I realize it could happen to anyone. As far as that goes, from a waitress to an executive secretary.” (29-02-02)

“You learn about the **brain and malfunction in the brain....It's a sickness.**” (38-01-38)

“I have a **disorder that causes me to have a hurt limbic system.** ...From what I understood I may have been terribly hurt by someone outside of the family between about birth and 5 years old. Once again between 5 and 7 years old. **It wasn't mom and dad's fault.** It goes back to what I understand. I have been told not unkindly that I **inherited a bunch of junk chromosomes.** See, schizophrenia is pasted along on chromosome pair 21. That's basically all

I know about it.” (48-02-16)

“My sickness is being under control, my mental illness, by the medication I’m taking. Even though I do have a mental illness.” (49-02-04)

e) Believing that recovery is possible (N=8, 17%).

“We don’t completely recover but we do recover, we do get well. We do get better. We can be successful people in society....There is hope for recovery.” (29-02-02)

“I’m coming from a mental illness, going off medication, going back to work, oh yeah, I’ve got a lot to look forward to.” (30-02-02)

“Cause I felt hopeless at first. You know, then I felt more hopeful....I am sure it is going to get better. I’m feeling that way.” (32-02-13)

“I think it (SA) made me feel like living again. It gave me hope.” (35-01-00)

“Things can only get better is one of them....How do I think things...I have hope and faith that if I don’t do something stupid, and I think I almost have the wisdom to know the difference.” (37-02-04)

“We all believe in each other and try to convey that there is hope for everybody.” (43-02-38)

“I don’t know what I am even doing her, because I have hope, I guess. I have hope that I can help. I can get my strength and help somebody.” (44-02-38)

“Each day is a new day and it’s gonna work. I have that attitude. It’s gonna work.” (49-02-04)

B. Beliefs about self (N=32, 70%)

a) That one is not alone in their experience or illness (N=15, 33%).

“But I felt comfortable. **For the first time in my life, I felt accepted.** You know, coming from a dysfunctional family, growing up eccentric and then becoming mentally ill at 25, **I was always on the fringe or farther out, pushed away by the group. And here, nobody pushed me away.** In fact, they invited me, come on in. You know. And I liked that. You know. I’d never been treated really with that dignity, you know. And they made a great impression on me.” (07-01-05)

“Then everybody went around and told their story and I told my story, too. And when I left, I had this great feeling of relief, you know. Everythings

gonna be OK. **There are more people like me** and everything's going to be OK and that's how I felt when I left. It was like, not only were they like me but they cared about helping me, too. So that was really exciting...Because when I left, I walked out and I was driving home and I just felt so relieved. Like you know, just the awesome feeling of everything's going to be just fine. **Because I knew that I wasn't so different than everybody else. I had something in common with them, that I had with nobody else in my life. I never knew anybody that had schizophrenia, you know? And it confused me.**" (10-01-10)

"I didn't really have a whole bunch to say but I could understand that **people were going through the same thing that I was and I didn't feel so isolated which was a big step right there, you know, feeling like you are not alone.** That was a big thing...the thing that I most got out of it is the feeling of not being alone. You know, there was nobody sitting around the table to judge you or point a finger at you for things that you've done wrong. We could all relate, you know, and I think the big issue of being able to relate to one another is a big step. You know, having something in common. And let's face it, that's what most relationships are based on is something in common, you know?...just listening those first couple times, I automatically sensed, **well shit, I'm not so different after all.** And just that feeling of not being alone is something because there were experiences that I was scared to talk about. You know, like I mean, you tell somebody that you're gonna sit and watch the TV and you think it's talking at you, they're gonna bust out laughing, like who's this idiot, you know? But when you go to a group and you sit down and tell people, oh, **I'm not so different after all. I think the bottom line with people is they want to feel accepted and common, you know? They don't want to be different.**" (11-01-03)

"Then, you know, we would hash it all out. **You know, you wouldn't feel alone.** Like I would think is it just me that they're doing this to and they said no. Or how to go about it." (12-01-03)

"Well, it's made me feel better about myself and **made me feel like I'm not alone.** Like the step says, I need help. I can't do it alone. One of the recovery steps. So it makes me feel like I'm a part of a group, a part of a family outside my family, an extended family...**I'm not the only shy, bashful female around. Who's alone.**" (19-02-13)

"Because it addressed my illness and it gave us guidelines to structure our lives and it also made us aware that **we weren't alone.** And that's a big factor. When I'd get phone calls, they'd say oh, my gosh. You have the same symptoms I do and you're working and you're, and I didn't think anybody else had those symptoms. You know, and even at the Gathering Place, you don't talk about your mental illness or at Clinton Valley...It's something you don't share. It's a secret. You're hiding it within yourself." (20-01-00)

“Acceptance. I think like you were there when we were thinking of a song, **There's a place for us. You know, there's a place for us. And mentally ill people think we don't, we think we don't belong anywhere** and SA is a, like there is a place for us. Acceptance and love, I can feel God's presence in those meetings. I could just feel, there's so much love. And then love heals all. You get medication and everything but love does heal.” (23-01-00)

“Since I've been coming to the group, I haven't been down. **I see that other people have the same thing and then I don't really feel that depressed.**” (26-02-14)

“Yeah, I was impressed and happy that there was a group that we could go to just to discuss all these things that everyone had pretty much the same experiences. Like, you know, the hospitals, we'd have group therapy. There's all different kinds mixed together. You know. Some that aren't so severely ill that you're kinda shocked, you know. And I was shocked and it upset me. There were some others. But this group, we were all having similar experiences. **It was just nice that there was a place you could go to. And everybody kinda understood you and what you were going through.** Laura, of course, she was just wonderful, the way she ran the group and was so inspiring. It was inspiring to see people talking and encouraging each other, you know, and the way they were tolerant of the others who were not as well, you know. Kind and... a lot of empathy. Encouragement... **To be a part of something, really a part of something, it's hard to be part of something in the outside world, you're not working. You don't really feel like you fit in anywhere. Here you fit in. You feel sort of a like a social outcast.** Not, I don't feel a stigma, not because of the stigma of the illness, I don't feel that. It's in myself. I experience things that other people don't, most people don't. You know. And it makes me feel like an outcast. Yes, it does. Like I say, you're experiencing, you have other people experiencing things you're experiencing that you can talk about. It makes you feel better, you know.” (28-01-15)

“Coming to the meetings, I hear things and I say things that you don't even tell your doctor. But the things that we talk about, **we say things and I'm not the only one, there's been more than one person who tells things that we don't even tell the doctor. Because we can relate.** There's nothing that either someone or several people in the group haven't done or its happened to them. We can relate to one another and express what we did if we want. And if you don't want to say nothing, you can pass.” (29-02-02)

“Yeah. And I got here and I don't mean friendly but it wasn't unfriendly. **I just sort or felt like I belonged.** Eventually everybody started interacting and I consider these people my friends. I feel very comfortable around them and that isn't always the case around people.” (34-02-05)

“So it was really a really, really good group because most of the people either, most of the people drove there and so it was a higher functioning group and I thought that's where I belonged.” (35-01-00)

“But I am not like I told you, I'm bi-polar manic depressive rapid cyler, and I didn't think that I'd belong or fit in, you know. This wasn't for me. It is. But I attend the meetings and the activities. And I have agoraphobia, I've had it worse. I've been pushing myself and I feel like... I don't know if you want to hear this right now but I could push myself like right now. I get there and I feel, I feel welcomed. I feel like just so, I can't think of the word right now, besides welcome; accepted. Accepted. And that there's no pressure. Just go just to hang out, sit, talk. You know, and the groups just talk about anything you want and I do like... a lot of problems, like I do feel embarrassed about but it seems like no one, maybe they're not listening, but they don't seem to be shocked by anything I say or I don't... you know. The same way with me....Because people gave input. I mean, it was younger people than I and I couldn't... we just seemed to fit. Like I know being in the hospital and that, there is like a kinship, kinmanship or whatever you call it. You know, camaraderie that we seem to share. That there's no age barrier. We know it's there but we know that there's something we have in common. The depression. And I just felt so, so good there....Well, that's kinda like one of those things I told you, you know. The acceptance and the compassion. I'm relaxing. I'm not getting my anxiety and panic attacks. You know, and wanting to run out, can't sit still, stand still. I just feel like nobody's really ignoring me or like I feel inferior to anybody or that anybody's acting superior to me. I feel like I belong. I don't know. It sounds crazy but I thought I found my niche for now, for now. Maybe a year from now, I don't know. Might be doing your job.” (44-02-38)

“Well, maybe everybody just wants to know people that, you know, they got something in common with.” (45-02-38)

”The group helps with that believe it or not. It's like you touch base, suddenly you find that you are as welcome in the swimming pool as the next guy and it breaks the water so to speak. So, I think that the group richly enhances my life.” (48-02-16)

b) Accepting the diagnosis of schizophrenia (N=21, 46%).

“Well, if they've got schizophrenia, they've got to realize that it isn't going to go away. And you've gotta live with. And other people have to live with them. And this (attending SA) is a great way to find out how you can make an advantage of it.” (01-02-11.1)

“Sure. Like I said, mental illness comes in degrees and like a lesser

amount or a higher amount of a degree that you're ill. And I guess there were some others that I was cohabitating with that were worse than me. And that kinda strung a light on what mental illness was for me. **Once I saw myself behaving in their manners, in their modes of behavior, I started to realize that hey, here I am, saying they're sick and I'm doing it myself. So I kind of got a grip and I guess you could say I did get a grip on it that I was gonna have to put an effort to participate.**" (02-02-11)

"I didn't accept it at first. **I began partially accepting it in spring of 1988.** I had been hospitalized 3 times, each time I had gone off my medications before being hospitalized. I don't believe in it, but I needed to start taking my meds." (03-02-11.1)

"**Now I'm not ashamed to admit my illness.** I don't wear it on my sleeve but I don't conceal it. The three jobs I've applied for I very prominently told them that **Fridays are a no no because I have my group.**" (07-01-05)

"**But had I never taken that first step, to admit I was schizophrenic and join the group, nothing would have developed,** I would still be waitressing and wondering, you know? Because I thought I reached as far as I wanted to go, as far as career wise goes. I just wanted to continue helping others and helping myself. Before that, I was always going to college and had aspirations of different career goals and never found anything I really wanted to do. Social work always, and I had a dream of being a nurse but I knew with my background... in fact, even with social work, I had no idea that that would be welcomed, with a schizophrenia diagnosis. I figured there was no career that would welcome me..." (08-01-02.1)

"...only hill that I ever have to go over is the fact that, you know, I am not normal. **I do have schizophrenia** and sometimes it's very hard for me to walk out that door and go to the meeting and lead it." (10-01-10)

"And the spiritual stuff I kinda like and **the first step is just, you know, you get away from, get away from denying the illness.**" (21-01-00)

"I just wasn't interested in it. I felt like, I'm just a normal person. I mean, I can do just about anything that I want to do normally. I wasn't collecting disability at the time. I thought there was nothing wrong with me. I felt like I could function in everyday life just fine. I felt like I had a few bad episodes back in '95. I had three of them in '95 but besides that, I feel like that I was doing just fine. I was still being checked out by the doctors and they were still deciding what medicine they were going to put me on. Then I didn't even want to take the medicine at first but I did it because my mother convinced me into doing so. It was my mother who kind of

pushed me along to do things. So I didn't really think there was anything wrong with me. Then I met other people that seemed like that they could function just like the way I did, the only thing is that they had a mental illness just like I did and they took medications to prevent them from having another episode just like me. So I just learned that there are people just like me...I felt like I didn't have any problems. I thought I was just fine. And meeting some other people, I guess I kind of learned maybe I do have some problems. You know, I haven't had any episodes since I've been taking the medicine, which I'm glad about that. But maybe I do have some problems with mental illness....I've learned that I guess I do have some mental problems. I do have a mental illness. I was in denial because I felt like I could work as a normal person. I guess that's what I've learned the most. But I've also learned how to deal, how to cope with it. Which, that helps out a lot. I learned how to deal with it.” (22-02-02)

“Accepting the illness and know that it's not so devastating. That there's hope for recovery. And it's just like a diabetic.” (23-01-00)

“And I think, for me, it was when I began to accept my illness. That's a big problem - denial. Big, big thing. And when I started to accept my illness and wanted to know more about it and got a little less psychotic and was able to drive and get out. Sometimes, too, you're not able to handle other people's psychosis and you know, things like that. But when we get on the medication we come back to reality more. When we start accepting our illness wanta know more about it, learn how people handle it, and wanta be with other people.” (28-01-15)

“Because I've been feeling better about myself coming. You know, at least I can admit, you know, in the group what's wrong. But I can't do it in a big group yet. You know, like one of them, you admit that you have a problem and you need some help. YOU FEEL THAT'S AN IMPORTANT ONE? Yeah. I do. DO YOU THINK THAT PERSONALLY, FOR YOURSELF, YOU'VE COME TO ACCEPT YOUR ILLNESS A LITTLE MORE? Yeah.” (26-02-14)

“I really never accepted it. I always passed it off as medical until I came here. Because I had no idea what symptoms were....And then it took a few meetings to really realize and understand and some tears were shed because after all these years, I just realized it. I was seeing all these doctors and getting all this medicine, I had no idea what was going on, why I was getting medicine or anything. And now I understand more and I'm open minded.” (29-02-02)

“I was working and I still wasn't really in my head that I was mentally ill. And I didn't like talking about it with strangers. My therapist, doctor, my parents,

they all know, but nobody else. I was going to keep it that way, too....And I didn't think I was, well maybe I knew I was ill but I didn't really want to admit it. **That was the first time I heard voices....I knew I was ill, but I still listened to voices and I still wouldn't admit to myself I was mentally ill. Eventually I gave the doctor permission to treat me.**" (30-02-02)

"It helped me to accept my disability. I worked fifteen years it was hard, being just disabled. One woman was telling me how she, it had started, had got to her, you know. I remember that. It did the same with me. And he told me he would go to work and have to leave and go to work and have to leave because that's the same thing that happened to me at the post office, that's what I was doing." (32-02-13)

"I felt not very good about myself and I think that's why I went back because I felt like maybe I was denying the schizophrenia, trying to go to a university. Maybe I should just go to SA and recover and see what else I can do. Because I did get 2 Ds, I think I got one E, two Ds... They put me on Trilafon, I think. I still had delusions but I thought I could live with the delusions as long as I don't tell anybody about them. As long as I don't tell anybody but my therapist about them. And I can live with them as long as I don't have this horrible, crippling depression." (33-02-05)

"And that's when I realized that I really did have the illness and I had to get on with my life and...I kinda let go of the SA..." (35-01-00)

"Well, I first, when I was sick, I didn't realize I was sick. I thought everybody was saying that I needed help but I wouldn't accept it. I thought there was something wrong with them....And one day I just woke up by my brother's house. I said I can't take it no more. There's something wrong and I need help. So he came to Sara's and Sara wrote something on a paper, I guess, the hospital, where to take me. And the psychiatrist talked to me and I thought that my brother had lines in his shoes, that that was a secret code to get into the hospital. And the doctor told my brother that I needed to be committed. My brother said he would not sign the papers that I was willing to get help but I would sign them myself. So the doctor came into the room and he asked me if I would sign the papers and I almost didn't sign them because he said you can't get out when you want to. You have to let a judge be over you to get you out of here. But I was in such a shape and I knew I needed help so I signed the papers myself. I thought I would worry about the other part of it later. And my stay at St. Joseph was very good and they put me on lithium. To be mentally ill and be a schizophrenia without medication out in the world is a living hell. Nobody could ever know what all you go through in your mind. You think the FBI is after you. You hear the television talking to you. You hear voices. [HAS IT IMPACTED HOW PEOPLE TREAT YOU?] Well, I just tell everybody that I'm mentally ill. I don't try to hide it. And so far, I've been accepted everywhere. Nobody's

ever said I'm crazy or anything like that. And I'm open with it, about being mentally ill. I'm not ashamed of it. It's a sickness." (38-01-38)

"And I would just be going down. You know, I'd just be going down so right now I really am focused on trying to better myself. Learn all over again. Maybe, you know, now that I do know that I have this illness that I, you know, just can't... I try to avoid what do you call it? Stress. Stress and situations. I'll walk away. It seemed before like I thrived on it." (44-02-38)

"Just that's the way it goes, I guess. You know, you can't say okay, I want it to go away. But you can Let it to a point where you can function semi, you know, good. I mean, it's normal for somebody to have good days and bad days..." (45-02-38)

"And I guess they're pretty pleased that with all my problems, I live separately. I carry on my life appropriately. Or as appropriately as I can. No getting around this problem, but we work at it." (48-02-16)

"I just say I'm now benefiting my health. I choose to get well, function and do other things. Cooking and learn other independent living skills. Coordination skills, driving, being mentally alert. You know. My sickness is being under control, my mental illness, by the medication I'm taking. Even though I do have a mental illness." (49-02-04)

C. Accepting ones' self (N=14, 30%).

"Of course, I've never really cared about belonging to anything. Or anybody because for a long time, I never felt like I fit anyway. And I didn't know what to do or how to change in order to conform and be accepted by other groups and things like that. And besides, I really didn't want to. I liked my thoughts and I like being a schizophrenic. I like what I think, what I feel, and For the most part, what I hear and see. Even though sometimes it's scary." (01-02-11.1)

"So I know I've been wool gathering again. That's how it's impacted on my life, you know? But I don't care. I used to feel bad about it but I take it like my therapist said, "Hey, that's you. You're going to be that way all the rest of your life probably so get used to it." So I'm trying to improve my shopping skills and being a little more speedy, you know. That's about how it's impacted on my life. Now I'm not ashamed to admit my illness. I don't wear it on my sleeve but I don't conceal it. The three jobs I've applied for I very prominently told them that Fridays are a no no because I have my group. It's made me more of a person, it's given me a bigger heart. I understand myself better. I'm more tolerant." (07-01-05)

"I felt like for the first time in my life, I didn't have to run, hide, or keep

trying to mask symptoms or trying to show everybody I was normal. I really was still working overtime trying to show how productive I can be and how normal I was and then I would have a breakdown and wonder, you know, which one of these is true about me? Listening to FN, I realized that there were people like me who had a mental illness and yet were people, too. People who had some similar thoughts and feelings about their illness and their experiences....I thought oh, my God, once I walk in that door and I join that group, because before I had the schizophrenia only during the times of illness. The rest of the time I wasn't schizophrenic. I was free from mental illness. Where as if I walk in and join SA, I felt maybe I could never deny it ever again. Now I'm a member. Now I am admitting it, openly, so I can't turn back. So I was scared of that, by being committed to being a schizophrenic. But then once I joined the group and I met FN and I met the other people that were at the table, like LZ and different people that have gone and they're an excellent, excellent group of people. And I laughed and talked with whoever was there. And when I left I was still a little bit apprehensive about joining because, like I said, I couldn't turn back and not be a schizophrenic anymore the next day. But it was in a way, to me, the beginning of my normal life. **Now I was normal. Now I was someone. I was a person and I had a mental illness at the same time. I couldn't ever accept being either one of those without knowing that there was another... in other words, I didn't want to just accept myself as mentally ill, an invalid and not, even though I have abilities and I do things and then couldn't be normal all the time because, you know, the illness comes on and you can't deny it. It's apparent. So I was able to accept myself as a whole person not long after that.** I was saying that was a beginning of my life when I understood. I didn't have to hide anymore. I didn't have to more or less suppress my own personality. I could be whole and know that I could have a break and still recover and move on.... every time I hear someone say when I first came to this group I was thinking of suicide until I met other people who, first of all, who would accept me as a person because that's what I had to have. I wanted to find some identity. I didn't know what my identity was. And it's funny, it's almost like once you admit you are schizophrenic you aren't mentally ill anymore. Now you can kind of put that aside and say OK, this is what it is, it's a disease, but it's not me. It's something that affects me, but it's not me, you know? So it's almost like you gain your identity through joining. And so I hear people say that" (08-01-02.1)

"But when you go to a group and you sit down and tell people, oh, I'm not so different after all. **I think the bottom line with people is they want to feel accepted and common, you know?** They don't want to be different.... You know, and I think it's taken me a long time. When I first got out of the service I didn't know what the hell to do. You know, I mean, here I am. I went in the service late. I couldn't finish college. I couldn't get through boot camp. You know, what the hell am I gonna do? You know, and I finally was able to buckle down and complete school and then be medication compliant. And

that was a big step towards my recovery, making those two things. And I could relate and seek therapy, saying you know, I'm not this stupid person or incompetent or whatever. I can do this. **It was because of my illness that I wasn't able to do this. Instead of blaming myself I could say it was the illness and not me because I had accomplished something.** So that was big stuff. **If people didn't accept me for what I was, well then, you know... let them do whatever they want to do. I don't give a shit. I don't want to know them anyways."** (11-01-03)

"It helped me change, it helped me **not be ashamed about having a mental illness....**I talk openly about it more than I used to. And I'm still a worthwhile person even though I have a handicap, a mental illness." (12-01-03)

"So I didn't really think there was anything wrong with me. Then I met other people that seemed like that they could function just like the way I did, the only thing is that they had a mental illness just like I did and they took medications to prevent them from having another episode just like me. **So I just learned that there are people just like me that feel like they're just fine....I felt like I didn't have any problems. I thought I was just fine.** And meeting some other people, I guess I kind of learned maybe I do have some problems. You know, I haven't had any episodes since I've been taking the medicine, which I'm glad about that. But maybe I do have some problems with mental illness." (22-02-02)

"I love the way he said that. I'll never forget it. **..There's a significant time and a significant place where you focus on your illness and not focus on it 24 hours a day. At home and every place else. And go on with your routine. I mean, go shopping go... like a normal person. You know, have girlfriends, have boyfriends and don't let the illness consume your whole life. I think it makes you more in charge of it, too. If you have a certain, you know, just like your doctor. I go every two weeks for 45 minutes and I focus on what's going on in my life and then I go on with my life. You know."** (23-01-00)

"I haven't been homicidal or suicidal. It took many years to get better but I'm better. So I still find it difficult to talk about, but I really don't, like I said, I don't need to talk about it now so much because **I've come to terms with it, kind of like with everything that happened. And now it's just everyday living a little bit, you know....**I'm not good at putting things into words. That we, there's things we can change and things we can't change. And we have to know the difference and work on that. Can't worry about things we can't change. That we each of us have inside of us, resources and SA can help tap into them....Even through my illnesses, I was observing other people and even in Northville. I was observing how I felt every day, how the medication changes, observing other people and how they acted. And I ask questions a lot. It irritates some people. **Like there was two parts of me. The one was**

real sick and the other one was observing and, you know..." (28-01-15)

"It's (SA) helped me realize that this isn't the main event of my life. This is just an illness that I have to deal with. It's not the main event of my life. It's so easy to get... that's such a charged question. It's easy to get negative, to fill in negative things for me. So I don't know what to say....That's what I was doing for a long time is struggling to have a career. I wanted to be able to support myself, to get off SSD. I realize now that's not going to happen unless some miracle drug comes out, which I don't think will be for a while. And if it does, I don't know what I would do with myself because I identify myself as schizophrenic and living here in this apartment. I work at the library three hours a day, 9-12 Monday through Thursday and that's just right for me. It's not too much and it's not too little. So I've been lucky to find that but I still had to struggle with was I ever going to get a Bachelor's degree and go on and do all that? Would I ever have kids and I've come to terms with those two things-no and no. I'm not gonna have any kids and I'm not gonna probably ever have a career that's full time. Strangely enough, it doesn't bother me. I just felt a release of negative energy when I gave up those aspirations...Then I figured, well, if I could have Steve, then I'm pretty lucky. So, I'm not feeling sorry for myself anymore because I have a happy life with Steve. I don't have all my goals fulfilled and everything, but I figure, you know, I don't have to do everything like modern women do. You know? And I can't anyway so I just accepted that." (33-02-05)

"To learn. I thought integration was really an important factor about everything. If you couldn't integrate who you were now, not who you were in the past or present, I mean past or future, in the present, you had, I had to re-integrate my whole personality, my whole life style. I'm starting from scratch. And I needed help doing that. I needed someone that I could talk to and say hey, I've got this problem.And then I just started to integrate it into being part of me and kinda said the heck with what everybody else thinks. You know, I've gotta do things for me and not worry about what everybody else thinks." (35-01-00)

"And so far, I've been accepted everywhere. Nobody's ever said I'm crazy or anything like that. And I'm open with it, about being mentally ill. I'm not ashamed of it. It's a sickness." (38-01-38)

"I get there and I feel, I feel welcomed. I feel like just so, I can't think of the word right now, besides welcome; accepted. Accepted. And that there's no pressure. Just go just to hang out, sit, talk. You know, and the groups just talk about anything you want and I do like... a lot of problems, like I do feel embarrassed about but it seems like no one, maybe they're not listening, but they don't seem to be shocked by anything I say or I don't... youknow. The same way with me.A few people here that do understand, God bless them, because somebody they've known or just for some reason, they're Christians or

the Lord. They don't understand all of it because they're not living it, you know. I'm a mystery to them, but down there, I'm not a mystery. You know, we can laugh and we can, it's calm. I haven't seen anyone get into an argument or, you know, a fight. Nobody else that stressed up or anything because it seems like they feel like the acceptance, you know. You're not gonna be jumped on like maybe some families, you know. And snap out of it. We know like that.... **And then I thought to accept myself I've gotta accept these people because I've never really been around until the last how many years? Five years maybe. You know, in a hospital and that and I've never known anybody like myself. I was the odd ball. But we all are different and have different personalities but I see myself, I see myself and them, I think I gotta... it's how people see me....**Well, at first I felt I don't belong here. I mean, these people are bizarre but there are some they're like street people maybe. But they are, there's different degrees of their illnesses that I feel some, for instance, D is above me. I mean, and there are some that I'm not saying beneath me. I'm just saying maybe like I'm in the middle. I'm not that, I thought well, I'm not necessarily but in my mind, I'm too good for these people. I mean, I don't belong here. Like going to the bar and sitting and just sitting there and drinking coke while they're drinking beer. That's, you know, I'm saying that's my comparison. I don't belong here. These people are schizophrenics for God's sakes. They might kill me, you know. You know, I don't wanta, I don't wanta get in an argument with them. But my impression of, I was shocked because they seem very normal. I mean, there's one guy that's, he's going to college. He told me he's on the dean's list and he had a speech impediment and he... And I read her books. She was more intelligent than I to begin with but I think she's saw blood on the wall or on the window and she did, she got to where she couldn't read the children's books. This was me. I couldn't read the newspaper, I couldn't concentrate, you know. **But it's, you know, I feel a settled. Maybe it's because I'm older, I feel like now, especially this last six months, that I'm getting well and I'm handling the stressful situations because, you know, the anger. Because I feel like I belong.** Although they're schizophrenic, they're, I think there's 80% of them that are manic depressive down there. But it's okay....Well, that's kinda like one of those things I told you, you know. The acceptance and the compassion. I'm relaxing. I'm not getting my anxiety and panic attacks. You know, and wanting to run out, can't sit still, stand still. I just feel like nobody's really ignoring me or like I feel inferior to anybody or that anybody's acting superior to me. I feel like I belong. I don't know. It sounds crazy but I thought I found my niche for now, for now. Maybe a year from now, I don't know. Might be doing your job.... **It's made, it's helped me accept myself because I feel like it's not all me. I'm not a bad person. I was raised that way, that I was lazy and bad.** You know, I was always, I was told that. And so it's been a blessing, that way." (44-02-38)

"But you can get it to a point where you can function semi, you know, good. I mean, it's normal for somebody to have good days and bad days...**No, I figure**

if people can't accept me for who I am, then they're just not worth being, you know, friends with.” (45-02-38)

“Well, I heard somebody tell me, they said aren't you glad that you didn't turn into society's accountant or something. Looking at it now I say, yeah, I am. No reflection on you. I just meant I would have been a little old man in a dusty room counting change. But by the same token, I wouldn't want to be a little old man on the park bench feeding pigeons on a Thursday afternoon, either.” (48-02-16)

d) Gaining power and control over life (N=15, 33%).

“...WOULD YOU SAY THERE ARE WAYS THAT YOUR MENTAL ILLNESS HAS IMPACTED HOW PEOPLE TREAT YOU OR INTERFERED WITH OTHER THINGS IN YOUR LIFE? No, I feel that I created that myself. I am my own atmosphere, I create my own atmosphere. No one can create it for me.” (02-02-11)

“...attribute that a lot to my therapist and my doctor. They've taught me how to deal with my illness instead of just letting it deal with me. And I got involved with SA because...of just get to a point where I'm stronger than that. I will not let this mental illness ruin my life. So I fight back. I feel sorry for myself sometimes and can get real woe is me. My sister really gets on my case about that. It doesn't help. She said I feel low as you do, but it doesn't help anything so let's not do it. I wish you could meet S...I guess when you come down to it, it's like me. I mean, you learn to take control of it before it controls you and you have nothing. It's insight....But I didn't do it until it was forced on me by my sister and my roommate, to take responsibility for myself. You know, like when I would stop taking medication, like people here do. I mean, they'd say you have to hold up your end of this. We're breaking our necks here to keep you out of the hospital and you stop taking your meds because you think you're being poisoned or whatever. It's a reality check....In the sense that I've learned that I have more control over these things than I thought I did, with the help of a higher power. Because I ask for help from this higher power and so far it's been given to me.” (05-01-11.1)”

“I try to be honest. I don't think I've ever really concealed anything of major importance that I can recall. Some members basically the small stuff, you know. Gee, if I mention, from their perspective, gee if I mention that to my doctor, he or she is going to throw me into the psych ward and I don't want to go to the psych ward. And these are not people who have not made it through high school, or grade school. These are people with college degrees. I think I mentioned there was...there for a week or two. Then I came home and I started getting better. This was in '85. I told myself I don't care how bad it gets, I don't care if I have to put duct tape on my mouth, I'm not going to

say anything like that. If I have to sit in a chair with white knuckles, you know, gripping it, I'm not going to give into the symptoms.” (07-01-05)

“You know, it's kinda like no one can make you feel insecure without your consent type of thing.... You know, to get inside my body and take hold of my mind and use it to the best of my ability despite its defects, you know?...But SA was the beginning of me being able to, being able to be a full person. You know, to get inside my body and take hold of my mind and use it to the best of my ability despite its defects, you know?...And the one thing that they do usually find out is if you talk about it, things get better. You can share more insight and gain more power over it....I began I learned a lot. I was able to put the disease in perspective, where before that I was just a victim. So it...You know, I can't remember what the philosophy is right now, but to me the most important beliefs are, wanting to be well, having some power over your illness. We teach that it can be done. That you do have some control over it. And empowering yourself over the illness is, I guess it's the same thing....pulling at me here. But then, you know, you continue to have symptoms if you can't talk, you know, because you have no insight to help yourself. You can't diminish anything. You can't dismiss anything. You're a total victim. And so SA helps you not be victimized anymore, you know? And forgive yourself cause it's not all you, but you are playing a role. You are playing the strongest role in your illness. Because all you've got to do is believe it and you can feel it all you want because you still think, you know? And if you have strange experiences and you feed them and no matter, you know, what level of intellect you have, you're still feeding it somehow. But and what you deeply believe is a lot what comes on your own, so if you deeply believe, oh, I just have a mental illness and I need medication and help, that's what your illness is gonna be about, I've learned. So what you believe is so damn important to your recovery.” (08-01-02.1)

“I'm doing a lot better today. I kept my job and I was never absent yet I sorta just decided to take charge of my own life. Stop just, do this little courses at JCC and just got a job and started saving some money. I think in some ways my parents should put more pressure on me to get a job.” (18-02-16)

“...medications and so along with medication and SA and the steps and the fellowship and leading a low keyed life, you can maintain. I've got a lot of people that have attended SA that stay out of the hospital. ...Well, because we do have the power to take our medication or not take it. Or to abuse alcohol or substance. We have choices that can help us to maintain a healthy lifestyle. ...Changes in medication when people become too successful. My illness has given me insight into what I am all about. I am recovered, but not as stable as I appear to be. I have tantrums where I am cursing and self pity. I have never missed a day of work because I have so much self control....forgive

yourself, especially yourself and others. The other one I like is that **you have full control of yourself**. That you, I forget, it's the second step. It's I believe in myself. OKAY. AND HOW'S THAT ONE HELPFUL? HOW'S HEARING THAT HELPFUL? Well, because we do have the power to take our medication or not take it. Or to abuse alcohol or substance. We have choices that can help us to maintain a healthy lifestyle....I read a pamphlet about schizophrenia and it had the symptoms and **I realized that's what I had and it was a severe mental illness and that it can be controlled by medication and I made a decision to never go off medication again and to try to maintain for at least a year.**" (20-01-00)

"I said what helped me the most? The most, for the sudden recovery is **when I realized I had a choice. I never thought I had a choice, so I chose. But I realized, I always thought you just reacted. I didn't know that, you know what I mean? You got angry, everybody gets angry. You gotta get angry. Well, I didn't realize you have a choice. That you could choose to control your emotion or that I had a choice for not being mentally ill. You know, not that it's all will but I thought when I was diagnosed in 1970, that I had a mental illness, I never dreamed I could be as well as I am today. ...six steps and what they mean. As far as SA goes. Just like God grant me the serenity the accept the things I cannot change and the courage to change the things I can and the wisdom to know the difference. The prayer as it applies to SA is God grant me the serenity to accept the things I cannot change, my illness, the courage to change the things I can, myself, and the wisdom to know the difference. So sometimes when we, you know, that's how I want it to be so that we take responsibility. You know, and not be a victim. If you, I think it's so important to accept it as a challenge. You know, I didn't always feel that way now, ...proactive? And I think they're action steps. They're things that we can do consciously to help ourselves. I think working on the steps, whether choosing to be well and there was some confusion in the beginning because people like Ken were choosing to be well. Well, it's a no fault illness but you can still choose to be well even though, like I never thought I had a choice. And I think that's kinda how Ken thought, that you had the illness and he is going to have thought insertions and there's not much you can do. But I learned to control the paranoia. My doctor said I had controlled paranoia. So there's symptom managing, there's reality checking, there's increase in the medication but with the doctor's approval. There's a way from substance abuse. There's so many things you can do to choose to be well but it doesn't mean it's your fault that you're sick....I am happy with SA, life and I realize that I have to make myself happy, always thought my husband could. You have to make your own happiness....I said what can I do and so I thought something positive, pro-active. Action, take action. They say when you're depressed, take a walk or some kind of action. Once you make that decision, it was like a sense of freedom. I was no longer a victim. In all my years, I thought I was a victim of this illness. And not that we're not victims. You**

understand what I'm saying? I have control. And it was possible. And I never dreamed it was possible. And so that's when I wrote up the steps. And...couldn't accept the first step that I was powerless. I couldn't handle that. I just... **there are things that I can do to help myself get better.** So that's why I didn't use those steps...**There's such a freedom, you know, when you're in charge of your own life. You know, like I say that in my speeches because my schizophrenia ruled me for 14 years. It controlled every aspect of my life. And now, I control my schizophrenia.** I'm in charge with God's help, of course, always with God's help. And I know when I'm getting sick. I know the right things to do. I am reality based. And now I'm totally in remission, the positive symptoms. And I haven't, and I'm on the right medication and like I think I've handled this medical emergency very well, considering. I'm proud of myself.” (23-01-00)

“Like when I lost my job I was told that I was an inconvenience by my boss and **they said that you've got to be responsible for yourself and I was being irresponsible. And they tell me to be more responsible. SO THE GROUP HELPED YOU TO SEE THAT YOU NEEDED TO TAKE RESPONSIBILITY? Yeah.**” (24-02-10)

“Oh, yeah. **But I made myself do things, you know. You have to make yourself, which is hard. Your brain makes new paths, when you keep on doing things that you have to do.** The uh, what do you call it, after the wears off. But you're not as animated as you used to be before you got on medication. You're kinda shut down a little of course it has to shut down the active parts of the brain that make you crazy.” (28-01-15)

“**The independent one, I decide for myself, I decide to be well. I decided to be happy. And I take full responsibility for what I do.** I also am very aware of my resources and that I can use these resources to help others. Of course, I got the resources here.” (29-02-02)

“About one year of being on social security, I went to St. Joseph's Hospital and told them I didn't like Haldol. At first I wanted an antidepressant, but he put me on Navane and took me off Haldol and that has made a world of difference. Haldol is like a chemical straightjacket, where Navane, you are still limited but your mind has a lot more freedom. But still, wanted to give out. The smartest thing that I did, when I was taking my Haldol once a week, I saved up about 500 tablets. I was saving them for that special day. **December I took my pills and poured them down the toilet, flushed the toilet and they went down. From that day, I just decided from now on, when my number comes up, I'll go. But until then, I want to enjoy every day of my life. THAT'S INCREDIBLE. SO JUST THIS PAST DECEMBER YOU THREW ALL THOSE PILLS AWAY?** Yes. I really can't go into a lot with group because you really have to experience it to see how it works out, but it does work to help me. OK. I'M GOINIG TO PAUSE

...trouble spelling and reading. I had this one lady, her name was Miss H and she was my teacher. I've been meaning to go back and talk to her about it but, you know, I've got to find the time to do it. She gave me advice, I didn't really use it before I became ill but I really use it now. **She said Josie, don't let anybody push you, or force you or do anything you don't want to do. Work at your own pace and do the best you can and if that ain't good enough then you have to go someplace else.** I may not remember the right words but I remember the feeling she put behind it.” (30-02-02)

“Had to do with the same theme of people not wanting to go off SA, not wanting to go to try with me, I think. **And it was like fighting a battle on my own. I couldn't find anyone who was fighting a battle except for K and she had two diseases. And so I became friends with her because she was fighting. And I wanted someone that would fight with me, to help me overcome this illness.** So I could lead a normal life again. And that was very important to me.” (35-01-00)

“**There's some things that you can go do. You still can make it. Because remember, it's up to you. You don't have to let your negativity take over.**” (36-02-04)

“**It's an opportunity to take the initiative to heal yourself.** And in the same way, Schizophrenics Anonymous is a self- support group which invites you to step out on your own and overcome your difficulties regardless of the discomfort, the suffering, the headaches, the failures, the setbacks. And to fight loneliness and I guess that's what I have to say about that....Also **I have sort of a schedule that I've set up for myself because I live in a foster care home and I have to be accountable to them where I'm going each day. So the way I do that is I sign in and I sign out. Sign out and sign in when I'm leaving the house.** Unless they know I'm going to the store or taking the dog for a walk or something like that. But if I'm leaving the area, you know, the local neighborhood, I have to let, I have to sign in and out and in. So they know where I am and when, who I'm with. And also when I'm due back. And I guess that's a state regulation, too.” (41-01-40)

”Because I didn't wanta be judged as a loser **so I was a fighter, like my mom said, and I just kept on going. I rose above it and I fought it,** because I don't like to be put down. I don't like people putting me down. I have no tolerance for that. That's why I keep on going, strive for the positive....I just say **I'm now benefiting my health. I choose to get well,** function and do other things. Cooking and learn other independent living skills. Coordination skills, driving, being mentally alert. You know. My sickness is being under control, my mental illness, by the medication I'm taking. Even though I do have a mental illness. **SO THOSE ARE THE TWO THAT SORT OF APPLY TO ...AND SUPPLEMENTS QUITE A BIT.** Thanks. I've helped myself do some figuring on my own, like on crack or on combination lock to

open the stuff, to close the stuff in the locker room, my bathing suit, so nobody takes, steals, you know. I'm able to do housework on my own. Basic house cleaning, keeping. I don't need any help there. My room mate and I take turns keeping the apartment in order and vacuuming and I dust my room and do the wash and the cooking. I'm able to walk and ride my bike. I feel I have good coordination skills on my bicycle, you know, with my mental illness, I feel under control. And so...WELL, IT SOUNDS LIKE YOU'RE VERY ACTIVE. ...Yeah, a couple of girls my age said that to me. And I'll never, and I'll always stay that way. **I know that being mean doesn't help and like I said, life is what you make of it. What goes around comes around. If you're mean and you chose to be mean to others, they're back to you, you know. And so whatever I do, I do for me. I don't do to please others.**" (49-02-04)

II. LEARNING HOW TO LIVE WITH SCHIZOPHRENIA (N=26, 57%).

A. Managing symptoms and illness (N=19, 41%).

"Well, I think when it comes down to the day to day experiencing of voices that I hear, they're my voices and the delusions that I have are my delusions. **And because they're delusions, even though I can call them delusions, since they are delusions, I can't, part of me really can't call them a delusion because if I can, if I can entirely call it a delusion, I wouldn't have schizophrenia. I'm thoroughly convinced of the things that I'm thinking. At the same time, I also know it's a bunch of hogwash. And I don't think anybody can really help me in that way. Nobody at all. Except for God. I talk to him a lot....I think a lot of delusional ideas that go along with it.** I sometimes get the feeling that I'm hanging by fingers from a ledge of a tall building. The building is reality. And the sidewalk below is delusion. And I'd really like to get on the sidewalk. Get off the ledge of that building because this doesn't feel as though I really like the building very much. Even though the sidewalk is drop, it doesn't make me afraid which is unusual for me because I'm terrified of heights. But I have a hard time so times being able to discern between what's a good idea and what's crazy." (01-02-11.1)

"ARE YOU ABLE TO PUT YOUR ILLNESS OUT OF YOUR THOUGHTS FOR PERIODS OF TIME? No. IT IS SORT OF ALWAYS WITH YOU? Yeah. It's a life long thing. **I take medicine every day...HOW WOULD YOU KNOW WHEN YOU'RE IN CRISIS? Things don't work out. LIKE WHAT? Hearing voices. I hope I don't hear voices again. SO HEARING VOICES IS KIND OF A BIG DEAL. YOU KNOW THAT WHEN THAT STARTS HAPPENING...Yeah, I'm getting ill. ARE THERE OTHER MARKERS LIKE THAT, THAT KIND OF TIP YOU OFF TO KNOW THAT YOU ARE GETTING ILL?** **Not eating right. Not sleeping.**" (6-01-04)

"I mean, usually involving sexual violence. I've studied up on it some. And in fact, that's the way you can tell whether it's real. Even if it's in your own voice. Because if it's something you wouldn't say in a conversation like here or in a group or, you know, and it's something really outrageous or offensive then it's like OCD focuses on you're most afraid of and then amplifies your fears, you know." (07-01-05)

"I'm not always stable, I have ups and downs during the year. ... pace myself, take it day by day. ... I was one of the guest speakers and I did a big presentation (inaudible). But something like that I had to work up to for a week and it takes me a week to settle down afterwards. (Inaudible). But I was satisfied with the speech. So something like that is like, you know, you have energy dedicated to this and energy dedicated to that." (09-01-14)

"If I had to, it would probably be I have learned the difference from what goes on in my head and reality. ... Totally changed me. I mean, I don't know what happened but it completely changed me. And all of a sudden, I just stopped and said, now I can tell the difference from reality and what goes on in my head. What needs to be done, what can be done. I learned all sorts of ways of coping with it, my illness and stuff like that. It's just all changed from there. And then I had been hospitalized a couple times after that because, of course, I stopped taking my medication and I ended up back in Havenwick.... So he helped me survive up until the point where I started, you know, going to SA and stuff. That's when I started really understanding the difference between reality and delusions, delusional thinking. I started learning different ways of coping with it and stuff, and having someone in my life that was going with me to my therapist...only hill that I ever have to go over is the fact that, you know, I am not normal. I do have schizophrenia and sometimes it's very hard for me to walk out that door and go to the meeting and lead it. Even though I know that they count on me to be there every Wednesday and that sort of thing, and I know I'm supposed to be there but sometimes I just don't want to go but I go anyway. Because that's usually when I probably need the meeting the most...TO COPE? Oh, it's quite a big difference. Although I still do have crying spells, they aren't as bad as before, but sometimes I will still get into a crying spell where I will sit in the same position with my legs crossed and my head in my lap and literally cry for 4,5,6 hours and just cry and cry and cry. Now I feel that it's OK for me to do that, I need to get it out because a lot of the things that had happened to me, especially the sexual abuses I never mourned. It was just like, OK, that happened to me, it's happened before, it's not a big deal. So, when I go into my crying spells I want to be left alone and just get it out. But now I don't pick up knives anymore, I don't pick up razors, I don't pick up pills, I don't jump in front of cars or trains, or all these other things that I did before. Now, if I'm feeling really, really stressed I'll pick up the Bible and read the Bible. Or, I'll play with my son, or I'll call somebody from my meeting. I'll call them

and talk to them and that always makes me feel better. Because even when I was able to call my therapist before, she was this old lady that was my therapist and really wasn't like a friend. But with the program I have people to call that are friends. Maybe they don't have all of the answers in the world but they are there for me if I need them and I know that they understand because they went through the same thing. That's how I cope now. I do other things like take deep breaths and try to relax. I'll go to bed early if I'm feeling depressed, I won't stay up and dwell on the depression. Like today I'm feeling a lot heavier, not so giddy. The last time you were here I was a lot more talkative and I was in more of a upper spirits, and today I don't feel so happy. I'm happy but I'm just not excited." (10-01-10)

"Very bad thoughts. ARE THERE OTHER WAYS THAT YOU TRY TO COPE WITH, WHEN YOU'RE HAVING YOUR BAD THOUGHTS AND YOUR FEARS? Well, I try to not take a nap during the day. I go to as many activities as I possibly can. They have a lot of activities here for us. UH HUH. Schizophrenics Anonymous is just one of them. HOW DOES IT HELP, GOING TO ACTIVITIES? Keeps my mind off my troubles. Even SA does...don't want you to get the wrong idea (laugh). HOW DO YOU, HOW DO YOU GO ABOUT THAT OR WHAT ARE THE WAYS THAT YOU APPROACH THAT, TRYING TO MAKE, GET THAT TO IMPROVE? Practice. Practice makes perfect. I practice reading again. I do that sometimes. I practice other attitudes, other thoughts and other opinions. UH HUH. There are other ways for a man to survive, too. UH HUH. OKAY. SO IT SOUNDS LIKE YOU DO HAVE SOME WAYS TO COPE WITH. Yeah. THESE THINGS. It all comes in from within and the problems are from within, too. UH HUH. AND DID YOU LEARN HOW TO COPE WITH THESE THINGS BY YOURSELF? I MEAN, IS THAT SOMETHING THAT YOU, OR HAVE OTHER PEOPLE HELPED YOU WITH THAT? I had so much help, but I have to say I do most of the work myself. They told me that would be the case. When I first started here, they mentioned that thought to me several times. HMM. Sure you don't want some ice tea?" (14-02-11.1)

"Well, I cope by trying to take my medicines daily. [ANYTHING ELSE?] That's all." (19-02-13)

"I know when I'm getting sick. And I've been in remission with the positive symptoms for three years, four years. You know, just the fleeting paranoia that you would have. You know, everybody gets paranoid to a certain degree.... I didn't know before. My doctor would say you wait too long. I keep thinking it's gonna get better and blow over. Or then I get too far off, and I don't think I'm sick. But I know now, I can tell Dr. F, well, I'm getting a little paranoid and I'm thinking these kind of thoughts. But it's okay; my psychiatrist told me I had controlled paranoia. That's how I was able to work. He called it controlled paranoia. I knew to dismiss it or, it was controlled. I could still

work. And sometimes it wasn't, you know. Sometimes I went back to the hospital on medication and what I learned from SA is the importance of medication. I mean, I took it for quite a few years because I knew the importance but I mean, I was reinforced from people that I've seen in SA and how well they do on their medication....More about my illness, more about schizophrenia. I learned how to handle my illness better, knowing when I get sick. And the importance of support and friends.” (23-01-00)

“It (SA) has made me more aware of my illness and less schizophrenic. WHAT DO YOU MEAN WHEN YOU SAY LESS SCHIZOPHRENIC. To keep my mind from wandering into unbelievable things. YOU HAVE MORE CONTROL OVER YOUR THOUGHTS? Right, right.....It probably helps with the medication, too.” (24-02-10)

“...you know, if they tell me to take off my clothes in public or something, it's... but no, I can really, I can distinguish, I don't do bad things or anything like that. But yeah, I guess to be myself.” (25-02-10)

“...start getting real active, I start getting like manic. I start going real fast and then you run into a brick wall and crash. You know. I have to stay low key. I have to keep myself calm and I need a lot of quiet, a lot of quiet. But then too much quiet... you have to interact, you know, to keep yourself going. I'll be in that bed, my bed, you know.” (28-01-15)

“They said they'd phone the police, but I was talking out loud to myself, I hadn't learned how to talk to my mind yet. Every time I heard a voice hit me I was answering through my mouth, I was mumbling to myself. And they did call the police, they showed up and I was gone again. I was on the run again, trying to get home.... Then my second time, the voices hit me, they hit me in the morning I think it was. I didn't talk through my mouth this time, I was mostly talking through my head and I went through the same thing all over again. My imagination was going wild and stuff like that. ...hospital, I knew I had to be on medication. But I knew I couldn't work with it so I started taking it on weekends. And it was really tearing me apart during the week because it's like going on a high one weekend. I was OK on Monday, but the more the week went on, the weaker and the more stressed out I got. On Friday I'd take my medication and that would help clear myself up. It lasted about a year and a half.” (30-02-02)

“Oh, I used to listen to music, get into listening to music, I used to listen to music and cope that way.” (32-02-13)

“Because I like the socialization I get with other schizophrenics. It's hard for me to make friends because I have all these symptoms on top of my head and they want to come out right away. I mean, I want to talk about them right away. I want to get feedback and tell people, you know, and connect with

reality somehow. The best place to do it is over at the SA meetings and the social groups afterwards because people who don't have the illness don't really, they shy away from you and they don't really... I'm not saying you don't, but most other people don't understand what it's like to have schizophrenia....drugs, the best everything, and I was still depressed. So it wasn't only schizophrenia, it was also depression. And as long as I just refused to do anything, then I wouldn't get psychotic but I'd still remain depressed. It was a fight between trying to do things to get myself undepressed, while in the process I was doing things that would stress me out and make me psychotic. Do you understand that? They put me on Trilafon, I think. **I still had delusions but I thought I could live with the delusions as long as I don't tell anybody about them.** As long as I don't tell anybody but my therapist about them. And I can live with them as long as I don't have this horrible, crippling depression.” (33-02-05)

“It has to do with my tardive dyskinesia, which is one of the reasons **I chew gum a lot.** It helps because it gives the impression that, oh, she's chewing gum. That's why her face is moving....I would like not to move so much. **I've been trying vitamins.** I was reading this thing on tardive dyskinesia so I'm trying that.” (34-02-05)

“I had to set some goals and by listening to all the other people, I was able to start piecing together my life again, and understand what schizophrenia was. **Understand what appropriate behavior was.** Understand why some medications did work and some medications didn't work for some people.” (35-01-00)

“She has something wrong. That's what it is. I guess it's my reaction. **Now, if I don't go singing it all the time and like grinning all the time, but there's something on my mind that made me grin.** Because I'm grinning all the time. They might read you wrong when you have a big grin. **I guess it all depends on how I respond to things.**” (36-02-04)

“Making motions that I'm making in the house. **And the only way you can cope with it is just try to put it out of your mind. I know it's not real. Because you know, reality, from what is not real....**Yes, you do. You learn about the brain and malfunction in the brain. You learn about the voices and different things that happens to us. Like the FBI after us, thinking people reading your mind and you find out that you're not the only one suffering from all those things....What I've learned... let me see. Well, I think **I've learned my disorder, all about my disorder.** I guess that's all I can think of right now.” (38-01-38)

“I mean, but I couldn't do it. I went to the hospital first. I knew. I know my... but before, I didn't know what I had. I didn't know my danger signs. ...focused on trying to better myself. Learn all over again. Maybe, you know,

now that I do know that I have this illness that I, you know, just can't.. **I try to avoid what do you call it? Stress. Stress and situations. I'll walk away. It seemed before like I thrived on it.** Controversy.” (44-02-38)

B. Recognizing need for help (N=10, 22%).

“WHY DO YOU THINK YOU'VE STAYED INVOLVED IN SA? Because **I need treatment.** I believe that I'm not very balanced when it comes to society, behaving like a citizen who's well, who's well adapted to the community.” (02-02-11)

“I'm learning to **accept help from others.**” (03-02-11.1)

“I knew **I needed all the help I could get**, you know, support. My counselor at Turning Point suggested I seek help, because she couldn't do everything. She told me to get hooked up with resources like First Resources North, and that takes time. It took several months to get into programs.” (12-01-03)

“I started articulating their condition better than I could my own. And I started to depend on a dialogue instead of the usual soul searching that's done, you know, it's like a self thing. **I started to depend on the dialogue with other people.** I've been carrying on this conversation now, the same one for a long time. We both, many times during the group, we talk about entertainment, we talk about pleasures we have. We don't just talk about problems. We talk about good things, too. As far as the problems are concerned, I always get some kind of emotional support. ...A lot of things I refused to talk about for a long time and I talk about them now. YOU DO? Yeah. WHO DO YOU TALK WITH ABOUT THEM? I'm in therapy and my social worker. He's BH, I have a social worker that talks to me about my problems.” (14-02-11.1)

“Well, it's made me feel better about myself and made me feel like I'm not alone. Like the step says, **I need help. I can't do it alone.** One of the recovery steps. So it makes me feel like I'm a part of a group, a part of a family outside my family, an extended family.” (19-02-13)

“You know, like one of them, **you admit that you have a problem and you need some help.** YOU FEEL THAT'S AN IMPORTANT ONE? Yeah. I do. DO YOU THINK THAT PERSONALLY, FOR YOURSELF, YOU'VE COME TO ACCEPT YOUR ILLNESS A LITTLE MORE? Yeah.” (26-02-14)

“When I first came, I was kind of skeptical because I didn't know exactly what they were going to have and what the meetings were about. **It was my first experience with any mentally ill patients on group togetherness. I'd never been for this. I always felt that it was wrong and I kept everything to myself.** After attending one meeting in fact, and Mary was the facilitator. She

had all of the information at her disposal and she did tell what the symptoms were, and **I realized yes, I do need help. I do choose to be well and I want to be a happy ...** Oh, it (SA) was just fantastic. I never expected that, I thought, well, you know, here I am going to a regular meeting and there it was, all the information. I did cry a little, because, you know, **I finally realized I need help and even though I was going for the help,** I didn't understand how come. I didn't know what the symptoms were and I discovered what the symptoms were. I discovered there's help out there. I discovered you can relate to one another. We are also very supportive of one another and that's been them most fantastic part about this, that by coming here, I find out that there are supportive people and you can't ask for anything better than that. **To be independent and supportive of one another. That is really, really great. I mean, these are better people. We are becoming better people by this. Very much so....hard to believe but off the record, I was told by a specialist, most people are ill and the ones that go for help are the better people. And I feel by coming here, we are the better people because we've come for help.**" (29-02-02)

"In fact, the first step is I surrender, **I admit I need help.** I cannot do it alone. So we have to admit that we have the illness or a related illness and we need the help of other people. And I also explain that in SA we rely on professional help." (41-01-40)

"Then there's steps. There's six steps and I'm still stuck up on the same dang one. I surrender. **I admit I need help.** I'm the same...about it, you know. And it's real hard for me to pray. It's hard for me to ask anybody, let alone God, you know, what's wrong with me? You know, but I have a strong belief in God and he's pulled me through other hard times physically. Surgeries, cancer. You know, good grief. Could have been worse. That's what people keep telling me. Could have been worse. But I feel bad. I don't even feel I have alive without them. It hurts....No. I don't go for help. I mean, it's there and I talk to people but I tell them after the fact. You know, I had a bad something or this happened bad or, you know, I don't go... I just keep it to myself... Hard to pray. It's hard for me to even pray, to go to God. Feel like I just gotta get through this." (44-02-38)

"HOW ABOUT THE SIX STEPS FOR RECOVERY? DO YOU FIND THOSE HELPFUL? Yeah, I always picked I choose and I understand. WHY THOSE TWO? Because it always applies to me. **When I say I admit I need help, I can't do it alone,** I don't need to say that because I'm already getting the help." (49-02-04)

III. Redefining Expectations and Goals (N=16, 35%)

A. Redefining expectations for life within the context of a disability (N=9, 20%).

“But had I never taken that first step, to admit I was schizophrenic and join the group, nothing would have developed, I would still be waitressing and wondering, you know? Because I thought I reached as far as I wanted to go, as far as career wise goes. I just wanted to continue helping others and helping myself. **Before that, I was always going to college and had aspirations of different career goals and never found anything I really wanted to do. Social work always, and I had a dream of being a nurse but I knew with my background... in fact, even with social work, I had no idea that that would be welcomed, with a schizophrenia diagnosis. I figured there was no career that would welcome me...**” (08-01-02.1)

“But talking to my parents, they suggested that I just stay on disability and work these menial part time jobs to earn extra money because at least I have that safety net. You know, and to get back on disability, they make it so tough to get back on it, then I would have went out there and tried to find a full time job. But I don't have any interest in doing that. because they make it so darn tough to get back on. And I don't want to be homeless and lose this (own house).” (11-01-03)

“I sorta just decided to take charge of my own life. Stop just, do this little courses at JCC and just got a job and started saving some money. I think in some ways my parents should put more pressure on me to get a job. (inaudible). ...**I really realized I'm not gonna graduate from JCC. All the really tough classes I failed so...DO YOU FEEL THAT YOUR MENTAL ILLNESS HAD A ROLE IN THAT?** Well, just a lot of these courses like probably and statistics are just very difficult.” (18-02-16)

“I do have an idea. Well, okay, the exercise is good as always. You know, it makes me just feel stronger, like I can get by. And thinking about what I wanta do, actually I wanted to do it this year but circumstances, I've got a grandpa who's in the hospital so my mom needs the car all the time. I have to use hers. Start my own lawn care service. As a matter of fact, I had the flyers made up and I found out that I can make pretty good money doing that. So that's, that's one thing that, you know, that helps me cope a little bit. **Thinking that maybe there is a way out because to think that I can go work a regular job, especially with the kind of money that regular jobs pay, I don't think it's realistic, that I can even feel good enough to do that job every day. And you know, something like this, where I'd work maybe six months out of the year at the most, and then all I would have to do is just hold it together for those six months and then, you know, if I wanta get sick in the winter time, I have time to do that. It's not something I'll have to do every day for years and years and years. I'll get breaks...mean, it's nice having friends. I don't ever want children, ever. Even before I had the illness I felt that way. But now that I, now that I do have it, I'm almost 100% sure that it's best that way. AND WHY DO YOU SAY THAT?** Well, because of the fact that I may not always be able to take care of them the way

that I should. You know, what's gonna happen when I'm too depressed to work? Or even talk to them? What if I'm too wrapped up in myself, and I am." (25-02-10)

"... I'm in my 50s. This happened when I was 28. I could have been more informed, I could have got medicine, I could have led a more productive life. A more productive and happier one. See, now I've got to think on the positive side. Where am I going? And I'm taking positive steps by being a caregiver and doing something worthwhile that I'm concerned with. Maybe going back to working with the blind. **I did think of being a doctor and going into psychology but I think I'm too old and I've lived through too much.** I'd have to talk better with my therapist." (29-02-02)

"A long time ago I thought you had to have a girlfriend in your life or somebody to have your life complete. I went through 3 girls, it wasn't their fault. Each time I broke it up, I couldn't handle the responsibility part of it. It's like I told my therapist and my doctor and Mary and the group, **I realize now it's good to have a girlfriend but if you can't handle it, find something else to enjoy, don't give up your friends.** So I got bad advise when I was in the ...**MIGHT HAVE DONE?** I know it has. A good job, a wife, kids, money. It's a shame, I'll never get to complete that but as I said before, you got to start over sometimes....What I told my therapist, before I started coming to the meetings, I said 'I know I can't be 100% again but if I'm able to get to the high 80s, I'll be happy.' I would consider myself right now, because of my therapist and the group especially, I think I reached my goal. I think I'm about 85%. I am satisfied with that." (30-02-02)

"I took a couple classes and got really bad grades, they were upper level classes. I felt not very good about myself and I think that's why I went back **because I felt like maybe I was denying the schizophrenia, trying to go to a university. Maybe I should just go to SA and recover and see what else I can do.** Because I did get 2 Ds, I think I got one E, two Ds or something like that in a couple courses I was taking and one of the instructors asked me what I was doing here because he found out I was schizophrenic. And it was in psychology. I said well, what am I supposed to do, you know? I have to have a life too. So they gave me a D in both those classes and I felt like I wasn't cut out for school but I didn't give up going to school. What I did was I waited, took some time off... that's what I always do. I take a lot of time off and then try again. And that went on for quite a while. I mean, that part in my schooling went on. But then after the classes were over, I thought I'm not gonna take any classes, I'm gonna go to SA instead. So that's what I did. I went to SA in the winter '90. **AND WAS ...**though they've got this illness. That's what I was doing for a long time is struggling to have a career. **I wanted to be able to support myself, to get off SSD. I realize now that's not going to happen unless some miracle drug comes out which I don't**

think will be for a while. And if it does, I don't know what I would do with myself because I identify myself as schizophrenic and living here in this apartment. I work at the library three hours a day, 9-12 Monday through Thursday and that's just right for me. It's not too much and it's not too little. So I've been lucky to find that but I still had to struggle with was I ever going to get a Bachelor's degree and go on and do all that? Would I ever have kids and I've come to terms with those two things-no and no. I'm not gonna have any kids and I'm not gonna probably ever have a career that's full time. Strangely enough, it doesn't bother me. I just felt a release of negative energy when I gave up those aspirations. Did I say that right? I kind of felt like I went off on...that's the crux of the matter right there. If we're talking about dating, like with other women there, or if we're talking about school. It all depends on how bad our illness is and how realistic we are in accepting the illness....degree. I've got my Associates so I don't have to, that's as far as I'm going, is associate degree because I just can't. I've been trying since I was 18 and if I haven't got it now, I'm not going to. But there were times when I...because I have a happy life with Steve. I don't have all my goals fulfilled and everything, but I figure, you know, I don't have to do everything like modern women do. You know? And I can't anyway so I just accepted that.” (33-02-05)

“Well, SA, see, before I got sick, I wanted to be a chief executive officer for a company so I had high goals for myself. And SA kept reminding me that I had an illness. That maybe that dream wasn't realistic for me anymore. And maybe I had to start re-dreaming and start, start setting new goals and more practical to what I could actually accomplish rather than what I wanted to accomplish. I had to become more realistic. I had to become more down to earth and I had to look inside myself. Every time I got sick of that job, I would look inside myself and I'd go to SA and I'd look around the table and see all these people and think to myself you're so fortunate because for one, you have a job, and for two, you're making progress. And even though you'd like to be doing something more challenging, you're still making progress. So I figured I would get my health together and go after a job afterwards. And I wanted to make sure my brain was still working so I went and got my masters at Eastern Michigan University. They even made a few comments. Hey, you know, this work isn't quite up to snuff or can you redo it so I had to redo some work but...needs help. But mainly, it's made me a better person. You know, I got off the fast track and got really down to earth and didn't think about, I wanted to make a million dollars by the time I was 30. Now I've kinda forgotten about that. And I just enjoy life now. UH HUH. I told one person if I couldn't be chief executive officer, I wasn't gonna do anything. And just recently, that's when I was sick, just recently I'm saying to myself, hey, I'm gonna get out there and do more. So I think I'm coming around to another phase again.” (35-01-00)

“And they met every week which I thought was great. When I first started my

group, I wanted it to be a weekly group but I felt that **I'm unable to operate that intensely**, you might say. Because you know, I'm mentally ...just graduated from high school the year before and I've got a lot of, a lot of, a lot **different perspective on life now** because for one thing, I know I'm never gonna have children of my own. I know that I don't care about getting married unless it's for just companionship. Or a platonic relationship. I don't even know what platonic really means. But now, I'm happy to live a day at a time and I'm more carefree. You know, then I was thinking oh, I've gotta make something of myself. I've got to show them that I'm not sick. You know. Show them that I have the ability to take care of myself. And many times when I was in foster care homes, my secret or private goal to myself was finally to get an apartment of my own. Live by myself so I could do what I pleased. And I know a lot of people now who have the same feeling. But I don't wanta do that unless it just happens. You know.... You know....OKAY, THAT'S OKAY. Perhaps I could say what Ken says often. And I think it's one of his ideas that being mentally ill does give you an appreciation for the lives of other people. You know, it shows you that nobody is perfect and that there, maybe you have, you know, there have been a lot of surprising, worthwhile people, outstanding people who have had schizophrenia, like Abraham Lincoln was supposed to have been schizophrenic. Einstein a queer and there are lots of them. Edison was eccentric. People are worth something nobody what their condition. And if you have a mental illness, that doesn't mean that you can't be productive or make life worthwhile. While there's life, there's hope. And one thing that recovery people say often because Dr. Lowe said it, you may be helpless sometimes but you are never hopeless. I do believe that perhaps mental illness has helped me because it has given me time to think. If that doesn't seem like a strange statement.” (41-01-40)

B. Developing goals, hopes, and dreams (N=10, 22%).

“I have a long **life goal to be married and have a family, and have somewhere to live and transportation and a nice, steady job or two jobs**, if I can manage my hours and my time. And I don't think that SA or SA members would be able to find a solution to my problem of getting married or a job. I feel that there's obstacles that only I, well, not just I but obstacles that are unpenetrable. **First, I gotta go to college to get a better job. I have to have a good quality brain to be able to study. If I don't have the brains to do the homework then I won't have the grades. So I'm just referring to that kind of goal.**” (02-02-11)

“I'd like to **have even better mental health**. Everything else would fall into place. I would like to be more thankful, more satisfied and to have more growth. Quite often I wish I had **lived on a busline**. I am quite dependent on my car. Last year, during bitter weather it wouldn't start. I know now there are people that I can call that I can rely on. I'd like a **mate**, not just for the

sex.” (03-02-11.1)

“I would like to **get married when I'm capable of holding down a job**. I want to be independent before I have anyone else sharing dependence. I want to be independent myself.” (10-01-10)

“WHAT WOULD YOU SAY THAT YOU'VE LEARNED FROM BEING IN SA? **I'm learning how to dream** and not look at my life... I'm learning how not to look at the terrible things that are happening right now. I'm learning how to dream and have hopes and aspirations. **AND HOW HAS SA TAUGHT YOU TO DO THAT?** Well, they've let me express myself by talking in the group and they let me hope and plan for the future....**Well, the dreams, the hope and dream is to get well one day and resume our former career, to start a new careers. To find a nice place to live. To own and operate a car. To have a family.**Sometimes they don't understand my fears and my ups and downs. They don't understand my dreams. Sometimes I need a lot of support and they're busy with their careers or housework. That's about it. **OKAY. AND WHAT SORTS OF THINGS DO YOU DO WITH THEM? FUTURE?** I feel hopeful. **ARE THERE THINGS THAT HELP YOU SORT OF TO FEEL HOPEFUL?** Listening to some of the group members talk about their hopes and dreams. I have some of the same hopes and dreams. I have some of the same fears. And some of the same obstacles to overcome that they have.” (19-02-13)

“I do have an idea. Well, okay, **the exercise** is good as always. You know, it makes me just feel stronger, like I can get by. And thinking about what I wanta do, actually I wanted to do it this year but circumstances, I've got a grandpa who's in the hospital so my mom needs the car all the time. I have to use hers. **Start my own lawn care service.** As a matter of fact, I had the flyers made up and I found out that I can make pretty good money doing that. So that's, that's one thing that, you know, that helps me cope a little bit. Thinking that maybe there is a way out because to think that I can go work a regular job, especially with the kind of money that regular jobs pay, I don't think it's realistic, that I can even feel good enough to do that job every day. And you know, something like this, where I'd work maybe six months out of the year at the most, and then all I would have to do is just hold it together for those six months and then, you know, if I wanta get sick in the winter time, I have time to do that. It's not something I'll have to do every day for years and years and years. I'll get breaks.” (25-02-10)

“...the years, I'm in my 50s. This happened when I was 28. I could have been more informed, I could have got medicine, I could have led a more productive life. A more productive and happier one. See, now I've got to think on the positive side. Where am I going? **And I'm taking positive steps by being a caregiver and doing something worthwhile that I'm concerned with. Maybe going back to working with the blind. I did think of being a**

doctor and going into psychology but I think I'm too old and I've lived through too much. I'd have to talk better with my therapist. ...forget him, never. But he's a confirmed bachelor. He won't marry. He's already told me this. I said OK, we'll still be good friends. But I would like to meet a man. I'm getting older in life. I don't have too many good years left. I would like to marry. I'm tired to being my own. I miss the romance, the attention, the love, the affection....IN THE FUTURE? In the future, I'm very hopeful right now because I've got a possibility of getting a good job as a caregiver. Which I like doing because I won't be confined. I will be on the go. I won't be in one place. That is an A+ for me, that is very good. And then I've got a possibility through a friend, of getting into a beautiful apartment complex. And see, I might be coming into an inheritance in another year and a half which would help. And I plan to help, use at least 20% of it to help, to help this organization. Definitely. To branch out. And there's hope for the children. We're having a family reunion and I'm starting to open up now so if I say the wrong things,..." (29-02-02)

"I was talking about it but, like I say, with my medication, I was really going downhill still. What I did, and Mary praised me about this, **was making goals for myself. Even though I sometimes wouldn't meet those goals, it gave me something to look forward to. And I started changing, every six months, I started changing. ... I set some goals for this year. The first goal is to get me a car. My second goal is to go back to work and I'm going through a process of going to do that right now. I want to work in September and it looks like it's going to be in September, too. Just work part time and still keep my social security....I knew I was getting...week and they want to share it with everybody. And then there are people like me who set goals and you want to share it with people when you meet it. DOES THAT HELP YOU, WHEN YOU SET GOALS TO SAY THEM OUT LOUD TO OTHER PEOPLE IN THE GROUP LIKE THAT? When you set a goal it's one thing. When you meet it, you want to share it with everyone and that's what I did.... WHAT WOULD YOU SAY YOU LIKE THE MOST ABOUT YOUR EXPERIENCE IN SA? Well, it opened my eyes up to the future and, you know, what could happen. The past, present, and future. Like I said, I like ...don't doubt my medications. I want to enjoy everyday of my life and I look forward to the future, making goals for myself now. ...away, doing that right away. When you have a mission, it puts too much pressure on. At least for me. When you set goals, if you don't make it, fine, start again. And if you do make it, good for you. That's how the group runs, too."** (30-02-02)

"...I wish I lived by myself and have friends." (32-02-13)

"To get married is one of my goals. I guess to get married is one of my goals. OKAY. Yeah, that sounds about right. That sounds about right." (37-02-04)

“...do think that the social worker, we have a thing called goal tracker, and he writes down a whole list of things that he wants me to accomplish socially by each quarters time going all the way through this time next year. And, not only is that helpful, but it is encouraging, because evidently they expect me to last another whole year. Sometimes it is a mystery to me, whether I am going to or not. But I go to him for, he is a brother, he is a father, he is my god he is my friend and I can go to him and say oh, I feel just terrible about this and he says the way I see it is you are doing fine. We like you here. We enjoy it when you show up and it is always a pleasure to talk with you too. And so I go to him for, because he is not doing a job, he is my friend.” (48-02-16)

IV. Developing strategies for change (N=23, 50%)

A. Identifying specific areas of change (N=9, 20%).

“Yeah. That I can draw. And it's like I just picked it up. Never took a class. That I genuinely enjoy being around kids. Most adults don't. And they like being around me. I can talk to a group of about 100 kids for an hour all by myself and they'll behave themselves. But if I have an adult sticking around to help me, I can't do a thing with them. I consider that a real blessing to be able to share with kids. I ...LEARNING ABOUTYOURSELF OR GROWING AS A PERSON? **Well, a lot of things. I can see a lot of significance into things. And if I can filter out what's valid and what's invalid, I feel that I have more insight than I might otherwise have if I was normal.** I do have to do some sifting. I think that's about it ...darn proud. That's one reason, there are four things that I believe I know I can do no matter how delusional I get, no matter how the voices get me, or hallucinations. Sometimes I kinda half close my eyes or close my eyes and I'll get, I'll see things. Sometimes I close my eyes a little bit and I'll feel like there's a whole bunch of people sitting in easy chairs across from me or some kind of thing like that. Or I'll see somebody walking by. **But there are four things, no matter what I know I'll always be able to do and that's to draw and to write and to tell stories and to do scout craft, which is, you know, outdoorsman skills.** Because no matter how bad I've been, I've done, I've been able to do those. These are things that nobody knows how to do any more. Or has the delusion surrounding it that it's a special gift ...right down to it. Those are the four things I love the most. And nobody can take them away from me because every person's heart, every person's ability to write and draw, who does write or draw, tells a story that is individual. And the other thing is skills of tying knots and building shelters. I've got a bungee tent. I'm probably one of the only people in the world who knows what, who knows why you're supposed to learn how to tie knots anyway. So they can't tell me what I'm doing wrong. So... as long as I know I've got boiled down those four things and so I've got life all figured out. Everybody else can do my math, they can

do my accounting, they can pay my bills, because I can't do that.." (01-02-11.1)

"I didn't have a ride there. Then when I got my own car, **I decided that I would go, make an effort to take myself and drive with my vehicle that I purchased, that I had bought. And I would make it like a regiment.** You know, I'm gonna do...problems. And I guess I was there to meet people that would help me instead of keep me from progressing. So that kind of made the decision on whether I would keep attending or not. UH HUH. But there were more good people than there were bad people so I kept on going." (02-02-11)

"You know, **I was looking to change my ways because I had very poor grooming skills.** I mean, I'd take a shower every day but I didn't want to shave and stuff like that. I had a beard down to here. I've just come a long way and I owe it a lot to SA, you know....**I needed help. I didn't want to live my life the way I had lived it in the past and at that moment. I was very unhappy.** I wasn't happy with women. I wasn't gay or anything but, you know, it was just that I knew I needed something to complete my life and I was looking for something at that time." (11-01-03)

"Though I have a mental illness. **I have some strengths that I didn't know I had and stuff like that.**" (12-01-03)

"Well, well, I've taken this step a few times and I say, well, I say it because I wanta get more interested in praying and doing things that are spiritual and I think that that would help my life." (13-01-15)

"Yeah, I've already talked about a lot of that. I guess the helping part of it is, I felt more, **I feel more confident in leading groups now.** Like I was in, I went to college and in seminars, I would, I was terrified. I never wanted to talk. The only thing that saved me was writing papers. I would have flunked every seminar if it hadn't been for term papers. **And leading the groups enabled me eventually to be talkative in small groups.**" (21-01-00)

"...found it (SA) very helpful to me. **And I found I could help others there, too.** Can't worry about things we can't change. That **we each of us have inside of us, resources** and SA can help tap into them....were wonderful. They were so patient and kind. Got me into volunteer work, raising funds for the center. I really enjoyed that. They saw qualities in me and talents and they helped me bring them to fruition." (28-01-15)

"And just by coming and, people talking, it helps an awful lot. It brings out a lot in you. It's brought out talent in me. **Things I thought I couldn't do, I tell her I can't do this and she says, well, I'll show you how. And now instead,**

if someone says can you do this, I don't say I can't. I say will you please show me how. And that has helped me a great deal. And coming to the meetings I ...hoping for hot lunches. But all in all, it's just been really wonderful. We're just starting and I'm real excited because I do have some other ideas. There's a possibility we might have a computer school. They might be opening this and this is one thing that scared me about looking for another position because I do clerical work but I do know nothing about the modern day, and computers is the main thing today. So I'm really thrilled about that, I'm really happy about it. Coming to the meetings, I hear things and I ...got no arms, what am I gonna do? What can I do with these hands? I never knew what I could do with these hands, you know? So I came here and then DLM got me started on things and she said, "Yes you do have hands." And she said, "Can you do this?" And I said, "No, I can't do that." And she said, "Yes, you can, here, I'll show you how." So she's gotten me doing some projects and some art work and everything. And that fear, that subconscious fear, it's all gone. It's all gone. I've been working on projects and doing paintings and loom weaving and we're gonna start on Christmas ornaments and that thought is completely erased from my mind. It's all gone so I'm very happy about it." (29-02-02)

"And I'm thinking, I'm here, at home. They didn't bother coming and talking to me. Seeing how things was or saying hi. **I realized then that I had to do something to meet friends, do something to change my life.** That's why I came to the meetings. My therapist told me about it and that's when I started coming to our group." (30-02-02)

"Yeah, I would say even if you don't feel that you're that improved by the meetings you feel better participating and trying to come than to stay at home. **Because staying at home you're just as you are, you know, and at least if you come to the meetings, you have some level of something you're getting out of it.** OK. IS THAT JUST GETTING UP, GETTING DRESSED? JUST THE ACTIVITY OF GETTING OUT OF THE HOUSE? **Yeah, even the activity of getting out of the house I think is very good because otherwise you become stagnant sitting at home.** ARE THERE ANY OTHER REASONS BESIDES THAT THAT YOU THINK OR WHY IS IT HELPFUL? I can't say that it was helpful other than that I knew that when I went there it would be something, or someone to talk to, and that's better than being at home. ISOLATED? Before, I would say you're more apt to be sitting at home on your own and I think it helps you to be involved." (31-02-10)

"Because I was all by myself. Nobody understood what I was going through. **And so I wanted to be with other mentally ill people as myself, you know. They help me out with this.** My parents didn't understand." (32-02-13)

“Well, I think I was 27 then and well, I guess I was lonely. **I was lonely and I felt that a group like that could help me**, not only meet people but you know, carry on the treatment that I was getting out of BH which was ending. I wanted something, another group to go to.” (33-02-05)

“INTERFERED WITH YOUR LIFE, INTERFERED WITH YOU ACHIEVING SOME OF THE GOALS IN YOUR LIFE? Recently? JUST OVER THE COURSE OF YOUR LIFE. **Well, it actually got me writing poetry. For which I've been published. I got some recognition. I've done poetry readings since my last child was born.** I wanted to join everybody else. I wanted be, hey I'm a mother, I go to the grocery, I do all these normal things. And so poetry began to look to me like being in love with yourself. You examine every facet of your mind. Oh, I'm so fascinating, I'm wonderful. Write it all down. It doesn't make too much sense to me. HOW MANY YEARS DID YOU SPEND WRITING ...Oh, sure. POETRY, I GUESS, IS ONE ANSWER TO THAT. Well, I have a good sense of nuances in other people's behavior and I observe a lot. Like one week I'll observe the shape of people's heads or ears. It's just, I love to look at art work. ...are girls. AND CAN YOU DESCRIBE YOUR RELATIONSHIP WITH THEM? I think I'm a terrific mother. I mean, I see my weaknesses but I'm a terrific mother and they think so, too. I don't use them as therapists, I don't use them as buddies. I no longer carve myself up or burn myself. I don't do that. I haven't been in a hospital in 11 years. I'm always there for them. They don't think I'm strange or think anything's wrong with me. Being a teacher taught me that I'd like to have my own children. My mother was this way and I am, too. Quite playful. Somehow a kid at heart type people. But I also take my responsibilities very seriously.” (34-02-05)

“And a lot of people who called me wanted me to pick them up and give them rides and I told them that was one thing that I couldn't do. I probably could of, but I didn't want. The way I looked at it, if they wanted to get to the meeting that badly, they would have someone drive them there or they would have taken the bus. Or they would have walked. They would have done something. **And I drove almost an hour one way just to get to Laura's group. And I think it is part of, it's part of recovery, learning to take those types of steps.** And so that was a little frustrating because I felt bad about saying no.” (35-01-00)

“BECOME A LEADER, WHAT DID YOU THINK? **I was afraid. I didn't think I could do it but I could see that I can do it.** WHAT ABOUT IT SCARED YOU? Well, because I thought I wouldn't be able to come up with the right answers to any problem that came up. But I'm past that. I believe I give good answers.” (38-01-38)

“I think it's (SA) good for you because it's, **if you're all by yourself and**

you're just staying by yourself and you're not doing anything with your life, if you wanta get better, you have to come out and talk about your problems. You can't keep them hid. That's what I go to a therapist for, too.” (38-01-38)

“Red Riding Hood. Sure are looking good. So her, she heard and she got the tape and I copied. **I feel good when I can do things.** I can copy that. You know, took it and made a copy of it. OH, THAT'S GREAT. We have fun.” (44-02-38)

“Not only that but A always gets me to read it if I am there because I am able to read, annunciate, and look at people all at the same time. **I enjoy doing that for people. I am able to pronounce longer words than they are sometimes....Uh, I, there is always I can count on, they're giving me 100% carte blanche and it is not blaisy it is appreciated. Feeling that I am popular and you tell me that I am doing good and boy that is like gravy on the mashed potatoes.” (48-02-16)**

B. Overcoming fear and impediments (N=14, 30%).

“I was in a program and we used to stay busy all the time and I didn't have time to think about bad stuff. I mean, I thought about it occasionally but I was so busy in that program that it made my head spin. Plus it taught me a lot of things. **LIKE WHAT SORTS OF THINGS? That I could achieve things I thought I couldn't. That I could stay the entire program which was physically demanding. Pull through with a good heart and a good mind.** Like an exercise program. I thought I was dying out there, my muscles aching and everything. I thought I wasn't gonna make it that night but the next day, there I am, you know and I am ready to go. You know, they taught me like things are ways. It has helped me to grow. I find myself pushing myself sometimes to study books. All because, you know, I felt that I was a vegetable when I was ill.” (02-02-11)

“But it was such a nice group and it was helping people and it was helping me that I said, well, **as nervous as I am, I'm gonna try taking a crack at being a leader.” (07-01-05)**

“...pace myself, take it day by day. For (inaudible), I don't know if you attended or not, but I was one of the guest speakers and I did a big presentation (inaudible). But something like **that I had to work up to for a week and it takes me a week to settle down afterwards.** (Inaudible). But I was satisfied with the speech. So something like that is like, you know, you have energy dedicated to this and energy dedicated to that. So that's...functioning clients. (Inaudible). I felt that there was a need for it. **I felt it was a mountain, a hill that I could climb. I felt that I had the ability, and the intellect, and the skills, motor skills and mental skills**

to be able to talk to somebody, to hear what they are saying. I felt there was a need for the job. I didn't think that anybody else around me would accept the job. Also, if there are any problems, or arguments with other staff, I can take it to JB.” (09-01-14)

“I was so nervous (about leading the group). I mean, I probably was shaking up a storm but I knew that this was what I wanted to do. That this was something that I had to do. For me and for anybody else who wanted me to help them, you know? So I just said OK.” (10-01-10)

“But anyways, I got to attend these classes and I thought it would be healthy for me just to be able to get up and, you know, go one step further from talking on a one on one to being able to talk in front of people. And that was a big step for me. I always wanted to get some leadership skills that I didn't get in the service. That was another reason why I wanted to participate in this.” (11-01-03)

“My parents are helping the best they can. I kept my job but I haven't got advanced any. I'm still just dishwashing. That's pretty frustrating. The thing is my job, I don't know. It seems like the job's going nowhere but I haven't been fired. And I read a contract, you can get fired for any old reason. I mean I'm pushing myself harder. I wasn't trying as hard early on.... I asked some people at Taco Bell and a few of them gave me their phone numbers but I don't really feel like I'm attracted to them. OH, LIKE PEOPLE TO CALL? Yeah. OKAY. SO KIND OF LIKE ASKING THEM OUT FOR A DATE? Yeah. I wanta show them my computer and try to get a conversation going.” (18-02-16)

“Yeah, I've already talked about a lot of that. I guess the helping part of it is, I felt more, I feel more confident in leading groups now. Like I was in, I went to college and in seminars, I would, I was terrified. I never wanted to talk. The only thing that saved me was writing papers. I would have flunked every seminar if it hadn't been for term papers. And leading the groups enabled me eventually to be talkative in small groups.” (21-01-00)

“It started with her. There were so many people. It made me awfully nervous, to be around so many people. But I continued with it for a while. Then I started....Well, K wanted to attend a co-leaders' meeting at Columbiere and she wanted me to go along because she didn't wanta go by herself so she said you're my co-leader. At first I was terrified. What am I gonna have to do? And she said you don't have to do anything. And I thought, well, it would be interesting. UH HUH. WHY WERE YOU TERRIFIED AT FIRST? WHAT WAS SCARY ABOUT IT? Well, what would I have to do? Making contacts and such, you know. Starting my own group, and I thought I can't do that. I could probably, I wouldn't know how to begin. Nobody comes here, you

know. And I don't know if I could be consistent, you know. And lead people and stuff, I am no good at that." (28-01-15)

"And she said, "Yes, you can, here, I'll show you how." So she's gotten me doing some projects and some art work and everything. **And that fear, that subconscious fear, it's all gone. It's all gone.** I've been working on projects and doing paintings and loom weaving and we're gonna start on Christmas ornaments and that thought is completely erased from my mind. It's all gone so I'm very happy about it." (29-02-02)

"Well, the voices, **the hallucinations. Nerves, everything. Because when I do the volunteer work, I get really nervous, you know.**" (32-02-13)

"...get out and meet more people and tell them my story and **tell them how hard it was for me to get started. I remember going down the halls of St. Joe's and just crying because I was so confused. I wasn't sure if I was on the right floor or not and I was a messenger at the time and one time a social worker came up to me and asked me if I was okay and I told her yes. And I was just going, get myself together, either in the chapel or else in the bathroom and then I was able to go ahead and do my job.** And since then, I've been promoted to a dispatcher and I have five people under me now and so that's working really well. But the beginning days were really difficult....And I was wondering why these people didn't wanta take this challenge to overcome the difficulty of the new beginnings of their lives, wherever it may lead them. You know, whether it was writing or an artist or, you know, going back to school or volunteering or doing something with themselves. It was a big question mark in my mind. I don't know if it was because of my age or if I was just that much of a fighter." (35-01-00)

"**I was afraid. I didn't think I could do it but I could see that I can do it.** WHAT ABOUT IT SCARED YOU? Well, because I thought I wouldn't be able to come up with the right answers to any problem that came up. But I'm past that. I believe I give good answers." (38-01-38)

"It's an opportunity to take the initiative to heal yourself. And in the same way, Schizophrenics Anonymous is a self-support group, which invites you to **step out on your own and overcome your difficulties regardless of the discomfort, the suffering, the headaches, the failures, the setbacks. And to fight loneliness and I guess that's what I have to say about that.**" (41-01-40)

"**But I thought I don't wanta do this but, you know, I have to push and make myself do it.** It's just like I feel, what do you call it? Paralyzed, you know, in my mind. I don't wanta do my housework but I got these things. And I have agoraphobia, I've had it worse. I've been pushing myself and I feel like... I don't know if you want to hear this right now but I could push myself

like right now.” (44-02-38)

Phase 4: Enhanced Well-Being and Quality of Life (N=32, 69%)

I. FORMING A POSITIVE SENSE OF SELF (N=23, 50%)

A. Regaining a sense of value and worth (N=20, 43%).

1) Gaining self confidence and self esteem (N=14, 30%)

“That **I could achieve things I thought I couldn't**. That I could stay the entire program which was physically demanding. Pull through with a good heart and a good mind. Like an exercise program. I thought I was dying out there, my muscles aching and everything. I thought I wasn't gonna make it that night but the next day, there I am, you know and I am ready to go” (02-02-11)

“I look at people like my therapist or staff here, especially Jim. He has taught me to grow so much. By being confident in me, so that **I learn that I can do more than I ever thought I could do**. Even though I don't work any more, he helps me to learn that **I have still value** even though it's not in a job per se. It's value to the people here. It gives something and I try to give to them everyday. Every single day. I owe them that.” (05-01-11.1)

“I feel a lot better since I was doing the SA groups. **More confidence**.” (06-01-04)

“But at the same time, it gives me **self esteem to be in a leadership position**.” (08-01-02.1)

“From one of the talks that I did. So they wrote me up a letter and that **made me feel good**. I ended up getting Laura's home phone number. That was kind of exciting, too, **like an accomplishment, you know. It just made me feel good that she felt comfortable enough in giving me her home telephone number. ...Proves I'm no dummy, you know? I think that's one thing that I wanted to prove to myself, that I could do something.**...You know, what the hell am I gonna do? You know, and I finally was able to buckle down and complete school and then be medication compliant. And that was a big step towards my recovery, making those two things. And I could relate and seek therapy, saying you know, I'm not this stupid person or incompetent or whatever. I can do this. It was because of my illness that I wasn't able to do this. Instead of blaming myself I could say it was the illness and not me because I had accomplished something. So that was big stuff.” (11-01-03)

“Well, it's made **me feel better about myself** and made me feel like I'm not

alone. Like the step says, I need help.“ (19-02-13)

“And it was really good for my self esteem to be a leader and my goal for starting a group was to help at least one other person accomplish what I had accomplished in spite of my mental illness.” (20-01-00)

“You know, I think they feel comfortable that they have a limitation, they can't handle a full time job but they're still a worthwhile person. And I think people that come to SA see that over time. They feel better, their self esteem. You know, I think it really affects their self esteem. It has mine. It has mine, and I've been one of the blessed ones. But I felt immediately I was not ashamed. I just was... I looked at life totally different. ...I'm not such a bad person, you know, that's what they were saying to themselves. It's a no-fault illness, too. A lot of them thought it was a weakness of character, like I did. I just, why did I have this weakness of character and I couldn't overcome this terrible sickness.” (23-01-00)

“... to believe in myself more....I'm more confident.” (24-02-10)

“Well, we all took turns telling about our high school years and when we first found out we had mental illness. And the first time I went, I started feeling a little bit better about myself. But I was kind of hesitant, you know? ...Yeah, cause the more I talk about it, the more I start liking myself ...it makes me feel good. My self esteem is getting up. And I talk anyways but, about other things but I never talk about my feelings, about what's going on with me or nothing. I learned not to hold my feelings in. And it helps me out with my self-esteem because George will say well, L, you look pretty today. You know, and I try my best to keep myself well groomed and that. I used to have trouble with that....When I come out of group, I feel, you know like I could take the whole world on. Because it makes me feel so good, you know?...Since I've been coming to the group, I haven't been down. I see that other people have the same thing and then I don't really feel that depressed.” (26-02-14)

“It makes you feel better, you know.” (28-01-15)

“And just by coming and, people talking, it helps an awful lot. It brings out a lot in you. It's brought out talent in me. Things I thought I couldn't do, I tell her I can't do this and she says, well, I'll show you how. And now instead, if someone says can you do this, I don't say I can't. I say will you please show me how. And that has helped me a great deal....What can I do with these hands? I never knew what I could do with these hands, you know? So I came here and then Mary got me started on things and she said, "Yes you do have hands." And she said, "Can you do this?" And I said, "No, I can't do that." And she said, "Yes, you can, here, I'll show you how." So she's gotten me doing some projects and some art work and everything. And

that fear, that subconscious fear, it's all gone. It's all gone. I've been working on projects and doing paintings and loom weaving and we're gonna start on Christmas ornaments and that thought is completely erased from my mind. It's all gone so I'm very happy about it." (29-02-02)

"... I started helping with retreats and I helped organize retreats and they gave me some confidence because I was talking to people directly and my confidence was growing because of all the experiences I was having with SA. And even though I did have one setback after I got my masters, I thought well, I have my masters degree and I'm working full time. I'm leading a group. I wonder if I really have schizophrenia." (35-01-00)

"They'll build you, we build one another up, you know. That kind of support." (44-02-38)

2) Identifying ones' inner strength (N=5, 11%).

"I admit that I, as a 22 year old woman am a lot stronger than any other 22 year old woman I have ever met...The things that I have now, and the way that I am now, I'm a very strong person." (10-01-10)

"I'm stronger for it, because of my insight in my own illness, I look at her and I see me. The way I was. And even though I know it's not so called schizophrenia, it's dementia and Alzheimer's. It um, I can deal with it. I know not to pressure her. That she really believes what she's thinking. And how to handle that and just tell her, reassure her." (23-01-00)

"I have inner strength that I never knew I had. Yeah. Well, sometimes I did know I did have it. Yeah, I have this inner strength." (28-01-15)

"Well, it made me realize that some people are better off and aren't as well off. And it put things in perspective for me a little bit. And it made me realize that if you're a strong person, you can go ahead and achieve whatever you need to achieve. Like cause I saw Laura and stuff and all the turmoil she went through. And so with just knowing that you can get through it and you can push working and living and having a family, having a house." (35-01-00)

"Helped me get stronger, function through other things, to move on. I told you I learned in cooking. I kept my job for almost two years now and Sarah says all right. You're working. We're so proud of you. A big clap, that's encouraging, that makes me want to go further. You get positive feedback from others and yourself. And even if I don't get my reinforcement from others, I just go ahead like positively because whatever I do, I do for me. And not to please or impress anybody else. Is that fine? I've been through a lot of difficult times, but I never gave up. It was rough. Oh, there were times when I would cry, I'd get emotional."

My mom shielded my illness from my family because she was worried about what they'd think. She was worried that they might be judgmental, judge, you know what I mean. Less tolerant, that stuff. So she thought it was in my best interest to shield it but she was always there for me. But there were times when I wanted to figure out and solve some problems on my own, and she was hard to tell at that time. **But then I did manage to solve some things myself. I learned to get quicker, learned to face my peers better.**" (49-02-04)

c) Regaining a sense of value and worth (N=5, 11%).

"I look at people like my therapist or staff here, especially JW. He has taught me to grow so much. By being confident in me, so that I learn that I can do more than I ever thought I could do. Even though I don't work any more, **he helps me to learn that I have still value even though it's not in a job per se. It's value to the people here.** It gives something and I try to give to them everyday. Every single day. I owe them that." (05-01-11.1)

"One thing I like about him is he comes to me for questions and answers. He just doesn't answer them all by himself. He'll say well, what do you think? You know, and not a lot of people do that to me anymore. **Makes me feel important.**" (35-01-00)

"Perhaps I could say what Ken says often. And I think it's one of his ideas that being mentally ill does give you an appreciation for the lives of other people. You know, it shows you that nobody is perfect and that there, maybe you have, you know, there have been a lot of surprising, worthwhile people, outstanding people who have had schizophrenia, like Abraham Lincoln was supposed to have been schizophrenic. Einstein a queer and there are lots of them. Edison was eccentric. **People are worth something nobody what their condition. And if you have a mental illness, that doesn't mean that you can't be productive or make life worthwhile. While there's life, there's hope.** And one thing that recovery people say often because Dr. Lowe said it, you may be helpless sometimes but you are never hopeless. I do believe that perhaps mental illness has helped me because it has given me time to think. If that doesn't seem like a strange statement." (41-01-40)

"But you can get it to a point where you can function semi, you know, good. I mean, it's normal for somebody to have good days and bad days. **No, I figure if people can't accept me for who I am, then they're just not worth being, you know, friends with.**" (45-02-38)

"Uh, **not only do I get help, but A has made it clear that she counts on my point of view at times in order to shore up the others,** believe it or not. When I am clear I can do this, but it is very hard for me to accept compliments. You can put that in there. But people have told me, P nobody

gets compliments like you do, you better appreciate itNot only that but A always gets me to read it if I am there because I am able to read, announce, and look at people all at the same time. I enjoy doing that for people. I am able to pronounce longer words than they are sometimes....Uh, I, there is always I can count on, they're giving me 100% carte blanche and it is not blaisy it is appreciated. Feeling that I am popular and you tell me that I am doing good and boy that is like gravy on the mashed potatoes. And it, I love to hear it, I don't admit it to too many people, but I love to hear, boy are you smart. Or you really helped me by saying this or that. But on the other hand I want to get into the common realm, not that they are common but the common things between us. In other words, what can I say, I don't want to be too out in left field, too esoteric, too hiding behind books, instead of socializing and I have done that from time to time. ...the guilt, like I wasted part of myself. I didn't but if I looked at it on a pretentious basis, I don't think I could handle a concept or... a close part, **I think, in every day is to prove to myself that I'm a worthwhile person.** I have to do that." (48-02-16)

B. Forgiving ones' self and others (N=5, 11%).

"Just being in the service. I felt shameful because I wasn't able to go through boot camp in the right amount of time. I wasn't able to complete schooling It's just like now you're another failure upon a failure. I was able to release some of those feelings and you know, forgive myself and release everybody that has harmed me or injured me in anyway. So it was very beneficial for me....There's a wonderful therapist that I had up at the VA and one of the first things she told me is that it's not your fault. You know, there's nothing you could have done and it wasn't the fault of your parents. I had heard that but you know, it kind of went in one ear and out the other. I kind of half believed her. And this group reinforced a lot of the things that she told me. So I started paying attention, you know, more so the second time around and plus I was in kind of "lala land" when I was seeing her....But as far as, knocking myself over not completing school at Ferris State and stuff like that, to forgive myself, that was the most important step for me." (11-01-03)

"It makes me realize that what I've done may be wrong, but it's not unforgivable. I hope it's not anyway. " (14-02-11.1)

"My favorite one is forgiveness. That it really helps to relieve the burden if you can forgive yourself, especially yourself and others." (20-01-00)

"Yes, there have been a few difficult times. Because sometimes the doctor will put you on medicine, a certain medicine, and you'll have mood swings. With the medicine, they have to do this to get the right dosage, so they'll take you down and then take you up to get you the right level to level you off. I have to be understanding because sometimes someone will make a statement that doesn't make sense or maybe will say, oh, you have enemies or something

demeaning. I just have to understand this person, **we are forgiving, we forgive one another** because we know we're going through this medical... it's like a medical experiment to get you on the right doses. It's not really an experiment, it's just trying to get you on the right level. And it's hard, it was hard for me to understand it at first but I'm beginning to understand more. That's the hardest thing for me to understand. That was the hardest thing, until I figured out about the medicine, going, he must have been at a low level or she must have been at a low level and that's why she said that because I'm a sensitive person....caused a lot of friction between us. A lot of friction, a lot of lies, a lot of deception. I forgive everything, I keep forgiving and I think, I just can't do it. I'm afraid I'm gonna lose my daughter's love now." (29-02-02)

"She felt so bad for the way she treated me for many years because my parents never explained to her my illness. She didn't understand or relate to where I was coming from. So she said do you wonder why I was that way with you and therefore forgive me. **So I wrote her a letter back and said I forgive you. That was best.**" (49-02-04)

C. Recognizing that one has grown as a result of their experience (N=12, 26%)

"Before when I was a kid and not having any really bad symptoms, if I saw somebody who really looked, stood out, I might giggle like the rest of the kids. Now, I would have compassion for the person. You know what I mean? People, some people come to the group. Here's a...a person. And when I was helping Ken write something in one of the booklets, I said that having a mental illness is something like an advanced course, a graduate course in humanity or something like that. I don't remember. You know?" (07-01-05)

"Yes, it did. It made me more human, too. Humane and more human because when I hear someone talk about their experiences, no matter how ugly, and believe me, with mental illness, it can get as ugly as you can imagine, you're dealing with heaven and hell, and it made me really I have compassion and I have empathy. And I know how deep the pain goes." (08-01-02.1)

"Also, I think that the illness and the traumas I have gone through helped me to be a nice person." (10-01-10)

"Well, I definitely learned a lot about myself. I think I'm more tolerant of people. You know, because I...GROW AS A PERSON? Well, I think I'm more compassionate. I can sympathize a lot easier than what I could have before." (11-01-03)

"I have a lot more respect for people. I seem to know how to keep my relationships straight." (14-02-11.1)

“It (having a mental illness) has made me **more compassionate** towards other people, **understanding**.” (20-01-00)

“I think I was kind of a compassionate sort of fellow before **but it forced me to spend a lot of time more on compassion**. I was more, **it got me to the person to person level**. I was really in the macro level in Lansing.” (21-01-00)

“...**I am more compassionate. I have more sensitivity**. I stop to smell the roses. I appreciate the little things and I am satisfied with the little things in life. I appreciate having a granddaughter. It gives me a sense of what life is all about, family. I still don't cook.” (23-01-00)

“I think I'm **more understanding and tolerant of other people** and their idiosyncrasies I guess.” (28-01-15)

“... it's (having a mental illness) opened doors for me. Intellectually, I'm not ignorant anymore. **I have more understanding, especially for people with illnesses**. I can relate to them. **I have more compassion** for them. And it's just all around, it's just been really awesome, I could say.” (29-02-02)

“I think it's helped me be **more caring and have more of an open mind about people and what they're going through**, you know? **More compassion**. Because you never know what people are going through until you really talk to them and that's what the people at Schizophrenics Anonymous do. They open up and talk, most of them. Not the new ones but the ones that have been there...**I've become more compassionate**.” (33-02-05)

“Being accepted. I've already said that. The acceptance. The.. so far, like I say, I'm just new in it. Non-judgmental, you know. Just like they, I know they're humans, **other people but it's just something that's from inside is the way I feel for other people**. I'm older, I know, I'm probably the oldest one there. **But it's just the compassion that they feel cause they know, like myself, that I feel it myself and I can see it in them, you know**. ...And so it's been a blessing, that way. But it's helped me, I think I'm too critical of other... **I think I used to be too critical of others. I thought there wasn't anything that I couldn't do if I applied myself. And I would look at other people, think get up off your ass, you know. You can do it. What's the matter with you? If I can do it, you can do it. But it's making me, the sensitive side, we're not all the same. You know, we're all different. We all have different lives. We have a right to that different life and to judge other people, I feel, guilty**.” (44-02-38)

II. Developing a new way of approaching life (N=16, 35%)

A. Focusing on the positive (N=9, 20%).

"I sort of just accept things I can't change. No things that I would like changed." (15-01-13)

"I choose to think the good things....perspective, coming from a person that has the illness. And I tell them I always thought of my illness as devastating and as a defeat and now, like step number one, I admit I need help. I can't do it alone. And I accept it as a challenge. And what do you do with challenges? You overcome them. **And that's what I tried to do with the steps, put it in a positive mode. You know, positive. And try and end every meeting with a positive feeling."** (23-01-00)

"Can't worry about things we can't change. That we each of us have inside of us, resources and SA can help tap into them...." (28-01-15)

"...really, I have forgot my past. I'm more focused on my present and future now. This gives me hope. Like I said, I don't doubt my medications. I want to enjoy everyday of my life and I look forward to the future, making goals for myself now. **THAT YOU'D LIKE TO SHARE?** Well, I wouldn't miss it no more for nothing. **I think the thing I learned from it especially is how to rebuild my whole life and make it positive instead of negative."** (30-02-02)

"...one I chose the most was I choose, I choose to be well. Because making choices is really up to you. And if you don't make the choices to be well and be positive, then you won't overcome anything." (35-01-00)

"...the causes of schizophrenia and what we should do. And acceptance of it and that you need to take your medication, and how their response is to it. And you just try to stay away from the negative. When somebody's negative, (inaudible) like that, that's negative. You don't have to look at it as being crazy. It's just that, you know, a problem that you have to deal with. I talked about that and ... **PRAYING BECAUSE THAT'S A BIG THING. Do more positive things. Doing positive things.** I like to sing. I find myself singing to the radio, even when it's off, I'll be LaLaLaLa, and that's bad too, isn't it? So I've been singing, I love to sing. I dance, it puts me in a good mood. **And try to do positive things** and my family helps a lot because my sister, the other day I went job hunting..." (36-02-04)

"Well, that's a good, I wish a lot of things were different. But there's only so, you know, so far you can go to change things. UH HUH. One at a time. So I would wish a lot of things were different but how they, how they, how I see them is important." (37-02-04)

“Everybody, I mean, most people feel like I'm friendly but I, you know, trying to think of something nice to say. Look for something nice and you usually can find something. You know, cause I don't like to argue. ...You know. That I'm not stupid and I know I'm not stupid. You know, I know I've been, I've done, used poor judgment, very, very poor judgment in my life because I had such a big heart, you know. And trusted people. **And that's okay. It's in the past. This is today, right?**” (44-02-38)

“Right. What kept me going? YEAH. I tried, **I believed that each day is a new day.** I wanted to socialize. I've been nice...do know a lot about life, you know. Because I didn't wanta be judged as a loser so I was a fighter, like my mom said, and I just kept on going. I rose above it and I fought it, because I don't like to be put down. I don't like people putting me down. I have no tolerance for that. **That's why I keep on going, strive for the positive.**” (49-02-04)

B. Choosing to be well: Focus on health and healthy lifestyle (N=7, 15%).

“You know, I can't remember what the philosophy is right now, but to me the most important beliefs are, **wanting to be well**, having some power over your illness...” (08-01-02.1)

“**You know, cause I don't smoke, I don't drink, I try to get 8 hours of sleep a night. You know, I try to do the things that are healthy** for me so I think I've come to a point where it's not so much getting something out of it, it's returning.” (11-01-03)

“Well, because we do have the power to take our medication or not take it. Or to abuse alcohol or substance. We have **choices that can help us to maintain a healthy lifestyle.**” (20-01-00)

“Like MDDA just has rap sessions. **I wanted to focus mostly on recovery. Not just the illness. Don't dwell on the illness, but just as it pertained to getting better.** So I adapted the, I went to a couple of AA meetings...” (23-01-00)

“The one, I can't remember them all, the God in my life, you know. **I choose to be well** and that kind of stuff. We would all prefer to be well you know. **It is a choice kind of, taking medication and doing what the doctor says. Work on your inner growth and stuff.**” (28-01-15)

“...tell what the symptoms were, and I realized yes, I do need help. **I do choose to be well and I want to be a happy...**” (29-02-02)

“...one I chose the most was I choose, **I choose to be well. Because making**

choices is really up to you. And if you don't make the choices to be well and be positive, then you won't overcome anything.” (35-01-00)

C. Learning to value everyday life and all people (N=5, 11%).

“It taught me to **count my blessings** more than I used to.” (03-02-11.1)

“They're, I think you **learn to appreciate the small things in life**. And just a nice day without depression or a delusion, you know...that not, nothing against the kids, but the mentally ill can appreciate the smallest, not expensive, materialistic type of thing as a blessing. ...I am more compassionate. I have more sensitivity. I stop to smell the roses. **I appreciate the little things and I am satisfied with the little things in life**. I appreciate having a granddaughter. It gives me a sense of what life is all about, family. I still don't cook.” (23-01-00)

“I want to **enjoy everyday of my life** and I look forward to the future, making goals for myself now.... So, with the illness I have now, like I said before, I don't know how to explain it. Until God calls me, when my number comes up, I realize now you've got to find some way to enjoy everyday and the future. Right now, **I'm a lot more content than I was in my whole life**. I realize what I did, I did a lot of accomplishments. A lot of things worked out. And maybe like I said, my last step is to get a part time job. After that, I can take a deep breath. And like I said before, just enjoy everyday of my life until my number comes up.” (30-02-02)

“Yes. I'm a better person. (K interrupted) I care about people more. I have more respect for life....But mainly, it's made me a better person. You know, I got off the fast track and got really down to earth and didn't think about, I wanted to make a million dollars by the time I was 30. Now I've kinda forgotten about that. **And I just enjoy life now**. UH HUH. I told one person if I couldn't be chief executive officer, I wasn't gonna do anything. And just recently, that's when I was sick, just recently I'm saying to myself, hey, I'm gonna get out there and do more. So I think I'm coming around to another phase again.” (35-01-00)

“Perhaps I could say what Ken says often. And I think it's one of his ideas that being mentally ill **does give you an appreciation for the lives of other people**. You know, it shows you that nobody is perfect and that there, maybe you have, you know, there have been a lot of surprising, worthwhile people, outstanding people who have had schizophrenia, like Abraham Lincoln was supposed to have been schizophrenic.... Edison was eccentric. People are worth something nobody what their condition. And if you have a mental illness, that doesn't mean that you can't be productive or make life worthwhile. While there's life, there's hope. And one thing that recovery people say often because Dr. Lowe said it, you may be helpless sometimes but you are never

hopeless. I do believe that perhaps mental illness has helped me because it has given me time to think. If that doesn't seem like a strange statement. ...they're understanding about my situation. You know, I'm not making a case for anybody who wants pity because mentally ill... I mean, I've just had a very happy, fortunate life.” (41-01-40)

III. ACCOMPLISHING VALUED GOALS (N=11, 24%)

“And I actually find, you find, a way of expressing myself so that I feel that I did something, like I accomplished... hey, I climbed this mountain and who's gonna say they did that, you know. There might be someone who did better but, and I would say you know, oh, man. Maybe he is better. But I'm saying I feel like I can accomplish something. That's something I can hold onto no matter what, as a principle that Guides me, an improvement.” (02-02-11)

“I own my own house, I have 2 nice cars, I have a little boy who is just the most wonderful child I have ever met.” (10-01-10)

“I knew what SA was, of course, because I had it and I saw these posters hanging up in the drop in center about the meeting so I thought I'd give it a try because I felt isolated and I was nowhere what I was today. I was very shy and very reserved to say the least. Shy wasn't even the word for it, I was just wasn't very talkative. It took a lot for me to learn to talk to women. It was a big deal, you know because of things that have happened in the past with my older sister. I was paranoid and my social skills were very poor too. So that's one of the things that I was looking for in SA, was to overcome that. I knew I had a problem in that area so I started going down to the drop in, just to make friends and associate with people and things of that nature....paid for it or the state paid for it or whatever. But anyways, I got to attend these classes and I thought it would be healthy for me just to be able to get up and, you know, go one step further from talking on a one on one to being able to talk in front of people. And that was a big step for me. I always wanted to get some leadership skills that I didn't get in the service. That was another reason why I wanted to participate in this...SA? From one of the talks that I did. So they wrote me up a letter and that made me feel good. I ended up getting Laura's home phone number. That was kind of exciting, too, like an accomplishment, you know. It just made me feel good that she felt comfortable enough in giving me her home telephone number. I like the easy-going-ness of meetings...Then about a year later, me and Janie started going out and that was a big step. So I gradually built myself up over the years, you know....about the days in college and how I felt. They introduced me as having a girlfriend and having a college degree which I completed....homeless and lose this. This is what I have worked for all my life, to have something like this. TO HAVE YOUR HOME? Yeah. You know, and it's not a mansion but hey, it's home. I can

put my feet up on the table if I want to, if Janie don't yell at me. I can do what I wanta do, you know? ...Honor Society. Proves I'm no dummy, you know? I think that's one thing that I wanted to prove to myself, that I could do something." (11-01-03)

"Well, I was sitting at a table with Sean and he came along and sat down and I started talking to him. Ten years ago, I would never have been able to do that. REALLY? When I was a kid, I was so shy and afraid and I was worse in high school and became ill when I was 17. I really never started going out with anybody til I was 30. SO WHAT IS IT THAT GOT YOU TO THAT POINT OF BEING ABLE TO TALK MORE TO PEOPLE OR FEELING MORE COMFORTABLE WITH THAT? WHAT DO YOU THINK CONTRIBUTED TO THAT? Going to the meetings. Trying to say things to people to help them out and learning from other people's experience." (13-01-15)

"I'm better off than I used to be but **at least I've got a car**. I sort of felt helpless, you know. That's, by definition, **an American's gotta have a car**. My parents are helping the best they can. I kept my job but I haven't got advanced any. I'm still just dish washing. That's pretty frustrating. The thing is my job, I don't know. It seems like the job's going nowhere but I haven't been fired. And I read a contract, you can get fired for any old reason. I mean, I'm pushing myself harder. I wasn't trying as hard early on." (18-02-16)

"I guess, I feel that **I have accomplished my first goal and that was to help other people**." (20-01-00)

"**I've got a car now**. I was four years without a car and now I've got a nice car payment to pay. But I like having the car because I can be very independent that way...an A+ student while I was there. But due to the illness and not having my medication, other than helping others I would say my whole life, my career is gone." (29-02-02)

"...group but I didn't have a lot to say when I went because I felt like it would be bragging to say oh, I'm doing great. You know, and I've got this new apartment and everything. Half the people there don't even have cars. I just felt like that would be bragging if I went and talked about how good I was doing. So I would just go to the Burger King...There's a lot of healing that takes place and that's nice to see. The biggest thing that I got out of all of it was Steve, to tell you the truth. **It was meeting Steve because I had been wanting to meet a boyfriend**. So when I met him, it...HIM...Oh, his sense of humor. He had a sense of humor like I did. I mean, I'm not as much of a bad boy as he is. And we had mutual understanding. We immediately connected. He's intelligent. He knows a lot about history and he can talk to me about it. It's very interesting. And it's like having my own SA group, you know, just him and me. We have our own little group. We gave each other a lot of

support over the years.” (33-02-05)

“...get out and meet more people and tell them my story and tell them how hard it was for me to get started. I remember going down the halls of St. Joe's and just crying because I was so confused. I wasn't sure if I was on the right floor or not and I was a messenger at the time and one time a social worker came up to me and asked me if I was okay and I told her yes. And I was just going, get myself together, either in the chapel or else in the bathroom and then I was able to go ahead and do my job. And since then, I've been promoted to a dispatcher and I have five people under me now and so that's working really well. But the beginning days were really difficult. And I was wondering why these people...in the office. More the business end of things. You gotta be educated enough about mental illness to be competent in the area. So that's why I've been going to Madonna, to get my degree. So I can say I have a degree in mental health. I have a masters in communication and I have a minor in business. So hopefully down the road where I wanta go is where all this has led me and everyone seems to think I would be good would be in the business end of mental health. ...AN IMPORTANT THING. Oh, yeah. Had to do with the same theme of people not wanting to go off SA, not wanting to go off disability. I wanted people to try. I wanted somebody to try with me, I think. And it was like fighting a battle on my own. I couldn't find anyone who was fighting a battle except for Kathy and she had two diseases. And so I became friends with her because she was fighting. And I wanted someone that would fight with me, to help me overcome this illness. So I could lead a normal life again. And that was very important to me....YOU WERE ABLE TO SUSTAIN YOURSELF ON THAT AMOUNT? I ended up moving home and my parents gave me food and shelter and they said you pay off all your bills, don't worry about rent, and just get through this. **And as time went on, I got insurance, with full time benefits and I was a full time employee in food service. And after that had happened, I really started my recovery. That's when I really started my recovery, wasn't before that. That's when I was able to afford a new car so I went out and bought a little Ford Escort. And it was only \$6000 so... The manager of the food service liked me so she gave me full time hours even though I was part time. So within a couple weeks, she made ...EXPERIENCE WITH BEING A LEADER OF AN SA GROUP?** I think I helped a lot of people. I know I've helped a lot of people. **And a lot of people have helped me in return. And I've done. And I got a lot of good feedback from the community, helping people out. People in my home town that knew of my illness or whatever. They would call and ask me for advice and a doctor to see or what to do and I felt really good about that.** And some of the people I just referred to doctors and so I was like a reference for people....AND WHAT ARE YOUR RELATIONSHIPS LIKE WITH THEM? My husband is the most important person in my life. We have a very good relationship. I can tell him anything or say anything and he's understanding and kind and generous and loving. If he loses his temper, he apologizes.” (35-01-00)

"I am one of their success stories. On the other hand, it wasn't until I got to the Clausaril draw, to Lifeways, and to SA that I had such a **long running job.**" (48-02-16)

"That's how I got involved. So I gave it a shot and kept an open mind, see how it goes and I feel I've benefited already because I've been repeating myself after we read articles again, like I'm better now, I don't hear voices anymore. I seldom see things in my mind. **I'm able to work. I have held my job at Big Lots for along time. All part of being stable and normal. So I'm still working at Big Lots and I'm gonna still continue to work there.** And I feel I was ready in my bedroom. And I was the winner out of all the workers there at the, at my job. CONGRATULATIONS. Thank you. WELL, YOU'LL HAVE TO SHOW ME THAT ONE WHEN YOU SHOW ME THE CERTIFICATEFROM Sarah. Yeah. Sure will. OKAY. I'll show you before I leave. OKAY. Two certificates, schizophrenics anonymous and certificate of appreciation from my work effort." (49-02-04)

IV. FINDING MEANING AND PURPOSE (N=16, 35%)

"Does that make sense to you? It makes me feel like **I've got something to give back to a system that's given to me. And it does definitely give me a purpose.** I need the people there as much as they need me. It is kind of a mutual thing." (05-01-11.1)

"Well, when I started leading the groups, then I began feeling better about myself. **I think God made me schizophrenic to help people.**" (06-01-04)

"**I'm able to give them advice, they're able to give me advice.** And believe me, I put out a little bit of effort every week, carrying a box full of coffee, instant stuff. I supply the cups. And being like a moderator. But otherwise, leading the group with a stop watch. I think I told you about that? YES. Everybody gets an equal share of time. I put out a little effort but I get repaid ten times over, you know? And I'm not in it for repayment, **I'm not in it for the awards or anything. But occasionally somebody will say something I might happen to overhear in the smoke break. Or some people just might say spontaneously.** Gee, I don't know what I'd do if I couldn't go to the group every week. That's worth more than all the plaques, you know. That's how I feel. **I've got people I can share with, who have got me over humps...** It's one of the few things I love in this life. **I like helping people.** They know they're getting help. Some people want everything laid out in front of them, but this way you have to work for it. That's about it I guess." (07-01-05)

“But at the same time, it gives me self esteem to be in a leadership position. I enjoy doing it and I guess the biggest thrill is like tonight we're expecting two new people. Whenever I know new people are coming, I get kinda excited because I like opening that door. **I love to be the one that says wow, you know, people are OK and they're mentally ill, you know? And I like having them leave and possibly feel comfortable, a little bit more comfortable with themselves.** To be able to look at themselves as a human being, not somebody who just doesn't deserve to be here.” (08-01-02.1)

“I volunteer for the SA meetings and I feel really good about that. I give them all individual help. I devote all my spare time to these people and this program because that's the kind of person I want to be. I want to be the kind of person that can help, that will help anybody. Somebody that will give up their own spare time to help others.” (10-01-10)

“Yeah, I was assertive because, I thought I had something to offer, you know? And you know, I wasn't from a poor family. I was from a good family. No marriage problems, just a good family so **I had something to offer, you know?... Well, I think I've come to a point where, I mean, I've been in SA for long enough now, I've worked hard at it where I don't think I'm gonna get a whole hell of a lot more out of it. It's just giving back that I'm more interested in.** You know, cause I don't smoke, I don't drink, I try to get 8 hours of sleep a night. **You know, I try to do the things that are healthy for me so I think I've come to a point where it's not so much getting something out of it, it's returning.”** (11-01-03)

“HOW DOES IT HELP A GROUP LIKE SA? Because it's the agenda, it's the agenda. It's the purpose. **SO COMING TOGETHER AS A GROUP GIVES YOU A PURPOSE? Yes. It's the purpose we convene every Tuesday.”** (15-01-13)

“And it was really good for my self esteem to be a leader and my goal for starting a group was to help at least one other person accomplish what I had accomplished in spite of my mental illness. So maybe that was not exactly SA philosophy but that was my goal and I thought by using SA I could help other people.” (20-01-00)

“Well, I got a lot of feedback from people, **how it helped and I felt it was worthwhile. It made me feel needed. I felt like, that I was helping other people and I think that's what we're all here for. To reach out and help other people...**“So I didn't have to speak a lot. **But SA has given me a purpose to my life so it changed my life.** It absolutely has changed my life. **I think when you stop focusing on yourself and your own problems and you start reaching out, and when you look at your blessings and how grateful.”** (23-01-00)

“You know, I know somebody's hurting, I can say something to them. That's really important to me, that I can say something to them and maybe help them. I can give them a few words of suggestion and they can decide if they want to accept it or not. But just being able to say something, and to help them....But due to the illness and not having my medication, other than helping others I would say my whole life, my career is gone.” (29-02-02)

“I find when I go to a meeting, maybe I need help that one day or somebody else will. It's my way, you know, of giving back. Plus I like everybody who comes.” (30-02-02)

“I think when you go to your therapist, you're expected to talk while he or she listens. But here, it's a give and take. You listen and you talk. And it's when you listen it's sort of like giving a gift to others. Probably they have family members that are sick of them.” (34-02-05)

“You know, I've learned that there's, I guess there's some kind, it gives me something that can be useful to me now, I can be helpful.” (39-02-38)

“So let's see, my involvement, I feel that I'm doing something with my life that's worthwhile and I've always wanted to be somebody who did something for others as well as for myself. I think that this is, has been the answer for quite some time...” (41-01-40)

“Just one word, life. That's it. Life, it's just, my life, I don't know what I'm doing here. I don't know what I'm even doing, sitting here because I have hope, I guess, Katie. I have hope that I can help. I can get my strength and help somebody.” (44-02-38)

“Uh, I am just thinking of one of my good friends. It was like 2 or 3 months ago and he was just furious with himself and we talked him down. It is almost like you don't even pay attention to yourself anymore. You are there for them. He felt better as soon as we got out of the meeting. It was just like that. WHAT SORT OF AN EFFECT DID THAT HAVE? It builds confidence in the group to be able to help like that.” (48-02-16)

“We would spend a whole afternoon that way and all we would be doing would be putting letters into envelopes and sealing them and stamping them and getting ready to mail. And I felt that that was important to me because I felt that I was beginning to believe that SA was giving me a profitable direction for my life. Which it has. You know...If I didn't have SA to go on, it might be very likely that I would be in the hospital again. I'd be hospitalized. I need to work on my recovery from the illness and I do believe that you need incentive to do that. You need some kind of motivation and SA gives me that. But I guess that's the answer to a lot of your questions. It's, that's what it does for me. That's what I think is important

to me about SA.” (41-01-40)

“And SA was, really kinda saved my life in a sense because I didn't have any direction and so very early on, I was beginning to think of ways where I could make contribution and the first way I could make a contribution was very small, which was making coffee and cleaning up the tables afterwards....Say in '92, it was hard dragging myself every week to those meetings. I was not feeling well and I still felt a sense of responsibility to show up. Oftentimes though, I'd be so uplifted by something cool going on say at the hospital or say I would be uplifted that some, some agency or group was working somebody in the Pontiac group and I would feel uplifted and I would feel like I was doing something really worth while. Like something cool was happening.... I have friends that I've made. It's saved my life a couple times. It's given me worthwhile things to do. I guess that's really a big factor. Big factor is giving me things, something worthwhile to do with my life at times when I was very down.” (21-01-00)

APPENDIX G

APPENDIX G

Within Case Narrative Summaries

#01-02-11.1

*Gene's Story

Gene is a 46 year old, white, Protestant, high school graduate who lives with his wife. They have owned the same home for over 4 years and he is extremely satisfied with his current living situation. He has four from a previous marriage who are grown and who do not currently live with him. His mother and a brother are other remaining family members. He reports being somewhat satisfied with his current level of social support and mostly satisfied with his current relationships. He is not currently working and last worked over 70 months ago, because of his psychiatric illness, but he volunteers working with kids on a frequent basis and engages in other meaningful activities such as writing and drawing. He is a little satisfied with how he spends his time. His spouse supports him and he reports being a little satisfied with this situation. He has only been hospitalized once in 1994, and he currently sees a therapist and a case manager for his medications. He is extremely satisfied with his current mental health treatment.

Gene describes how at 15 years old he had a hallucination that was a "watershed" experience, which has become a strong part of his belief system and what he believes about himself. In high school he describes feeling different and having some symptoms. However, after high school, he went to Vietnam, got married had a family and held down a job at a Federal Agency for 24 years. In 1977 he describes what he identifies as his first breakdown. He describes himself as being in denial during this period "I couldn't believe that I was mentally ill because I was trying to rule it out." He also describes how he did not seek treatment from mental health services at the time because of the stigma attached to mental health services. He describes how he lived in two worlds - the one of work and his family and the one consisting of his delusions. During this time he believed his inability to control his thoughts "was a flaw in [his] character". During the interview, he relives the pain of having absolutely no recollection of the first few years of his daughter's life because he was experiencing symptoms. During this time he volunteered working with kids which he describes as "the one thing in my entire life that I did almost entirely without pretending or being in a delusional world. It felt so purposeful and so good." It was after become involved with this volunteer activity that he and his wife decided to separate and he started seeking out and accepting help for the difficulties he was having. He started attending a support group, where he met his current wife, and receiving therapy. When he got married the second time, he quit the post office. Gene describes knowing that he was becoming schizophrenic because there was "something in me saying this is what's gonna happen to you and it's okay. And it's not gonna be bad. And so I felt okay about it before and then I started needing people." He also says that "I always seemed as though, felt as though I was being set up to become mentally ill" and "it felt like it was part of my nature to be crazy." Gene is the only participant who describes liking "being a schizophrenic" and "enjoying what I see, hear, and feel".

Gene recognizes that he experiences voices and delusions and that these experiences make him isolate himself more than is probably good for him. He started attending SA about 6 months prior to the interview and he describes the sense of belonging and feeling like he is not alone that he derives from the group as "...they talked like me, they understood. And it felt like I, instead of making me feel like I didn't belong anywhere, it made me feel like I was an exclusive member in an exclusive club." He recognizes how his illness makes him unable to hold down a job, has made his oldest daughter ostracize him, and caused his divorce from his previous wife. He also describes how his illness has helped him to discover that he has a number of strengths including drawing, story telling, writing, and spending time with kids. He also feels his illness has given him the ability to read significance into events and have more insight than "if I was normal." He describes his experience in SA as "it adds to all I feel about myself." Gene draws a lot of strength and feelings of positive sense of self, and meaning, and purpose from knowing that he can always be able to draw, write, tell stories, and do scout craft.

05-01-11.1

***Mary's Story**

Mary is a 44 year old, Protestant, high school graduate, who has never married and has no children. She has been living with a roommate, who she describes as very supportive in her own home for approximately one year. Both her parents are living and she describes them as being supportive. She is extremely satisfied with her social support and current relationships. She is extremely satisfied with her living situation. She is not currently working and has not worked for approximately 72 months because she cannot find another job. Prior to becoming ill she worked for 17 years at the same job, which she felt she was very good at. She supports herself by receiving Social Security Disability and reports being extremely satisfied with her financial situation. She is not currently volunteering or involved in any kind of school or training program. She does however attend religious services on a regular basis, a psychosocial clubhouse, and a drop-in center. She reports being mostly satisfied with how she spends her time overall.

Mary has been hospitalized 22 times between 1972-1996. She has a diagnosis of schizophrenia, takes medications, receives individual therapy, and medication management services. She has been seeing the same therapist for about 5 years and feels she is very, very good. She reports being mostly satisfied with her mental health treatment.

Mary was 16 years old when she had what she calls as her first hallucination or delusion and "...saw Christ." She recognizes that she experiences voices and that when she gets upset or stressed they get louder. She also acknowledges that she continually functions with the voices. She recognizes that her family treats her differently because of her illness - "my family treats me with kid gloves." She also describes how for years she felt worthless and like "nobody's going to have anything to do with me." During the course of the interview she actively mourned the loss of her job and expressed her anger at the illness for this loss "When you look back, it was ugly. This is an ugly illness. I gotta tell you, I hate it. I hate every day of it. I want my job back (crying). I had a loss. It's been a loss for a long time." Because she lost her job she feels that "[she's] not good at anything anymore."

Her doctors and therapist have taught her to "deal with my illness, instead of just letting it deal with me." She also has enough control not to cut herself with razor blades, which has been a problem in the past and has resulted in being hospitalized. She describes fighting back and knowing that she is strong enough not to give into the symptoms. She describes the importance of "taking responsibility for herself" and being an active participant in becoming and staying well. She also feels that she has learned to be more patient and tolerant of people who have trouble as a result of her illness. She feels that the mental health professionals that she has worked with have really believed in her which has taught her that "I can do more than I ever thought I could do. Even though I don't work anymore, [I] learn that I still have value even though it is not in a job per se." However, she also recognizes that she still has times when she feels sorry for herself and "gets real woe is me."

Mary has been a leader of an SA group for over 2 years and she feels that SA helps to change beliefs about schizophrenia and people who have schizophrenia. She states how it has been important for her to be able to tell her family that "it wasn't their fault. It wasn't anything they did. It wasn't anything I did." She feels that leading her group "helps me to give back to the system that has given to me." Leading and participating in the SA group gives Mary a sense of meaning and purpose in her life. She also feels drawn to the group because she "can share her own story and they understand." She has also surprised herself by being able to lead the group for such a long period of time, because she "didn't think she would be after two weeks."

*06-01-04

*Nancy's Story

Nancy is a 42 year old woman with a BA degree. She is Protestant and attends regular religious services. She has never married, does not have any children, and both of her parents are deceased. She has been living in a supervised apartment situation with another mental health consumer for a roommate for about 20 months. She reports "being blessed with a lot of friends" and that she is extremely satisfied with her social support and current relationships, but she reports only being somewhat satisfied with her living situation. She is last worked 3 months ago, but is currently not working because of her psychiatric illness. She spends most days doing volunteer work for SA, including running groups, public speaking, and helping with the organizational tasks and activities. She also attends church every Sunday. She reports being somewhat satisfied with her work or volunteer activities, but extremely satisfied with how she spends her time.

From 1978 to 1980 Nancy was a nursery school teacher. Then she was hospitalized 4 times between 1985-1991 and diagnosed with schizophrenia. She was on medications in 1985 and 1986 that made her like a zombie and in 1987 her dad and aunt died and she had a breakdown. Still in 1985 and 1987 she worked as both a bookkeeper and receptionist. In 1990, she moved into an AFC home. During this time, she was on prolixin for about 8 years before finally being put on clausaril. Nancy recognizes that schizophrenia interferes with her concentration and states that she "would like to be able to read again." She describes some ways that she tried to cope with her illness before getting on Clausaril which included singing Christian songs, sleeping a lot, and just staying in bed. She also describes her family's reaction to her illness as "they just wanted the old Nancy back" and "[they] kept on saying you've got to get better...my family just didn't understand." Her family's lack of understanding made her feel "bad" and "upset". Currently, she takes medication, sees a therapist, and participates in many facets of the SA organization to maintain and promote her recovery.

She became involved in SA in December of 1987 because a family member saw the leader of SA on a television program. It took her a few months, but she says that after a few months of going every week she loved it. She attributes getting better to attending SA and getting on a new medication, Clausaril. She defines her purpose in her life as "I think God made me schizophrenic to help people." Nancy describes feeling better about herself and having more confidence. She also describes learning to live with schizophrenia by not taking the voices literally and how she has come to believe that "it is a life-long thing" and "it's a chemical imbalance in the brain."

*07-01-05

*Joel's Story

Joel is a 48 year old man, who lives in his own apartment. His mother is still alive and he has a steady girlfriend. He reports being mostly satisfied with his current relationships and with his current level of support. He is not currently working, but he is a long-standing leader of a SA group and is sporadically involved in organizational activities of SA.

Joel had quite a few work and educational experiences prior to becoming ill between the years of 1966 and 1981. However, he describes himself as always eccentric and as an outsider who lacked social skills and the ability to connect with people. Starting after high school he had experience working in a grocery store, as a medical tech for the US army, and in a series of civil service jobs. He also got his BA degree in three years while maintaining a high GPA. Joel describes a turning point in his ability to function as occurring when he was working full time in a civil service job. He describes becoming overwhelmed by the background noise of the office, including ringing phones and typewriters. He describes it as if "someone flipped a chemical switch in my head and all of a sudden, the work in front of me became incomprehensible..." and that he "hasn't been the same since." During this time he tried to commit suicide by swallowing 72 pills. Although Joel describes it as if his "whole life shifted" his current therapist did not make much of it. Following this experience Joel was hospitalized for a physical illness and quit his job. After recuperating, he got another job and experienced a series of events related to his symptoms and the death of his father in 1980. Joel was hospitalized five times between 1981 and 1985. He describes this period as one of going in and out of hospitals because of his experience of symptoms. Finally, in 1985 he describes getting better.

Joel attributes this change to sheer will power. He describes telling himself that "I don't care how bad it gets, I don't care if I have to put duct tape over my mouth, I'm not going to say anything like that. If I have to sit in a chair with white knuckles, you know, gripping it, I'm not going to give into the symptoms. During the time between 1985 and 1987 he participated in a number of mental health settings. In 1986, he saw a psychiatrist who told him that "there's not a heck of a lot I can do for you...that I would never work again. I'd never have any friends so I'd be the way I was, alone for the rest of my life. And that I should just do things that were pleasing for myself." After reflecting on this advice Joel concludes that the doctor helped him stay true to himself by encouraging him to find his own interests and to do what he wants. He states how he doesn't currently have any friends, but that he doesn't want any friends. He also describes how he has discovered enjoying reading, writing, drawing, and watching movies. Although Joel described accepting the doctors advice, in 1987 the symptoms got so bad he decided to go to Canada to get access to a new medication. In 1987, he started to take the new medication and eventually found he was getting better and he was especially able to push the thoughts away and focus. After he started feeling better he tapped into his verbal abilities and wrote a movie review for a local paper. It was well received and led to a weekly column in the local newspaper. Then, in the Spring of 1987 he discovered SA.

Joel saw an article about SA in the local paper and clipped it out. After having it on his bulletin board for several months he eventually attended his first group. It is through attending the SA group and eventually becoming a leader that he has been able to achieve one of his life-long goals - finding a girlfriend. He has been dating the same woman for over seven years and is happy with the relationship. Although Joel has reached some of his goals, he still struggles with symptoms and is still trying to improve certain skills so that he does not stand out as much and attract negative attention. As he discovers different ways his illness impacts him, he continues to struggle with accepting those aspects of himself although he is not ashamed of accepting his mental illness.

08-01-00
"Joelle's Story"

Joelle is a 42-year old Caucasian woman, who rents an apartment with her husband and reports being somewhat satisfied with her current living situation. She finished high school and attended some college. She is Catholic. She has one grown child and her mother is still living. She reports being mostly satisfied with her current relationships and the amount of social support that she receives. She has been working full-time, up to 55 hours a week, in a competitive position for the last seven and a half years. She supports herself with income earned from her employment and additional support from her husband. She reports being mostly satisfied with her current financial situation and mostly satisfied with her current employment situation. She also reports being mostly satisfied with how she spends her time.

Joelle has been hospitalized a total of two times, the first time in 1977, when she was 22 years old and the last time in the spring of 1996, when she was 41 years old. She describes realizing that something was wrong when she was 22 years old. The radio and TV were talking to her and she was becoming very paranoid. She moved home with her mother because she had a two-year old son to take care of. After a series of events linked to her experience of schizophrenia, her mother had her hospitalized. After she got out of the hospital she moved into her own apartment with her son. She described this first year as a time when she "lived in psychosis" and the next ten years, from 1977 to 1987, as a time when she lived in denial and in and out of psychosis but still managed to live on her own, work and care for her son. She did all of this in a state of fear, hiding, and half reality. During this time she developed strategies to cope with and cover up her illness. She describes her deep love for her son and fear that she would lose him as what motivated her to try harder and to continue to maintain. She also describes him as her only link to reality during this time. Joelle describes this ten-year period as a time when she was maintaining, going back and forth between psychosis and being well and working, but not moving forward. Then, finally at about age 32, ten years after she was first hospitalized, she describes needing to find answers.

She started by trying to find out her diagnosis. After an encounter with an evasive psychiatrist, she eventually obtained her medical records and saw the diagnosis of schizophrenia. She immediately denied the diagnosis and began to search for ways to get it taken out of her medical history. This led her to having a conversation with a leader of SA and to her eventually attending a SA group.

The event identified by Joelle as really helping her to move forward from a place of confusion and just maintaining to an understanding of what it means to have schizophrenia was when she connected with SA. She describes how she felt after talking with a SA leader as "when everything settled down, made sense and started falling into place." She attributes this to the realization that there were other people who had similar experiences and a diagnosis of schizophrenia and yet were also whole people. She

describes this as the "beginning of my life...I didn't have to hide anymore....I didn't have to suppress my own personality. I could be whole and know that I could have a break and still recover and move on." Joelle describes this realization as key to her being able to accept herself and the illness and to view herself as a person with a mental illness, instead either as a person or as an illness.

Joelle attended a SA group for two years and when the group closed decided to start her own group in 1989. She decided to start her own group because she felt SA had really helped her and would continue to help her and she wanted others to have the same experience Joelle still leads her SA group, but feels it is more about helping others than about getting help herself. However, she does acknowledge that she derives a sense of meaning and purpose from running her group and helping others.

Prior to attending SA, Joelle describes her battle with trying to both understand what was wrong with her and hide what she was experiencing. She did not accept the diagnosis of schizophrenia because her beliefs about schizophrenia conflicted with her beliefs about herself. She believed that people with schizophrenia were always sick, they could not work or love, and they spend most of their lives in the hospital. However, she saw herself as having periods of both health and illness, as being capable of working and caring for her son and also as having occasional breakdowns. As she describes it she "wondered which one of these was true for me." At this point she was not sure how to see herself - as either being sick or well or "schizophrenic" or "normal" - she found that she did not fit into either category.

Joelle describes the most challenging aspects of the recovery process for her as overcoming the stereotypes and misconceptions about what it means to be "schizophrenic" and integrating schizophrenia and the associated experiences into her identity.

She currently has a diagnosis of schizophrenia for which she takes medications on a daily basis. Overall, Joelle reports being extremely satisfied with her mental health treatment. Sarah describes how prior to attending SA she did not have the chance to talk about her illness because her therapist was afraid to talk about it. She attributes this to the belief held by both mental health professionals and parents that if you talk about it you'll get sicker. She describes her mental health treatment over the years as sustaining her, but doing nothing for her recovery.

#10-01-10

*Anne's story

Anne is a 22 year old, high school graduate, who is not currently married but who lives with the father of her baby. Both of her parents are currently living. She has lived in an apartment for the last 2 years with her boyfriend and describes herself as extremely satisfied with her living situation. She last worked 2 years ago and describes herself as not currently working because of her psychiatric illness. She supports herself with Social Security Disability and reports being a little satisfied with her financial situation. She is not currently involved in school or other training programs, spends time volunteering as a group leader for SA, and spends the majority of time taking care of her son. She also attends religious services on a regular basis. She reports being extremely satisfied with the way that she spends her time.

Anne recalls knowing that there was something wrong with her when she was a small child. She describes knowing that she "was different from everybody else somehow" and how she was sexually molested and traumatized. She also describes herself as a worry wart and a perfectionist. At age 11 she received a diagnosis of manic depressive disorder and later at the age of 16 she received a diagnosis of schizophrenia disorder. She describes doing a lot of drugs during these early years and having very severe side effects from the psychiatric medications she was on. She recognizes how having a diagnosis at such a young age and looking weird because of the medication side effects impacted her peer relationships in school and set her apart from the other students and made her feel out of place. She also recognizes her need to get upset about her experiences of sexual abuse and that it is okay, and normal to react this way to trauma. She has been hospitalized 11 times between 1988 and 1995. She attributes these repeat hospitalizations to when she would "relapse back into a bad state of mind where I was trying to commit suicide more than once a day, everyday. She describes the hospital as a place to keep you safe from killing yourself, but that it is not really therapeutic. She currently receives individual therapy and is mostly satisfied with her mental health treatment. She started attending an SA group at the age of 18, and sometime during one of her hospitalizations the SA group she attended dissolved. Eventually she decided that she needed SA to stay well so she decided to start her own group. Although she was very nervous "shaking up a storm" she knew she had to overcome this fear because this is what she wanted to and had to do.

In SA, she found that she had things in common with other people and she got to learn about what it means to have schizophrenia. She also learned strategies to live with schizophrenia such as telling the difference between reality and what is going on in her head and what it means to be on SSD. She describes being able to tell the difference between reality and what happens in her head as when she really started to be able to cope with her illness. Prior to finding SA she describes being confused and alone with the illness and not knowing "why was I this way and how come and is there anybody else? Like maybe I was an alien or something." Attending SA and hearing about others get better and doing things like holding down a job also gave her a sense of hope. She has also come to realize that I [can] have setbacks and stuff nowadays, but I don't turn to

suicide." Currently, she describes herself as a lot stronger than most 22 year olds and as proud to own her own house, have cars, and a beautiful son. She feels like she has her feet firmly on the ground and that she knows what she needs to do to achieve her goals. She also feels that the traumas and the illness have made her a better person.

#11-01-03

***Jim's Story**

Jim is a white 33 year old who just bought a condominium with his girlfriend. Both his parents are living and he is extremely satisfied with his living situation, his social support, and his current relationships. He has a BA degree and has never married or had children. He also identifies himself as being a Catholic. He works 15 hours a week in competitive employment and supports himself with his wages, Social Security Disability, and subsidized housing assistance. He reports being somewhat satisfied with his current financial situation and his current work situation. He does not currently participate in a training or education program.

Jim describes noticing trouble concentrating in the first grade and the first time he experienced symptoms was in Junior High School. His parents sent him to see a psychiatrist at that time because he was having problems getting along with other kids. In his junior year in High School he recognized not wanting to take care of himself and starting to feel isolated. He has been hospitalized 2 times between 1984 and 1991. He currently has a diagnosis of schizophrenia and takes medication, receives therapy and medication management services. He reports being extremely happy with his current mental health treatment.

Early on, Jim refused to seek help with his problems even though his parents suggested that he go see a psychiatrist. He denied that he was having difficulties that he could not manage by himself. He recognizes how he lost friends from the illness and how people have discriminated against him in the workplace because of his mental illness. He recognizes now that he felt terribly alone and ashamed when he got a diagnosis of schizophrenia. He also recognizes that he felt ashamed because he wasn't able to complete boot camp or schooling in the "right amount of time." He started to attend SA in about early 1994, because he felt that he needed help and didn't want to live his life the way he had lived it in the past or at that moment. He also felt he needed to socialize more and become more outgoing. He also states that he "was looking to change my ways because I had very poor grooming skills". When he started attending a SA group he "didn't feel so isolated...like you are not alone. That was a big thing." Through his participation in SA he saw himself as gradually growing and changing as he started to "open up more and more" and started to do public speaking. SA in conjunction with his therapist taught him that the illness is not his or his parent's fault. So, he was also able to recognize the role of his illness in not being able to accomplish some of the things he set out to do and was able to forgive himself and others. He is currently working on completing additional schooling, which he states is "just for my own goals and satisfaction." Currently he leads his own SA group with his girlfriend who he met at the first SA group. Meeting a girlfriend and having an intimate relationship is a valued goal of Jims, which he was able to accomplish through SA. He feels that he has now become "normal" people and that he is no longer ashamed. He also feels that he has grown and learned a lot about himself through SA and that he is a much more tolerant and compassionate person.

#20-01-00
Sara's Story

Sara is 48 years old, White, has completed some college and describes herself as affiliated with no religion in particular. She is divorced with two adult children both of whom live independently. Both of her parents are living and she describes herself as mostly satisfied with her current social support and extremely satisfied with her current social relationships. She owns her own condominium and lives by herself. She reports being extremely satisfied with her current living situation. Sara has always worked for pay except during the time when she was married and a full time homemaker. She was laid off from her full-time job 8 months ago, so she is only working 8 hours a week. She reports being somewhat satisfied with her current work situation. She completely supports herself from her earned income and reports being extremely happy with her current financial situation. She does not attend religious services or any formal mental health treatment.

She has been hospitalized four times, has a diagnosis of schizophrenia, and takes psychiatric medication. She reports being extremely happy with her mental health treatment, which consists of taking medication. Sara attributes her recovery and being able to work to her will power and staying on medication. She describes how she didn't realize that she had a mental illness until she was in foster care 7 years after her first breakdown. She found out she had schizophrenia by reading about it in a pamphlet "and all the symptoms and everything" and realizing "that's me." She also read in the pamphlet that it can be controlled by medication and from that point forward she made a decision to never go off her medication. She has been on the same medication and the same dose since 1991. She describes the most difficult consequence of the illness as being her divorce and losing her children. She feels that the things that contribute to her being able to maintain are medication, SA, the recovery steps, fellowship, and leading a low-key life.

Sara decided to start a SA group because she felt that she "wasn't giving herself back to the community. And felt that it would be beneficial for me to do it as a volunteer." She describes recognizing in one of the meetings that the rude behavior of a member was "part of the illness" and learning that there are "varying degrees of the illness, that we're not alone, and that a set back doesn't mean that you're not successful, and that success has a lot of different meanings. She describes the SA steps that are most helpful to her is to forgive yourself and others and that you have full control over yourself. For her this means that you have choices and that you can make choices to maintain a healthy lifestyle. She also describes SA as providing her with a lot of friends and a huge support network. Participating in SA at the organizational level also makes her feel important.

#21-01-00

***Matt's Story**

Matt is a 45 year old, White, man. He holds a graduate degree and he is not married and does not have any children. His mother is still living. He has been living in his own apartment for about three years by himself. He reports being somewhat satisfied with his living situation and somewhat satisfied with his social support and current relationships. He has been working in a transitional employment position for 7 months for about 20 hours a week. He supports himself with earned income, SSD, rent supplements, and contributions from his family. He reports being somewhat satisfied with his financial situation. He is also in a part-time training program as part of his work and reports being mostly satisfied with his work and training program. He spends his time in a number of activities. He attends a psychosocial clubhouse, a drop-in center, works, attends religious services, volunteers for SA, and hangs out. He reports being mostly satisfied with how he spends his time.

Matt first remembers something strange happening in 1976 just when he had graduated from graduate school. However, he did not really accept it until 1981, when he had a big break and everything fell apart. He has been hospitalized 8 times between 1983-1992. He has a diagnosis of schizoaffective disorder, takes medication and has a therapist, medication management services. He reports being mostly satisfied with his mental health treatment.

Starting attending SA because one of the social workers at the day hospital suggested it. When he attended his first SA meeting he was impressed because it was orderly and people were acting appropriately. Also, the leader was strong role model because she was taking her meds, staying out of the hospital, working full-time and "making it." Early on in his participation he started to try and find ways that he could contribute. At first it was small ways, like making coffee, and later it evolved into leading meetings, writing literature, and working at more of the organizational level. These activities gave Matt a sense of meaning and purpose and helped to build his self confidence. Doing the literature also gave him a valued role in the organization and helped him to learn a lot about the illness and how to manage it.

Matt recognized at the time he attended SA that he was very lonely and that he had essentially no friends since the onset of his illness. He recognizes that one of the things that he has in common with other members and leaders is that they have "all been hit with this diagnosis. We've all had these symptoms. Almost all of us have been hospitalized...We've all had very deep emotional pain." Matt feels that his life was wiped out in a sense and that he doesn't have any of the vestiges of a normal life, but he describes himself as applying himself the very best I could with SA...writing for the newspaper staff for 5 years...and [that] there are still happy moments." He also feels he has grown as a person to become more compassionate and understanding.

#23-01-00
#Liz's Story

Liz is a 52 year old woman who has two children, divorced, and her mother still living. She has had some college, describes herself as Protestant, and has owned her own home for over 20 years. She reports being extremely satisfied with her current living situation and with her social support and current relationships. She has worked in competitive employment for over 20 years and supports herself with her wages. She is not participating in school or a training program. She is extremely happy with her work situation. She attends religious services and volunteers by participating on a number of community boards and with SA.

She was diagnosed with schizophrenia in 1970 and hospitalized 8 times between 1970-1990. She describes how she didn't realize she had a mental illness, but when she tried to commit suicide in 1970 she was taken to a hospital. While in the hospital she read her chart and when she saw "schizophrenia" she "went beserk." She denied it, because it was frightening and devastating, and tried to commit suicide twice. It wasn't until 1984 that she truly accepted it. She believes that it was the stress of filing bankruptcy during the holidays that triggered the illness. Throughout this time when she was struggling with the symptoms, she views her strength as emanating from her job and her need to feed and house her kids. She describes her schizophrenia as ruling her for 14 years and that it controlled every aspect of her life. She recognizes that her illness has probably impacted her advancement at her job and how people treat her in the workplace. However, she is not ashamed of her illness and does not hide it and now feels that she controls it because she knows when she is getting sick and she is able to seek appropriate help. Currently, she sees a private therapist, but does not currently receive any other mental health treatment. She reports being extremely happy with her current mental health treatment.

After her hospitalization in 1984, a "light switch went off in my head" and "I understood everything". She attributes this to when she surrendered her will and asked for God's help and that changed her life. It was after this experience that she fully accepted her illness and she decided she wanted to participate in some kind of activity that focused mostly on recovery, not just the illness. In deciding what kind of activity to focus on she decided that she didn't want to dwell on the illness, only as it pertained to getting better. She also felt that she was no longer the victim and making the decision to be proactive in dealing with the illness gave her a tremendous sense of freedom. She strongly believes that there are things that people can do for themselves that help them get better and that one needs to choose to be well. One of the things she feels is very important is education so that people can "accept the illness and know that it is not so devastating. That there is hope for recovery."

Liz feels that SA is "God's plan for [her] life" and it gives her a tremendous sense of purpose and meaning. It also helps her to stop focusing on herself, reach out to others, and count her blessings. Focusing on the small things is also important to her as well as believing that recovery is possible. She also believes that going to the hospital is not a

failure, because you are seeking help and hopefully learning how to better manage your illness and she views herself as growing and changing over the years from these experiences. Overall, she describes how she looks at and approaches life totally differently from how she used to. However, she also recognizes that she still struggles with depression and when things happen, such as weight gain from medications, her self-esteem suffers.

She describes recovery as "not meaning that you have to have a full time job. It's recovery to your potential with your limitations. ...There's a possibility out there but there's a handicap and a challenge to overcome, but you have limitations. Just like somebody in a wheelchair or any other disability." She also stresses the importance of the whole person - the physical, mental, emotional, and spiritual. For Liz, it was not until she addressed the spiritual aspect of her life that she became totally well. She stresses the importance of believing that you are a worthwhile person even if you don't have a job, because you are still a person with many other qualities and aspects.

#33-02-05

***Jill's Story**

Jill is a 35 year old, White, female who has been living in the same place without a roommate for about a year. She has completed some college, describes herself as a Protestant, does not have children and is not married. She reports being somewhat happy with her current relationships and mostly happy with her social support. She currently works in competitive employment 12 hours a week and does not participate in any volunteer activities. She supports herself with earned income, SSD, and family contributions. She reports being somewhat happy with her financial situation and mostly satisfied with her work situation. She does not attend religious services and is somewhat satisfied with how she spends her time.

Jill describes having a nervous breakdown when she was 19 years old and being hospitalized. She describes the period between 1984 and when she started to attend SA in 1989 as a time when she struggled with depression, anxiety, and a number of other symptoms. She was hospitalized approximately 10 times between 1981-1988. Eventually they put Jill on Prozac in 1988 and she describes this as when everything changed.

Jill started attending SA when she was 27 years old because she was lonely and she wanted to carry on the current treatment that she was getting in a group setting. She went to a few meetings but then stopped because she decided to go back to college to finish her degree. After taking a few classes and getting some really bad grades, she decided to go back to SA, because she felt that maybe she was denying the illness. So she started attending SA again, where she met her current boyfriend. She also learned strategies to manage her illness, including stress management. Right now she feels like she is doing really well - she has a new apartment, a car, and a boyfriend - all goals she wished to accomplish. However, she still recognizes her need to talk to others who understand about her delusions and other symptoms

She currently takes medications and has a diagnosis of schizoaffective disorder. She also sees a therapist, receives medication management services and sees a case manager. She reports being mostly satisfied with her mental health treatment.

#34-02-05

***Ruth's Story**

Ruth is 55 years old, married, and has 2 children. She has her BA degree, does not attend religious services and does not affiliate with any particular religion. Neither of her parents are living and she has lived with her husband and children for 1 1/2 years in the same place. She expresses being mostly satisfied with her social support and somewhat satisfied with her current relationships. She is also mostly satisfied with her current living situation. She is not working because of her psychiatric illness or volunteering and spends the majority of her time caring for her children. She and her family are supported by her husband's earned income and her SSD. She reports being a little satisfied with her current financial situation and mostly satisfied with how she spends her time.

She was hospitalized approximately 30 times between 1969 and 1987. She has a diagnosis of schizophrenia and takes medication. What happened during this period did not emerge during the interview. She reports being mostly satisfied with her current mental health treatment.

Ruth recognizes how schizophrenia and the side effects of medication impact how people treat her. She describes using strategies to manage people's impressions of her such as chewing gum to try and disguise the movement of her mouth. She describes herself as using the SA group as a time to get help in dealing with her symptoms and experiences because her "husband doesn't want to hear about it." She also describes herself as a "terrific" mom. Ruth recognizes that she has grown and changed in some positive ways from her illness including being more insightful and more observant and taking time to really explore her mind. She has also undertaken a number of personal growth activities, such as writing poetry, the martial arts, and signing in a choir. Ruth derives a great sense of meaning and purpose out of being a really good mother.

The SA group's role seems to be limited to helping Ruth manage her symptoms and providing her with an outlet to talk about her experiences and issues related to her mental illness. She has been a member for between 6 months and 2 years.

35-01-00
"Lee's Story"

Lee is a 36-year old woman, who owns a house with her husband, works full-time, has two cats, a diagnosis of schizo-affective disorder, and is thinking about having children. Lee attends regular religious services, both of her parents are still alive, and she has 8 siblings. Although she states that some of her siblings do not feel they have much in common with her, she spends time with one and has a close relationship with another who lives out of town. In addition, she describes her husband as very supportive and as someone who makes her feel valued because he seeks her advice and opinions. Overall, she reports being somewhat satisfied with her current level of social support and extremely satisfied with her current relationships.

Lee has been successful in acquiring a Masters degree in communications and holding down full-time employment at a local hospital for 11 years. When she first started working, after she was diagnosed with mental illness, it was very difficult because the medications made her very groggy and "hard to keep my eyes open." However, she stuck with it and after about 3 weeks became a full-time employee with insurance and benefits in food services. Eventually she moved to a position as an ambulance dispatcher and has been in her current position for over 4 years. In this position, she makes over twelve dollars an hour and supervises 4 employees. Lee reports being mostly satisfied with her current financial situation.

Lee has been hospitalized a total of three times, the first time in the spring of 1987, when she was 23 years old and the last time in the spring of 1994, when she was 30 years old. During this time, Lee briefly received mental health services through community mental health, but when she got benefits with her job, she started to see a private therapist whom she found very helpful. Although Lee has had several diagnoses, she currently has a diagnosis of schizo-affective disorder for which she takes medications on a daily basis. The only type of mental health treatment that Lee currently receives is seeing a case manager about once a month. She no longer sees a therapist, because the insurance company will not pay for it because she isn't experiencing enough symptoms. Overall, Lee reports being mostly satisfied with her current mental health treatment.

Lee spends her time working, with her husband, doing some volunteer work, and making a home. Overall she reports being somewhat satisfied with how she spends her time.

After Lee got out of the hospital, after her first hospitalization in Spring of 1987, her parents told her that they could not afford to financially take care of her and that she needed to take care of herself. However, her parents did support her by allowing her to live with them rent free until she was able to pay off all of her bills. Three weeks after being discharged from the hospital she got a temporary job at the hospital cafeteria scraping plates and serving food.

In 1989, two years after being discharged from the hospital, she started attending SA on the recommendation of her therapist. Her therapist felt she needed additional support and needed to find out more information about schizophrenia and manic depression. First Lee went to a group in Ann Arbor, which she felt was not a good match, because the group was disorganized, too big, and consisted of people who she classified as lower functioning (i.e. lived in AFC and were driven to the group). When she told her therapist her impressions, her therapist suggested that she find out where the leader of the organization held her group and attend that group. She took the initiative, found the group, and put forth the effort in order to attend the group, which was at least a 15 mile drive from her residence. Lee felt that this was indicative of a really an important aspect of her recovery process and recovery in general - the ability, motivation, and spirit to overcome what may seem to be insurmountable barriers to ones' success. She felt that she was able to set a goal (i.e. to attend an SA group to learn more about mental illness) and to overcome barriers (i.e. long driving distance and finding a good group match) to achieving it.

When Lee was first diagnosed with mental illness she was scared, lonely, embarrassed, and felt like a failure. Some of the things that have been difficult for her to cope with or accept include a loss of status in jobs, the ability to not have a baby or a healthy baby, and the lost dreams. She also feels that having a mental illness has impacted how people treat her, including distancing her from friends and family and experiencing stigma and discrimination at work. All of these losses and experiences impacted her identity and made her feel disjointed and not like herself. One of the reasons Lee wanted to attend SA was to learn more about schizophrenia and manic depression and to "come together with who [she] was."

Lee attended the leader's group for about two years and described her participation in that group as contributing to and shaping her recovery process. She felt a great sense of camaraderie and belonging, which allowed her to talk openly and freely about her mental illness and problems. She also identifies the leader as a role model who helped her to change some of her beliefs about schizophrenia. For example, Lee learned from the leader's experience that set backs and relapses are part of the illness and that a set back does not mean a person has failed. She also learned that achieving valued goals(e.g., getting back a normal life, holding a job) is possible.

In 1991, after attending the leader's group for 2 years, she decided she wanted to start her own group, because she was working on her masters in communications and felt that it would be good practice. She describes the experience of starting and maintaining her own group as frustrating and overwhelming, but she eventually developed a consistent, small and intimate group consisting of members who all had jobs, but also severe disabilities. Lee's ability to face fears, anxieties, and doubts and to overcome barriers that get in the way of her self-identified goals, is a recurrent theme in her recovery process. It occurs when she decides to attend the second SA group and has to drive a far distance. It occurs when she first starts working at the hospital and she gets overwhelmed and upset, but is able to pull herself together in the chapel or bathroom, and

to keep working. It also occurs when she becomes frustrated and overwhelmed while starting her own SA group, but perseveres in spite of her frustration. For Lee, the ability to overcome barriers in order to achieve a self-identified valued goal, plays an important role in her recovery process.

When describing her group, Lee emphasizes how it provided a context to share views about schizophrenia, work, and relationships and how it gave her strategies for dealing with these areas of life within the context of her mental illness. Lee connects with one member in particular who had a "similar story", meaning she was married, working full-time, and had a masters degree. This member served as a role model for her, because she was also battling a serious physical illness and although she had two strikes against her, she was still fighting and maintaining a "normal" life. This friend inspired Lee to fight and to try to overcome the barriers that stood in the way of her dreams. Again, this was a very important aspect of the recovery process for Lee.

Another important aspect of the recovery process for Lee involved redefining the goals and expectations for her life. Before Lee got sick she had dreams of becoming the CEO of a big company and she was convinced that nothing short of this goal could make her happy or fulfilled. By attending SA, she was reminded that she did have an illness and that she needed to refocus and start setting new, more practical goals based on where she was at the time and what she felt was realistic. She was also reminded that she could be doing much worse and that she should be thankful for what she has been able to accomplish. For Lee, redefining her goals and expectations was not viewed as a compromise or as settling for less, but as a necessary step in reframing her life in order to be successful and to make progress and to not to exacerbate her symptoms or illness. At a minimum this would allow Lee to survive and lead a normal life, which was one of the things that she realized she valued.

SA also helped Lee cope with some of her losses by putting things into perspective and making her realize that if she is strong and perseveres then she can still achieve what she needs or wants to. Seeing role models, like the leader of the organization, made her have hope because the leader of the organization had lived with schizophrenia for many years and yet she maintained a productive life, a house, a job, and a car. Although this may seem to contradict the need to redefine goals or expectations, it is in fact compatible because although in the short-term it may assist in the recovery process to keep the focus on attainable realistic goals, the recovery process also consists of hope.

After leading her group for 2 years, she decided she wanted to encourage people diagnosed with mental illness to fight by telling her story. She did public speaking and eventually helped SA at the organizational level to organize conferences and events. It was during this time that she decided to stop leading her group because she was becoming tired and overwhelmed with working full time, leading a group, and volunteering with the SA organization. About 7 years after she was first hospitalized, when she was doing well (e.g., got her masters, working full time, volunteering for SA), she went for a second opinion at U of M and they took her off her medication, she

relapsed and ended up in the hospital. This is when she describes really accepting that she did have a mental illness and realizing that she had to stop trying to prove herself and doing things to please others.

From this point, she continued to improve and get stronger and felt like she no longer needed to participate in SA. She worked in residential home for people with mental illness, but found it "stressed" her out. She participated in a work assessment and found that her interests really lie in the business end of mental health, so she has decided to do things to pursue that type of a career. This cycle of trying new things, seeing how they feel and whether or not one can handle it and integrate into ones' life, is a very normal process of growth. These can also be times of stress, doubt, and challenge and can precipitate movement back to previous stages of the recovery process. For example, Lee describes how she relied on her aunt to help her cope with some of the losses she experienced in her life, but now that he aunt has passed away, she is thinking of returning to SA. This implies that Lee has recognized that she is lacking feeling connected to others and needs additional support and so she is going to seek out help. Recognizing a need for help is an important component of learning to live with schizophrenia. So, although Lee may have been currently experiencing some aspects of the recovery process that are found in phase two, she has also clearly experienced many of the aspects of the recovery process described in phase three.

Lee has achieved a more positive sense of self and has achieved self-identified valued goals in her life. In some ways Lee feels that having a mental illness has helped her to grow as a person. She feels she is a better person who cares about people more and respects life more. She also feels it has provided her with a greater understanding of her family's situation and the effect of her father's mental illness on the family. She feels she has become more down to earth and has a greater capacity to enjoy life. Lee has clearly developed a positive sense of self while simultaneously integrating her experience of mental illness into her identity.

One of Lee's valued goals or achievements was to make sure she never ended up on disability and to live a normal life again. If a normal life is defined as having a spouse, owning a home, and working full-time, Lee has achieved her goals. However, Lee also recognizes that she has achieved all of these things in the context of a psychiatric disability and that she will continue to lead her life within this context. For her that means, setting realistic goals, appreciating every day, engaging in meaningful activities and goals, and being happy and content.

#41-01-40

***Beth's Story**

Beth is 67 years old. She has taken some college classes, identifies herself as a Protestant, she has never married and she does not have any children. Neither of her parents are living, but she has other relatives who she keeps in touch with. She reports being mostly satisfied with her social support and extremely satisfied with her current relationships. She has been living in an AFC home for about 79 months and reports being extremely satisfied with her current living situation. She supports herself with SSI, SSD, and family contributions. She is currently looking for work. She reports being mostly satisfied with her financial situation. She spends her time doing volunteer work at the library and attending religious services. She reports being somewhat satisfied with how she spends her time.

She was hospitalized 12 times between 1949 and 1987. Many of these hospitals were for extended periods of times. Because Beth is older than many of the other participants she was in the mental health system when longer periods of confinement were more common. Beth describes go in and out of the hospital interspersed with periods of living at home with her mother trying to work. Her story of her earlier years is not very detailed which makes it difficult to tell a complete story. What is clear in her story is the role that SA has played in her life.

She currently has a diagnosis of schizophrenia and receives medication and case management services. She reports being extremely satisfied with her mental health treatment.

Beth has been a SA leader for more than 2 years. She describes SA as " a great idea for somebody who is in despair and that wants a way out..." She describes how SA helps to counteract some of the negative societal views by providing members stories in the literature. She derives a strong sense of meaning and purpose from her role of group leader and her membership in the SA organization.

#49-02-04

#Claire's Story

Claire is a 29 year old woman who is a high school graduate. She is not married and does not have any children. Her father is living and she has a number of siblings who she stays in touch with. She lives with a roommate in an independent apartment and has been in the same location for about 4 years. She is extremely satisfied with her current living situation and her level of social support and her current relationships. She has been working in competitive employment for about 2 years for about 20 hours a week. She also does some volunteer work. She supports herself with her earned income, family contributions, and SSI. She reports being somewhat satisfied with her current financial situation and her work situation. She spends her time working, going to the drop-in center or psychosocial clubhouse.

She has never been hospitalized, she takes medications, and has a diagnosis of schizophrenia. She reports being mostly satisfied with her mental health treatment.

Claire describes her illness as starting a long time ago when she was a child in school. She describes throwing her stuff around and getting really emotional. She describes how she could not participate in a lot of the activities of her siblings and peers because she was afraid. She describes how she went through many difficult times, but she never gave up. She describes her mother shielding her illness from the rest of the family because she felt like she needed to protect Claire. Claire describes how her mother's intervention took some of her ability to grow and change on her own. She describes needing to be liked by everyone as a child, but how she no longer feels that way and that she realizes that the only thing that matters is what she thinks.

Claire describes how taking care of herself, her life, and her things is very important to her sense of self. She describes how she and her roommate keep the apartment clean, take turns cleaning, and doing the shopping. She feels that her illness is under control because takes her medications and does other things to stay healthy like swimming, taking walks, riding her bike, and taking vitamins. Participating in SA has also given her self-confidence and encouragement when she has needed it.

Table 1

Description of Derivation of Final Sample

Group ID	Leader's Estimate of The Number of Current Group Members	Total Number of Members Who Volunteered	Volunteer Rate (column 3 divided by column 2)	Number of members who volunteered to participate broken down by length of participation category			Number of Members who participated in the interviews broken down by length of participation category.			Number of Leaders Interviewed	Total Number of Members and Leaders Interviewed
				2 - 6 months	6 months to 2 years	2 years or more	2 - 6 months	6 months to 2 years	2 years or more		
00	4	4	100%	0	0	4	0	0	0	4(more than 2 yrs)	4
02	10	7	70%	2	2	3	1	1	1	1 (more than 2 yrs)	4
03*	3	0	0%	0	0	0	0	0	0	2 (more than 2 yrs)	2
04	15	13	87%	4	6	3	1	1	1**	1(more than 2 yrs)	4
05	6	4	67%	0	2	2	0	1	1	1(more than 2 yrs)	3
10	12	10	83%	5	1	4	1	1	1	1(2-6 months)	4
11***	6	5	83%	3	2	0	3	2	0	1(more than 2 yrs)	6
13	4	3	60%	0	1	2	0	1	1	1(more than 2 yrs)	3
14	6	6	100%	5	1	0	1	1	0	1(6 months – 2 yrs)	3
15*	1	0	0%	0	0	0	0	0	0	2(more than 2 yrs)	2
16	12	6	50%	1	4	1	0	1	1	0***	2
17†	1	0	0%	0	0	0	0	0	0	0†	0
38‡	6	7	86%	5	1	1	4	1	1	1(2-6 months)	7
40	10	4	40%	4	0	0	1	0	0	1(more than 2 yrs)	2
Total	96	69	72%	29	20	20	12	10	7	17	46

Summary of Table 1

72% (69/96) of the SA members of active community groups in Michigan volunteered to participate.

Overall response rate of 94% (46/49) which equals a 89% (17/19) response rate for SA members and a 97% (29/30) response rate for SA members

*At the time the interviews were conducted, there were no members attending this group.

******The first member randomly selected for participation was unable to complete the interview because of psychiatric problems that resulted in hospitalization, so another member from the same category was selected. This accounts for the one member who did not participate in the study and the 29/30 or 97% response rate.

*******This group was being followed longitudinally (interviews were conducted at three time points) and therefore all current members of the group were interviewed (N=6).

********At the time the interviews were conducted, this group did not have a leader.

‡ Interviews were conducted with all members of this group because at the time the interviews took place, the research team thought the group would be followed longitudinally. However, because of limited resources this did not occur.

† This group had very low attendance and was struggling. After consenting to participate in the study, the two co-leaders, the only active members of the group, decided not to participate. This accounts for the two leaders who did not participate in the study and for the 17/19 or 89% response rate for leaders.

Table 2

Description of Groups Not Included in the Sample

Group ID	Start Date	Setting	Rationale for Not Including the Group in the Sample
01	7/15/95	Community Building	No one attending the group at the time the interviews took place. The leader was interviewed in her role of leader of another SA group.
06	1/15/96	Prison	Group in a prison setting and it was decided that groups in institutional settings would not be included
07	8/15/95	CMHC	Group on hiatus at the time the interviews took place.
08	10/15/95	CMHC	Group on hiatus at the time the interviews took place.
09	3/15/93	Drop-In Center	No one attending the group at the time the interviews took place.
12	6/15/94	Clubhouse	No one attending the group at the time the interviews took place.
17	12/2/96	CMHC	This group had very low attendance and was struggling. After consenting to participate in the study, the two co-leaders, the only active members of the group, decided not to participate.
18	4/15/95	CMHC	This group's makeup was very different from other SA groups. Also, its' typical attendance is 30 or more members.
19	7/15/95	Prison	Group in a prison setting and it was decided that groups in institutional settings would not be included.
20	11/15/87	In-Patient Psychiatric Hospital	Group in a hospital setting and it was decided that groups in institutional settings would not be included.
21	6/15/91	Staff Supported Apartment	Group members were not interested in participating in the study.
22	9/15/94	In-Patient Psychiatric Hospital	Group in a hospital setting and it was decided that groups in institutional settings would not be included.
23	4/15/96	Prison	Group in a prison setting and it was decided that groups in institutional settings would not be included.
24	6/15/94	Church	Group is located too far away to pursue data collection.

Table 3

Summary of Groups not Included in the Sample

# of groups	Summary of Why Groups Were Not Included in Sample
3	Groups were not included because no one was attending at the time the interviews took place
5	Groups were not included because they were in prison or hospital settings
2	Groups were on hiatus at the time the interviews took place
1	Group was atypical
1	Group was too far away to pursue data collection
2	The group members were not interested in participating in the study

Table 4

Description of Groups Included in Sample

Group ID	Start Date	Setting
00		Organizational Leaders Not Currently Associated with a Group
02	6/15/91	Drop-In Center
03	2/15/96	Church
04	3/15/94	Drop-In Center
05	3/15/88	Church
10	10/15/93	Community Mental Health Center
11	10/3/96	Clubhouse
13	10/2/90	Community Mental Health Center
14	7/15/96	Clubhouse
15	6/15/93	Church
16	11/15/96	Clubhouse
38	5/15/97	Drop-In Center
40	10/15/95	Church

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