HEARING THEIR VOICES: PSYCHOTIC PATIENT PERCEPTIONS OF LIVING WITH MENTAL ILLNESS: A FIFTEEN-YEAR FOLLOW-UP

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DEDICATION

In memory of my father John M. Digman, Ph. D., who knew the magic of numbers and the power of words, and whose memories of our times together remain vibrant and alive in my heart and mind.
ACKNOWLEDGEMENTS

This project would not have been possible without the vision and hard work of many individuals. While space does not permit the acknowledgement of each person who contributed to the International Study of Schizophrenia (ISoS), they are recognized collectively.

I would like to thank those who worked at the Honolulu Field Research Center on the most recent portion of the study of which this dissertation is a part, the Long Term Course and Outcome of Schizophrenic disorders (LTCOS). Specifically, I am indebted to Anthony J. Marsella, the principal investigator of the LTCOS project in Honolulu, for his organization and persistence in enabling the project to continue. Personally I want to thank Dr. Marsella, who was also my academic advisor, for his mentoring during my graduate school career. He never faltered in his support and encouragement and his wisdom and enthusiasm have always inspired me. He truly showed me the value in listening to people and the importance in distinguishing between their messages and what I perceive through my personal biases.

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Finally, I would like to thank Christine Butler, and Jane Rawson, for their very valuable assistance and feedback in reviewing qualitative themes, and Cindy Peters for her feedback and helpful suggestions on early drafts.
ABSTRACT
The present study explored responses to questions concerning recovery process issues, among 57 adult men and women, who experienced a first episode of psychosis in Honolulu, between 1979 and 1984. The following topics were examined: 1. understanding of illness, and recognition of factors influencing changes in understanding; 2. perceived impact of illness 3. social relationships; 4. coping behaviors 5. experiences with psychiatric coercion, 6. future goals. This study is part of the World Health Organization (WHO) International Study of Schizophrenia (ISoS), which embodies the Long-Term Course and Outcome of Schizophrenia (LTCOS) study and the initial Determinants of Outcome of Schizophrenia and other Mental Disorders (DOSMD) study. Between 1994 and 1999, trained researchers conducted fifteen-year follow-up interviews with members of the initial cohort. The present study used the Rochester Recovery Inquiry (RRI), a 32-item semi-structured interview, to explore recovery-related aspects of living with mental illness. Analysis of responses, with qualitative methods, and basic tabulations, revealed: 1. a tendency toward increased clarity of illness understanding over time, described in medical and psychological terms, and attribution of changes in understanding to influences by mental health professionals, friends, and family members; 2. a tendency to perceive the illness as having had an overall negative impact on their overall lives but gave mixed responses about impact on relationships, with equal numbers reporting negative and positive impacts respectively 3. reciprocal interactions with small social groups; 4. a variety of individualized methods to cope with stress and to deal with their illnesses; 5. experiences of psychiatric coercion; 6. goals for the future that included maintaining employment, stable housing and relationships. Results suggest the following: 1. Individuals
diagnosed with serious mental disorders strive to make sense of these experiences and utilize shared medical and psychological conceptions of mental illness and their social networks to do this, suggesting a role for mental health professionals and family members in helping to clarify experiences at early stages of illness. 2. Issues of perceived stigma and impact of illness on relationships should be explored on an ongoing basis as part of treatment; 3. Relationships with family and friends are important in helping to meet basic and social needs; 4. Individuals who live with mental illness develop a variety of individualized coping mechanisms and can play an active role in their treatment; 5. The emotional impact of psychiatric coercion needs to be further explored; 6. Stability in employment, housing, and relationships remain critical issues to address in community treatment; 7. Males and females may experience the social impact of their illnesses differently.
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CHAPTER ONE
LITERATURE REVIEW

Introduction

Longitudinal research concerning the course and outcome of serious mental illness has largely focused on objective measures such as number of hospitalizations, symptom patterns, and global assessment of functioning (Marengo, 1994). While these factors are essential to our understanding, there is heterogeneity of outcome that cannot be explained by these objective characteristics alone (Strauss, 1989).

There is growing evidence in the psychological and psychiatric literature that inclusion of subjective factors in research designs may help to clarify issues related to individual variations in outcome (Corin, 1990; Davidson & Strauss, 1995; Davidson, 2003; Estroff, 1989). The ways in which a person defines, copes with and understands the experience of living with a serious mental illness are now believed to influence the course of the illness and also to play an integral part in the recovery process (Strauss, 1989; Young & Ensing, 1999).

Serious mental illness is a singularly life-altering experience especially when psychosis is involved. Symptoms of psychosis result in extreme alterations of perception with resulting feelings of anxiety, loss of control, and loss of sense of self (Estroff, 1989; Hatfield & Lefley, 1993). Additionally, individuals afflicted with psychosis and other symptoms often experience a loss of independence and dignity and become involved with mental health systems that can result in feelings of confusion and intimidation.

Although numerous advances have been made in the treatment of these disorders, especially in the areas of neuroscience and pharmacology, it is only relatively recently that mental health researchers have begun to examine how
individuals themselves adapt to the experience of living with mental illness (Hatfield & Lefley, 1993; Lieberman, 1989; Strauss, 1989).

For centuries individuals have documented their experiences with psychiatric disorders and this has supplied medical science with a rich source of information about symptoms, diagnosis, and responses to treatments (Sommer, Clifford, & Norcross, 1998). Unfortunately, the experiential and subjective aspects of these accounts have not been fully utilized, in large part, because of an adherence to and bias toward strictly quantitative and conventionally empirical methods among those who study these phenomena (Lieberman, 1989; Strauss, 1989).

Research utilizing patients' perspectives has increased our knowledge of serious mental illness in many ways including: delineating stages of recovery from psychiatric illness (Young and Ensing, 1999), and helping to shed new light on the concept of insight (Greenfeld, Strauss, Bowers, & Mandelkern, 1989). Studies to date have focused on a variety of subjective factors including meaning and identity in recovery (Estroff, Lachicotte, Illingworth, & Johnston, 1991; Davidson & Strauss, 1992; Petit & Triolo, 1999), delineating specific themes of recovery, and describing the process of adaptation to mental illness (Young & Ensing, 1999). Although these studies have focused on one or a few of these domains, few have combined several of these recovery-related topics in the same study with a carefully defined sample.

The present study addressed these issues by: 1. Use of a more comprehensive instrument that included a wider range of recovery-process domains; 2. Inclusion of a recovery issue inventory as part of a comprehensive data base that also included information on psychosocial and psychiatric functioning; 3. Description of illness-related experiences for a specified group of individuals as part of a 15-year follow-up investigation.
Statement of Purposes

The purposes of the present study included the following: 1. To explore reports of illness experiences, among individuals with a history of psychosis, at a 15-year follow-up period through a semi-structured interview, the Rochester Recovery Inquiry (RRI), designed to illicit perceptions regarding “recovery-related” topics (Hopper, et al., 1995); 2. To contribute to the research and clinical literature on subjective accounts of illness experiences among individuals with a history of psychotic disorders; 3. To encourage increased use of subjective accounts to promote inclusion of patient involvement in treatment and research.

Two assumptions are made in this dissertation research: 1. Individuals who have mental illness are the best source of information about how they experience and adapt to their illness; 2. In the process of living with various aspects of their illness over an extended time period, they will have accumulated knowledge about what has helped them and affected their adjustment.

Because this study did not link responses to outcome, it discusses “recovery-process issues” and not “recovery per se. The questionnaire items represent recovery-process issues or particular attitudes and experiences that have been shown to be related to the process of adapting to and recovering from serious mental illnesses.

The present study is part of a multinational longitudinal investigation of the course and outcome of schizophrenic disorders initiated in 1978 (WHO, 1979). Subsequent investigations addressed methodological shortcomings of previous studies. The Long-Term Course and Outcome of Schizophrenia and Other Severe Mental Disorders (LTCOS; Jablensky et al., 1992) study included standardized, reliable, and culturally sensitive assessments to assess psychiatric and social
adjustment as well as the longitudinal course of the illness. The present research included data from the fifteen-year follow-up point only and only responses from the RRI.

**Literature Review**

The literature review is presented in three sections. After a brief introductory overview of basic issues, section one provides a historical context for the present study. Section two discusses the contribution of various research approaches, and section three considers contributions of narrative data to the mental health literature, discusses qualitative approaches to research, and summarizes the literature relevant to the present study.

**Basic Issues**

**Scope of the Problem**

Serious mental illnesses such as schizophrenia, acute psychosis, bipolar disorder and major depressive disorder are widespread social and public health issues that affect a sizeable portion of the population. The monetary costs of these illnesses are often staggering, but psychological and social losses to patients and family members are immeasurable (Andreasen, 1991; Torrey, 2001; U.S Surgeon General, 1999). Schizophrenia, considered the most costly, often begins early in life and affects a wide range of activities and functions. Those who sufferer from this most devastating of disorders are often unable to sustain employment, requiring society to shoulder the cost of supporting them for a lifetime which usually includes substantial medical expenses (Andreasen, 1991; U.S. Surgeon General, 1999).

While numbers of those afflicted cannot be determined precisely, recent epidemiological studies have estimated that at any given time between 5% and 7% of
adults experience a serious mental illness (Department of Health and Human Services, 2001; Kessler et al., 2001; U.S. Public Health Service Office, 2001).

The health and medical costs involved in treating these illnesses are enormous. According to the New Freedom Commission Report on Mental Health (2003), in 1997, the latest year for which comparable data are available, the United States spent $71 billion dollars on treating mental illnesses. Total direct and indirect costs of schizophrenia in the United States in the year 2000 were approximately $40 billion with an estimated $10 billion spent on federal disability payment. Schizophrenia is the largest diagnostic category for individuals receiving these federal subsidies (Torrey, 2001).

Incidence and prevalence data represent only the surface of a multidimensional problem. Many do not receive appropriate treatment for these disorders. According to the New Freedom Report (2003), “...the mental health delivery system is fragmented and in disarray... leading to unnecessary and costly disability, homelessness, school failure and incarceration” (p. 4).

Serious mental illness also presents an immense challenge to the loved ones of those afflicted (Lefley & Johnson, 1990). According to a National Alliance for the Mentally Ill (NAMI) survey, approximately 42 percent of seriously mentally ill persons live with family members at any given time (Torrey, 2001). With such a substantial number involved with family members it becomes imperative that professionals understand what this experience is like for families and for their mentally ill members.

The greatest impact of mental illness is felt by those who experience these disorders directly. The challenge to merely survive let alone maintain any sense of dignity and meaning in one's life, while experiencing multiple hospitalizations, societal stigma, and an often unpredictable illness, is often overwhelming. Individuals who
suffer from these disorders often lose hope entirely and become passive recipients of federal financial aid, or fare worse. A sobering statement by the World Health Organization (WHO) reported that worldwide incidents of death by suicide exceeded those of death by homicide or war (WHO, 2002).

Societal successes and failures in understanding and treating the mentally ill have a long and complex history. While remarkable progress has been achieved in the area of symptom management, we know comparatively little about the social and emotional experiences and needs of those with serious mental illness. This may be partially the result of a tradition in psychiatry that tends to objectify and categorize patient accounts of their illness experiences, and to not acknowledge their intrinsic value and utilization in research and treatment.

**Historical Context**

In the mental health professions, there exists a tension between those who utilize, understand, and respect patient accounts of their mental illness experiences and those who tend to deny the value of these, and to make efforts to objectify patient accounts. In order to better understand this, it is necessary to review psychiatric history. While it is beyond the scope of the present dissertation to discuss the entire history of psychiatry, readers are referred to a partial list of references below for more comprehensive coverage.
History of Psychiatry References:

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<td>5. Grob, G. (1994)</td>
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For present purposes, it is the aim of this review to understand how and when, in the history of psychiatry, mental health professionals began to value communication from patients, not just for purposes of diagnosis or clinical interest but in its own right. This overview will discuss some of the events and individuals that have influenced the mental health profession in this direction.

**Early History through 18th Century**

During the early history of psychiatry, including Greek and Medieval times, patient accounts of their experiences with mental illness were simply deferred to the responses and opinions of experts who were usually either physicians or members of the church (Grob, 1994; Longrigg, 1993; Porter, 2002). Approaches to treatment were based upon prevailing societal views of mental illness and included exorcisms, bloodletting and other physically invasive treatments which were usually antagonistic violent, and destructive to patient and physician relationships (Alexander & Selesnick, 1967; Grob, 1995; Shorter, 1997).
People who suffered from a mental illness were viewed as fundamentally different and were thus isolated from the rest of society. Even within the family system mentally ill members were often caged, housed in stables with animals, chained, or otherwise segregated and controlled (Alexander & Shorter, 1967; Shorter, 1997). If their behavior was not bothersome, they were allowed to wander the countryside, but were often taunted by members of the community as the “village idiot” or set off to sea in a “ship of fools” (Alexander & Selesnick, 1995; Foucault, 1965; Shorter, 1997).

The Nineteenth Century

During the nineteenth century the predominant influences on prevailing attitudes were the development of moral therapy and asylum reform. The publication of a first-person account of mental illness was also a factor in influencing the way some members of the psychiatric profession viewed the experience of mental illness.

Moral treatment. Toward the end of the eighteenth century asylums were merely warehouses to keep mentally ill segregated from the rest of society. An important shift in perception occurred however, when certain individuals began to view the mentally ill as human beings who were ill rather than as objects to be controlled. At this time (1789), the French Revolution played a major role in promoting a change in ideas that ultimately resulted in asylum reform and other events in psychiatry (Alexander & Selesnick, 1995; Grob, 1994). The revolution promoted ideas of liberty, equality and the notion that human beings could govern themselves through the powers of reason (Bankart, 1997).

In 1793, at La Bicêtre, a large asylum in Paris, Philip Pinel was appointed chief physician there and held radically different views regarding the treatment of patients, than the majority of physicians of the time. He believed that most patients would respond well to support and kindness and ordered a stop to all beatings and chains
(Grob, 1994). For perhaps the first time, patients were listened to and validated and the relationship between doctor and patient was seen as significant and conducive to healing in and of itself. Others who practiced variations of moral therapy in their own countries included William Tuke in England, and Vincenzo Chiarugi in Italy (Alexander & Selesnick, 1995; Shorter, 1997).

This approach, called moral management, involved changes in environment and direct patient interactions including talking and listening to patients, exercise, and other activities, and was remarkably successful for many patients. Many who had previously been locked away or chained were improved to such an extent that they were released from asylum (Bickman & Dokecki, 1989; Grob, 1994).

Although asylum reform was not maintained, in large part due to large numbers of immigrants and decreasing funding, its influence was not forgotten. However, as the century progressed, Institutions became crowded once again and therapeutic treatment was again replaced by control by physical means. Patients were again not listened to, but controlled and segregated. However, John Perceval shared his experiences with the world in 1838 and 1840.

**Perceval’s Narrative.** John Perceval, the son of a Prime Minister of Great Britain was institutionalized after suffering a psychotic episode and composed a comprehensive narrative of this experience that was to become perhaps the first such of these accounts to be taken seriously by some members of the psychiatric community.

In his account, Perceval not only described his psychotic symptoms in great detail but also his struggles to make sense of the experience and the experience of being a patient in a mental hospital. His may be one of the first pleas of patients to be listened to as sources of knowledge about their own disorders. He asserted repeatedly
that "the patient knows more about the nature of insanity than either the general public or the lunatic doctors" (Bateson, 1961, p. viii). He repeatedly expressed the therapeutic value of being listened to and understood. "It is the task or duty of the physician or of those who love the patient to understand. The patient’s utterance is not to be brushed off as crazy nor is his behavior to be penalized with cold tubs or manacles" (p. viii).

While his account did not have any immediate impacts on the practice of psychiatry, it has been an influential work throughout the years due to its detail in description of symptoms and other phenomena and its early pleas for treatment reform that resonate to this day.

**Twentieth Century**

Twentieth-century developments in the mental health professions have been varied and far-reaching and can only be highlighted here. This section focuses on some key philosophical influences, and political and social events that have interacted and led to greater appreciation and utilization of patient accounts.

**Psychoanalysis and the Origins of Psychotherapy.** At the turn of the century, Sigmund Freud's (1909) *The Interpretation of Dreams*, was published beginning a revolution in psychiatry that ultimately led to the psychotherapy movement and an intellectual debate that ultimately led to alternative views (Alexander & Selesnick, 1966; Bankart, 1997). Thus, while psychoanalysts viewed patient accounts as inherently pathological to be guided by the analyst, the psychoanalytical movement was an overall essential influence (Kaplan, 1964).

Freud’s ideas about unconscious drives and developmental stages influenced an entire generation of mental health professionals and resulted in hope that many less severe forms of mental illness might be alleviated through verbal treatments from
trained therapists or psychoanalysts. This technique of talking therapy became widely influential and was applied mainly to patients with less severe forms of psychopathology who did not require hospitalization. Patients would visit a therapist or psychoanalyst in the office for sessions of approximately one hour then continue their daily activities. This format later became known as outpatient therapy and this concept was very influential later during the community mental health movement (Mosher & Burti, 1994). The understanding and treatment of the mentally ill has been impacted by individuals and theoretical developments, as well as by philosophical and socio-cultural developments.

**Philosophical Influences.** In the first half of the twentieth century the two original and ultimately highly influential philosophical movements of phenomenology and existentialism developed (Misiak & Sexton, 1973). At the beginning of century, Edmund Husserl founded the philosophical movement of phenomenology that continues to have far-reaching influences on mental health research and treatment. Phenomenology is concerned with the exploration of the true nature of things by their representation in human consciousness. Thus, the true nature of experiences and feelings, for example, can only be discerned from the individual and only by certain procedures known as the phenomenological method (Polkinghorne, 1989). The philosophy and methods originally developed by Husserl are the basis of research currently being conducted on recovery and other subjective aspects of schizophrenia (Davidson, 2003).

Existentialism and phenomenology are closely related and use the same method. However their basic concerns are different. While the main concern of phenomenology is determining the essence of things, the main theme for existentialists is the human experience of existence. The original thoughts for the movement are
found in the writings of Kierkegaard in the mid-nineteenth century but the movement itself began in Germany with Martin Heidegger and Karl Jaspers. Other important names associated with existentialism are Jean-Paul Sartre, Maurice Merleau-Ponty, Paul Ricoeur, Albert Camus, and Simone de Beauvoir, in France, Paul Ortega y Gasset, in Spain, and Paul Tillich, in America (Misiak & Sexton, 1973).

For present purposes, the most influential existentialist has been Karl Jaspers, who was also a psychiatrist and one of the original founders of existential psychiatry in Germany. He published an influential text on psychopathology (1963) in which he stressed the importance of obtaining detailed descriptions of patients' subjective experiences as a diagnostic aid, and on developing empathy with patients' feelings as an adjunct to therapy (Corin, 1990; Misiak & Sexton, 1973).

The Third Force in Psychology. Just as philosophy reacted against traditional rationalism and empiricism so too did psychology react to the prevailing influences of behaviorism and psychoanalysis by adapting the ideas of phenomenology and existentialism to their field. Basically the term "third force" refers to the organization of alternatives to behaviorism and psychoanalysis that became organized during the 1950's. It is beyond the scope of this discussion to cover the entire history of this movement. For present purposes it is important to note the development of Humanistic psychology and the influence of such individuals as Abraham Maslow, and Carl Rogers.

Humanistic psychology is concerned with issues that are uniquely human including: a focus on individual experience and meaning, and the study of unique human qualities such as choice and potential (Bugental, 1967; Misiak & Sexton, 1973). The influence of Maslow, and Rogers are important for our purposes because of their influence on the field and on clinical applications. Abraham Maslow is considered by
many to be the most influential leader in the humanistic movement because he defined the goals of humanistic psychology to include the study of mental health and human potential. Rogers was influential in his development of non-directive therapy and demonstration of the inherent therapeutic benefit of the very act of listening to a person with acceptance and empathy (Rogers, 1951).

There are many other therapists and theorists in the areas of Existential, Humanistic, and Phenomenological philosophy and psychology that have, by necessity, been excluded from this brief discussion. Readers are referred to Allers (1961), Giorgi (1970; 1994), Moss (1999), Rogers (1951), Solomon (1998), and Valle and Halling (1989) for more comprehensive treatment.

The ideas of phenomenology and existentialism were originally European, mainly German. The reception and growth of these philosophies and their influence on the mental health professions is due not only to the hard work and vision of many individuals but also to certain social and ideological conditions. This movement gained influence at a time in America of rapid technological changes and industrial development, with corresponding feelings of alienation. A recent history of war, threat of nuclear destruction, and growing disillusion among professionals regarding the idea that all problems could be solved by empiricism led to a reception of new ideas and approaches to the problems of humankind (Polkinghorne, 1992).

**Postmodernism.** The expression postmodernism refers to an ongoing cultural transformation, in Western societies, that began in the 1950's and 60's, as a response to the perceived inadequacies of modernism (Hyussen, 1990). The premise of modernism was that we live in a logical and orderly universe the laws of which can be revealed through the application of science (Lyotard, 1984). Science was also viewed as having solutions to social problems such as illness and poverty. When it became
increasingly evident that pursuit of knowledge and application of scientific methods were inadequate for the understanding of more complex situations, modernist ideas were challenged and alternative viewpoints emerged.

In short, this has resulted in an interest in the problems that science in modernist times had ignored as unmeasurable such as diversity, individuality, and that which is chaotic and ephemeral (Polkinghorne, 1992). For present purposes, the postmodern atmosphere has resulted in a climate in which alternative viewpoints and approaches to problems are now possible. Postmodernists recognize that experience is context-bound, that there is no reality separate from the observer. These are ideal conditions for the practice of qualitative methods and for the recognition of the value in examining inner experiences.

**Contemporary Scholars.** While many in the mental health professions continue to distrust the validity of personal accounts of mental illness, there are a growing number of individuals who are demonstrating through their work, the value in utilizing such accounts. This has become a multidisciplinary endeavor which includes in part, anthropology, psychiatry and psychology. Leaders in these professions include Sue Estroff (1989; 1991), and Ellen Corin (1990) in anthropology, Larry Davidson (1992; 1995; 2003) in psychology, and David Strauss (1989; 1990; 1998) in psychiatry.

Anthropology was one of the first disciplines to fully utilize and appreciate the subjective accounts of individuals with mental illness, because as a discipline, it already utilized a qualitative approach to investigation of other cultures. It has approached the study of mental illness in a similar manner. It has been said of Sue Estroff that she "...is a medical anthropologist who has played an important role in opening up and rigorously studying subjectivity in serious mental illness..." (Davidson, 2003, p. 13). An example of her work was published in her book "Making it crazy"
(1985), an ethnographic investigation of ways in which individuals with mental illness adjust to aspects of daily life in the community including the mental health system and struggling to meet basic needs. Her current and ongoing work involves longitudinal exploration of the interdependence of socio-cultural factors and self-labeling on illness identity.

Ellen Corin, also a medical anthropologist, has also made significant contributions using subjective accounts investigating narratives for characteristics of inner experiences linked to various aspects of successful community living.

John Strauss can be considered a pioneer in contemporary psychiatry for his contributions to literature using qualitative methods of subjective accounts. He has developed and utilized phenomenological approaches to understanding adaptation to and recovery from serious mental illness.

Larry Davidson continues to contribute to the understanding and treatment of serious mental illness. He has collaborated with John Strauss to investigate the sense of self in recovery from mental illness and has, using phenomenological methods, explored in over 100 interviews, the process of and experiences involved in living with and recovering from serious mental illness.

Social and Political Influences

While philosophical and cultural developments have resulted in an atmosphere that is receptive to alternative approaches to understanding and treating the mentally ill, social and political events have also interacted to impact the lives of individuals who have mental illnesses. These include increased public awareness of the deplorable conditions in psychiatric hospitals, the discovery of antipsychotic medications, deinstitutionalization and the community mental health and consumer movements.
Two events coincided to set the stage for the large scale reduction of state hospital populations. One was the increase in public attention to the conditions existing in these institutions and the other was the advent of medications to control the most troubling symptoms of severe disorders.

**Increased public awareness.** Little public awareness of conditions in psychiatric hospitals existed until the following events occurred: the publication of Clifford Beer's autobiography, the actions of a large number of conscientious military objectors, and the writings of journalists of the time.

**The Influence of Clifford Beers**

Clifford Beer's autobiography "A Mind That Found Itself" (1907) was the first narrative written by a psychiatric patient that had widespread social influence. Beers was a Yale University graduate and young businessman when he suffered an acute mental breakdown precipitated by the death of his brother. After attempting suicide, he was hospitalized in a private Connecticut mental institution where he reported poor treatment, including mental and physical abuses. He spent the next several years in various state-run and private institutions. As a result of the treatment he received and his experiences, he vowed to make it his life goal to create reform in care for individuals with mental illnesses.

The following passage from *A Mind that Found Itself* conveys both the emotional impact of Beers' treatment by psychiatric staff and his sense of commitment to help other patients:

...Because I refused to obey a peremptory command, and this at a time when I habitually refused even on pain of imagined torture to obey or speak, this brute not only cursed me with abandon, he deliberately spat upon me. I was a mental incompetent, but like many others in a similar position I was both by
... antecedents and by training a gentleman. Vitriol could not have seared my flesh more deeply than the venom of this human viper stung my soul! Yet, as I was rendered speechless by delusions, I could not offer so much as a word of protest. I trust that it is not now too late, however, to protest in behalf of the thousands of outraged patients in private and state hospitals whose mute submission to such indignities has never been recorded... (p. 36-37)

Beer's account also influenced several prominent thinkers of the time, including William James and Adolf Meyer and led to the formation of a movement in preventive mental health approach known as the Mental Hygiene Movement and led to the first community mental health associations and clinics (Mosher & Burti, 1994). This was an example of society and professionals listening to and hearing, in a new way, the voice of a mental health consumer. He also had a large influence on the later consumer movement.

Conscientious Objectors and Journalists

Mental health consumers or patients were also listened to by a group of men who worked with them in the psychiatric wards and shared their experiences. The rejection of a large number of men into military service during WWII due to mental illness, and the activities of a group of conscientious objectors who were assigned duty in psychiatric hospitals also increased public attention to mental health concerns. The military objectors who served in the institutions were appalled by what they observed to be inhumane conditions and brought these situations to the public attention via the media (Mosher & Burti, 1994). Further media attention occurred in 1948 with the publication of The Shame of the States (Albert Deutsch, 1948) written by socially minded and outspoken medical journalist.
This work, in combination with a series of articles that included graphic descriptions and photographs, outraged the public, most of whom had thought little about the treatment of psychiatric patients. The other major event that led to the closing of institutions and creation of the community care movement was the introduction of the first effective antipsychotic medications, reserpine and chlorpromazine in the 1950's (Marder & Van Putten, 1995; Torrey, 2001).

Development of Pharmaceuticals. The development of the first effective antipsychotic, Chlorpromazine, can be traced back to a seemingly routine medical consult between a French surgeon who observed the drug's anxiety-reducing effects and a pharmaceutical company that promoted the new medicine. He convinced a number of psychiatrists to administer Chlorpromazine to psychotic and agitated patients. The resulting publication in 1952 on the drug's efficacy was the first public report on the effective drug for the treatment of a major mental disorder (Marder & Van Putten, 1995).

Major changes within mental hospitals of Paris were seen within a year of the introduction of Chlorpromazine including a decrease in the need for restrictive interventions such as seclusion and need for locked units. Shortly after the introduction of Chlorpromazine, the drug was accepted worldwide mainly due to the lack of any other effective treatment for psychosis (Marder & Van Putten, 1995). These events provided further impetus to pharmaceutical companies to research and develop increasingly effective antipsychotic agents. The stage was now set for the scaling down in the number of state institutions housing the mentally ill. While the advent of antipsychotic medication resulted in a lessening of symptoms, and overall great improvement in functioning among patients, it also resulted in a tendency among
psychiatrists to distance themselves from patients and focus on symptom management.

**Deinstitutionalization.** The combination of the increased public attention and development of psychopharmaceuticals led to the large scaling down and closing of psychiatric hospitals across the country. The social movement known as deinstitutionalization was undertaken, in large part during the 1960s and 1970s, for purposes of the establishment of community support systems and psychiatric rehabilitation. Unfortunately, the professional organizations involved in implementing the policies of deinstitutionalization were not able to collect adequate data regarding the impact on communities and patients of this large influx of patients (Torrey, 2001).

The complications arising from the deinstitutionalization movement confronted mental health professionals with the reality that people who suffer from severe mental illnesses need more than mere symptom relief. In fact, the complexity of these needs in many areas including social, vocational, residential, and educational has been brought to light (Anthony, 1993). This enlightenment led to a series of meetings at the National Institute of Mental Health (NIMH) in the mid 1970s and resulted in the creation of a system of services referred to as a community support system (CCS) (Anthony, 1993).

**Community Support and Psychiatric Rehabilitation.** As community services became implemented, greater attention was paid to the individual and societal consequences of mental illness. This in turn led to the development of the field of psychiatric rehabilitation, which emphasized treatment of the consequences of illness rather than just the illness itself (Anthony, Cohen, & Farcas, 1990; Anthony, 1993).

Rehabilitation models had come a long way in addressing the various needs of patients but still remained focused almost entirely on disability and negative aspects of
mentally ill. The need to consider strengths along with dysfunction led to the creation of a broader field. As those who suffer from psychiatric disabilities have improved, they and their families have become increasingly concerned with the mental health system and have become involved in improving services. The consumer and family advocacy movements have become influential to the point that it has been said that today we are actually moving toward consumer-driven systems at a policy level (Carling, 1995; Mosher & Burti, 1994).

The Consumer Movement. The mental health consumer movement developed in the 1970s mainly as a protest by former patients who had been in psychiatric hospitals. Currently their goals include overcoming stigma and preventing discrimination, promoting self-help groups, and promoting the recovery from mental illness (Mosher & Burti, 1994).

The movement arose in a sociopolitical context of the civil rights movement and the Viet Nam war protests, widespread consumerism and the women's movement. These social events inspired psychiatric patients to become better organized. They shared the experiences and feelings of outrage and degradation from treatment in mental institutions that included forced medication, restraints, harmful labeling and stigma (Mosher & Burti, 1994).

Another significant influence in the consumer movement was the book "On Our Own" (1978) written by a former patient, Judi Chamberlain. This book is said to have inspired many ex-patients to join the consumer movement. Along with the networks mentioned above consumers were also linked by a newsletter entitled "Madness Network News" (Hatfield & Lefley, 1993; Mosher & Burti, 1994).

Mental health policy makers are finding it increasingly difficult to operate without taking consumer viewpoints into consideration. In turn, consumers provide first-hand
information that influences mental health policy to include services tailored to their needs. This influence is a part of the empowerment movement which essentially involves people with mental illness increasing the control they have over their lives by, in part, influencing the organizational and societal structures in which they live in and interact with. (Clark & Krupa, 2002). Consumers have become involved in the full range of mental health services including planning, delivery, and evaluation, and in protection of individual rights.

Empowerment. As discussed above, the most influential change in recent mental health care history has been a shift away from a predominately medical model to a model that focuses on ability, potential and health (Clark & Krupa, 2002). The effect of the consumer movement and other activities involving community involvement is a change in overall philosophy and behavior at both the individual and group levels. This social phenomenon known as empowerment has been key in the continual shift in focus to a rehabilitation and wellness model (McLean, 1995).

Several definitions of empowerment exist and although they come from diverse professions they share certain basic qualities including a process of participation on an individual or group basis that involves increased personal control through critical thinking, action and resource mobilization (Clark & Krupa, 2002). As it pertains specifically to mental health policy, empowerment refers to a paradigm shift from a deficit model to a focus on health and wellness. (Clark & Krupa, 2002).

The preceding historical discussion is highly selective and its purpose was to highlight key event and individuals, that either directly or indirectly, have influenced an approach in mental health research and practice that values first-person accounts of mental illness experiences. This history is summarized below in Table 1.
<table>
<thead>
<tr>
<th>Time period</th>
<th>Event</th>
<th>Individuals</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>1838-1840</td>
<td>Publication of Perceval's diary</td>
<td>John Perceval</td>
<td>Narrative account taken seriously by scholars</td>
</tr>
<tr>
<td>20th Century</td>
<td>1909 Publication of <em>Interpretation of Dreams</em></td>
<td>Sigmund Freud</td>
<td>Beginning of psychoanalytic movement</td>
</tr>
<tr>
<td></td>
<td>1908 Publication of <em>A Mind that found Itself</em></td>
<td>Clifford Beers</td>
<td>First patient narrative to have a social impact</td>
</tr>
<tr>
<td>1950s</td>
<td>Third Force in psychology</td>
<td>A. Maslow, C. Rogers</td>
<td>Attention to uniquely human qualities; demonstration of inherent therapeutic value of listening to patients</td>
</tr>
<tr>
<td>1950s</td>
<td>Discovery of Chlorpromazine</td>
<td>H. Laborit, et al.</td>
<td>Control of symptoms, deinstitutionalization, community mental health</td>
</tr>
<tr>
<td>1950s-ongoing</td>
<td>Postmodernism</td>
<td></td>
<td>Cultural and academic atmosphere receptive to diversity and exploration of inner experiences.</td>
</tr>
<tr>
<td>Recent &amp;</td>
<td>Publication of <em>Inner world of Mental illness</em> (1964)</td>
<td>B. Kaplan</td>
<td>Collection of patient narratives with sensitive and scholarly coverage by the author.</td>
</tr>
<tr>
<td>Contemporary scholars</td>
<td>Research in Anthropology</td>
<td>S. Estroff, E. Corin</td>
<td>Contributions to literature on adaptation, recovery and Inner experiences.</td>
</tr>
<tr>
<td></td>
<td>Research in Psychiatry</td>
<td>J. Strauss</td>
<td>Contributions to literature on recovery, adaptation and therapeutic value of listening to accounts.</td>
</tr>
<tr>
<td></td>
<td>Research in Psychology</td>
<td>L. Davidson</td>
<td>Contributions to literature on recovery using phenomenology.</td>
</tr>
</tbody>
</table>
The historical developments discussed above have had the net effect of changing both mental health policies and intervention, and conceptions of prognosis and recovery. The concept of recovery has evolved as input from consumers and family members has been included in research and other policy decisions. Research on course and outcome of serious mental disorders now considers the meaning of recovery from the psychosocial aspects as well as the natural history of disorders. The concept of recovery continues to evolve as more is learned about the experience from the viewpoint of consumers and as prognosis is improved with increasingly sophisticated medical interventions. It is increasingly realized that recovery is a complex and dynamic concept and one must consider multiple factors when attempting to define or understand its meaning and implications. The concept has evolved from a strictly medical and disability-centered consideration to one of possibility and empowerment.

**The Concept of Recovery**

There is no one agreed upon definition or concept of recovery. There is rather a range of definitions (Lefley, 1994). Because the mental health field is deeply rooted in the medical model, historically a medical definition of recovery has predominated. This definition is: “regaining a former state of health” (*Taber's Cyclopedic Medical Dictionary*, p. 1682). If this definition underlies our understanding and approach to recovery in serious mental illnesses, few will recover. Indeed, this is a static concept ignoring that recovery is really a dynamic process not very well understood.

No one would have predicted that a person diagnosed with a severe mental illness such as schizophrenia would someday be considered to be able to recover and contribute to society, but recovery is not cure. With the combination of new medications, community services and increased awareness of individual rights,
recovery is now discussed and researched as a real possibility for all mental illnesses. What is meant by recovery though is an important consideration. As described below, recovery from serious mental illness does not necessarily refer to an absence of symptoms or a return to a pre-disease state of functioning.

Recovery has been defined in a number of ways including elimination of symptoms, improvement of symptoms, and improvement of function in spite of symptoms. At issue here is the question of whether recovery is the absence of illness or the ability to cope with illness. Objective indicators tell only a partial story. Some have defined recovery by specifying factors and time periods. For example, Sullivan (1994) defines “participation in some form of vocational activity, residence in at least a semi-independent setting, and having avoided psychiatric hospitalization for at least 2 years” (p. 20).

Only recently have researchers begun to consider recovery from the point of view of the individuals experiencing it. When subjective views are considered, a much different definition of recovery and factors which may predict it, emerges. The differences in definitions of recovery originating from mental health professionals and consumers reflect the change in focus from medical model to empowerment and are worth noting. Professionals have been partial to operational definitions which are cleanly quantified and amenable to observation, research and publication. Sullivan’s definition cited above is an example of such a wording.

In contrast, Anthony, derived the following definition from the writings of consumers:

Recovery is described as a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with
limitations caused by the illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness. (1993, p.19)

A definition of recovery and a representative model are vital because states and counties propose to create recovery-centered policies. Currently two views of recovery are being discussed: the rehabilitation view and the empowerment view (Fisher, 2000).

Rehabilitation View

The rehabilitation view considers recovery of function although the mental illness has not been cured. This is a similar concept to spinal cord injury or stroke. The person cannot return to premorbid state due to permanent injury but they can learn to adjust to the results of the injury and function in society (Anthony, 1993). This view sees mental illness as a permanent impairment. According to Fisher (2000), this view has many shortcomings including: 1. it is based on physical and medical models of stroke, paralysis, and so on; 2. It isolates functions; and 3. it doesn’t consider the whole person and the individual nature of recovery. It also involves possible negative social stigmata such as loss of privileges, loss of esteem, and dependence on social welfare systems which tends to promote labeling and loss of hope and motivation.

This model of recovery is a creation of mental health professionals and researchers. It has validity, it has usefulness, and the whole field of psychosocial rehabilitation is based on it. Many have benefited from it. However, it has shortcomings, most apparently that it does not incorporate the experiences of recovery from the viewpoint of the consumer or person who has had the mental illness.

The Empowerment Model

The empowerment model assumes a connection between recovery and healing, and that humans strive for a state of feeling balanced and whole. The authors
posit that we achieve this state only to varying degrees but lose integration to varying
degrees as a result of conflict and loss and stress of daily living. We all differ in our
ability to integrate after challenges and setbacks. If a person's losses are relatively
great and their resources relatively limited, he or she may become severely emotionally
distressed.

Severe emotional distress is viewed in this model as temporary and still
within the possibility of recovery. "If the person's social, cultural, economic and
psychological worlds support him, as he goes through this deep reintegration
process, his thoughts will return to shared reality and he will eventually return to
a state of healing" (Fisher, 2000, p. 3). However, if a person loses social role
and identifies with the role of mental patient she or he is likely to also lose
societal stature (Fisher & Ahern, 2000).

In summary, current models and practice of psychiatric rehabilitation are based
on assumptions that persons who have experienced a severe mental illness do not
recover, but rather can be taught to regain a certain degree of functioning. Newer
models of recovery operate on a premise of innate health and potential for healing.
They also take the individual's experience with the illness and mental health system
into account. More recent models of recovery incorporate elements of both
empowerment and rehabilitation (Fisher, 2000).

Changing notions of recovery, developments in psychiatric and pharmaceutical
treatment, and advances in community approaches have also influenced the questions
researchers have posed regarding the prognosis of those with psychotic disorders.
The research on course and outcome of schizophrenia exemplifies the evolution of
scientific thought in mental health research, and a discussion of this area at this
juncture also serves as an introduction to the section on the ways in which mental health research has been approached and the impact this has had on our understanding.

Research Approaches and Understanding

Due to its challenge to psychiatric classification and resistance to treatment schizophrenia has functioned as an exemplar of major psychiatric disorders (Corin, 1990). An overview of outcome research illustrates the profound influence that prevailing theories and research paradigms have had on dominant conclusions about the disorder. Such a discussion also clarifies the evolution in thinking among researchers and shows the gradual move toward a more flexible, holistic approach among schizophrenia researchers.

Course and Outcome of Schizophrenia

Researchers have been examining schizophrenia for over a century, and as Corin (1990) has stated: “It is as if the more we improve our tools to describe and study schizophrenia, the more it seems to escape definition, to be clouded with uncertainty, to defy treatment” (p. 153).

Since the time of its description by Kraepelin as “dementia praecox,” controversy has surrounded the definition and assumptions about schizophrenia. The most prevalent historical schizophrenologists (Kraepelin, Bleuler and Schneider) all disagreed over the pathognomic features of the disorder, specifically, which of these are endemic to the illness and which are a consequence of psychological reactions to pathophysiological changes resulting from the illness itself (Hoenig, 1983; Corin, 1990).

The past two decades have seen a rapidly accumulating body of evidence indicating a wide diversity of outcomes in schizophrenia. For example an entire issue of Schizophrenia Bulletin (1988, 14 (4)), was devoted to a review of the literature on
course and outcome and highlighted major findings and issues. According to the reviewers, the most salient and consistent conclusion was that outcome in schizophrenia is heterogeneous, varying widely from single episodes of psychosis with prompt resolution to long-term symptoms and disability (McGlashan & Carpenter, 1988).

According to Kraeplin "dementia praecox" was, by definition, a chronic illness resulting in a decline of functioning and a worsening of symptoms over time. Variation in outcome indicated to him that definitions were not specified carefully enough and improvement in symptoms a sign that the case in question had been misdiagnosed (Hoenig, 1983).

The developments in pharmaceuticals and improved, less restrictive community treatment options have greatly improved odds of recovery and positive outcome for individuals suffering from schizophrenia and other serious mental illnesses and challenged Kraeplin’s conclusions (McGlashan & Carpenter, 1988). Hence the current focus in schizophrenia outcome research is to explain this variability in outcome. Researchers are faced with the daunting challenge of sorting variations due to methodological issues, socio-cultural factors, and the natural courses of these illnesses.

**Methodological Concerns.** In a comprehensive meta-analysis of schizophrenia outcome research, involving 821 follow-up studies between 1895 and 1992, 51,800 subjects, Hegarty et al. (1994) reported difficulties in arriving at any conclusion regarding a typical course and outcome and cited diagnostic and sampling inconsistencies as major barriers to consensus.

Attempts to address sampling issues have arrived at suggestions that reduce error due to variation in course of illness. That is, in many studies, treatment effects
such as length of illness and treatment have not been accounted for. One way to address this issue is to select subjects experiencing their first episode of psychosis (Ram et al., 1992). Although difficult to achieve, this approach does reduce variability in outcome due to treatment effects.

Another methodological confound in outcome studies is a lack of diagnostic agreement among researchers and clinicians. Diagnostic criteria have changed over the years making interpretation of meta-analytical results that much more complicated. Availability of subjects has also influenced outcome data. Over the years, chronic, hospitalized patients were over-represented in outcome research.

In summary, the following suggestions have been made in order to decrease error due to diagnostic and sampling issues: 1. Samples should be defined by similar broad or narrow definitions of schizophrenia; 2. Samples should include similar initial severity, length and treatment of the disorder; and 3. Samples should utilize similar assessment criteria including measures of course and outcome.

In order to address these methodological issues, comprehensive collaborative, multinational study was initiated in 1978 by the World Health Organization (WHO, 1979). Subsequent research by this group was undertaken to address previous methodological shortcomings. The Long-Term Course and Outcome of Schizophrenia and Other Severe Mental Disorder (LTCOS; WHO, 1992) utilized standardized, reliable, and culturally sensitive assessments and included as subjects only individuals who presented with a first episode of psychosis (Harrison et al., 2001; Jablensky et al., 1992).

Interpretation of outcome study results is strongly determined by theoretical presumptions of the interpreters. These presumptions have, in turn, been dominated by two main approaches to analysis. The first of these is based on the Kraepelinean
goal to demonstrate the relationship among clinical symptoms, anatomic pathology and etiology and to describe the natural history of clinical syndromes (Corin, 1990). Prognosis is seen as an essential part of the syndrome and diversity of outcome as evidence of heterogeneity in the syndrome itself, resulting in a refining of the diagnosis, identification of subtypes, and an attempt to find a biological mechanism responsible for the various categories of the disorder (Hoenig, 1983).

This approach has been criticized for its circularity of reasoning, artificial narrowing of the syndrome, and the closing off of investigation into variation of outcomes. A second major trend in interpretation, initiated by those who criticized this position, begins with recognizing heterogeneity and attempting to identify the factors that might predict the course and outcome of the disorder. This approach has resulted in studies that have identified many potentially relevant factors influencing the course and outcome of schizophrenia including both individual and socio-cultural influences (Corin, 1990).

These seemingly disparate approaches are both predominated by a basically similar underlying supposition. In the first of these trends a general assumption is made that the course of schizophrenia can be understood by identifying conditions originating from the disease process itself. The second of these argues that understanding will come from an explanation of external factors (Corin, 1990). Both involve an "externalization" of the disease process as an entity existing beyond the individual. This trend is also a reflection of an overall objective approach to the study of mental illnesses and a distrust of subjective phenomena. The objective approach has dominated the study of psychopathology and prompted the development of research paradigms and designs leading to powerful statistical tests.
A third approach considers the interaction of the individual with the illness and the internal experience and meaning of the illness in understanding some of the variation in outcome studies. The concept of outcome is static and a more realistic concept becomes one of evolution. This change in perspective also leads to different research questions such as "what does influence a person recovering" and "how does that happen" (Corin, 1990, p. 157).

The differing approaches to the study of outcome in schizophrenia illustrate not only the influence of theory on interpretation of results but more importantly, the choice of what "lens" to view the phenomenon in questions or specifically, which research approach to utilize. This choice is often the result of institutional and academic biases and hence may not always be the most appropriate for the question being asked. The following section will discuss some of the influences that have shaped the trends in psychiatric research and some of the more recent developments shaping research choices.

Recognizing the psychosocial dimensions of recovery and outcome in schizophrenia and other serious mental disorders, the Rochester Recovery Inquiry was included as part of the fifteen-year follow-up interview package. This was the first time that such an instrument has been used in this follow-up interview package and the timing is not accidental. The following sections will provide the background and context that has developed to create an atmosphere that recognizes the contribution of subjective accounts of mental illness.

**Quantitative and Qualitative Methods**

The decision of whether to use a qualitative or quantitative design is basically a philosophical one, as these approaches are based upon different philosophies and overall paradigms. Traditional quantitative approaches to research have their roots in
the philosophical paradigm of positivism while qualitative approaches are rooted in a
paradigm known as naturalistic or constructivist (Polit & Hungler, 1995).

**Positivism.** Positivism was a philosophical doctrine that emerged partly in
reaction to metaphysical beliefs at the time and that maintained that such beliefs are
essentially unanswerable and thus not worth investigating. The tenets of positivism
were initially delineated by the French philosopher Auguste Comte (1798-1857), who
described it as the third phase of humankind toward the search for understanding. The
first phase, he held was the theological, involving a search for God and spirituality, and
the second, the metaphysical involved a search for philosophical truths. The third
phase of human search for understanding, according to Comte, involved a search for
facts and was first referred to as a positive or scientific phase. This phase initiated
scientific exploration and objective data collection and observation with the belief that
this would lead to a “positive” truth rather than a theological or metaphysical truth.

Other influential thinkers shaping this doctrine were Mill, Newton, and Locke.
Positivism was also part of a broader cultural movement known as modernism, which
emphasized the rational and scientific approaches and explanations of natural
phenomena. A fundamental, ontologic assumption underlying positivism is that there
exists an objective reality, independent of human experience or observation and that
events in nature are not random, but have antecedent causes (determinism) (Guba,
1990).

It was a goal of positivists to unify the branches of science, in the sense that
they should all utilize the same methods for discovering the positive truths about the
natural world using the process of induction to gather and summarize data. As will be
discussed below, the positivist approach was hugely influential on psychology because
it was believed that if psychology could adopt the scientific method of the positivists it could be accepted as a true science (Guba, 1990).

Naturalistic Paradigm. The naturalistic paradigm, also known as constructivist or phenomenologic, originated as a countermovement to positivism and is part of the larger cultural transition of postmodernism. Postmodernists valued the process of deconstructing prevailing ideas and thoughts and reconstructing ideas and structures in new ways. The naturalistic paradigm maintains that reality is dynamic, a construction of individuals living in the world, and is assumed to exist within a context always involving multiple and individualized interpretations (Polkinghorne, 1992). This is known as relativism or the idea that there are multiple interpretations of reality and that the absolute truth or falsity of these constructions cannot be determined. Furthermore, investigators do not strive to maintain objectivity, but instead often interact with subjects and realize and incorporate results based on this interaction.

As mentioned above, the positivist and naturalistic paradigms have been the major influences upon currently utilized methods of knowledge acquisition and involve very different techniques of collecting and interpreting data. Quantitative research is most frequently associated with positivism while qualitative methods are usually based on naturalistic paradigms, although positivists sometimes use qualitative approaches and those using naturalistic approach may also utilize quantitative methods.

Quantitative Research. Reflecting their positivist heritage, quantitative methods are utilized to objectively measure characteristics of phenomena. The quantitative and positivist approach are the foundation of empiricism and the scientific method and utilize powerful tools that have resulted in advances in both the natural and social sciences. Due to their numeric nature they have particular characteristics and advantages. The scientific method is based on the positivist paradigm and
includes a specific set of very orderly, disciplined procedures to obtain knowledge (Polit & Hungler, 1995).

The process of scientific research is linear and systematic starting with the specification of a particular problem, design of the study and collection of information, usually in a numeric form in a manner that controls the influence of any factors not defined in the research. During this quest for a problem’s solution, every attempt is made to remain objective as possible, thus personal beliefs are viewed as potential contaminants of the phenomena being investigated. Methodological approaches arising from the positivist paradigm are deductive, emphasize discrete, specific concepts and focus on verification of theory and hypotheses. Numeric data are amenable to mathematical laws and statistical operations. They may be combined, scored and analyzed in a number of ways that produced results that increase both validity and reliability (Marsella, 2000). Two of the most powerful properties of quantitative methods are generalizing of results from a sample to a population, and the measure and control of variables (Marsella, 2000; Edwards, 1998).

In sum, quantitative methods are appropriate for generating norms, generalizing from samples to populations, making statements about causality based on controlled experimental design, building large data bases, limiting costs of and standardizing test administration, scoring, and interpretation (Marsella, 2000; Edwards, 1998).

Quantitative paradigms are powerful techniques for assessing particular questions about reality but are not appropriate for certain other questions. As Liebsher has stated: "A quantitative research methodology is appropriate where quantifiable measures of variables of interest are possible, where hypotheses can be formulated and tested, and inferences drawn from samples to populations. Qualitative methods,
on the other hand, are appropriate when the phenomena under study are complex, are social in nature and do not lend themselves to quantification" (1998, p. 669).

**Qualitative Research.** Qualitative research approaches are based on a naturalistic paradigm also known as constructivist or phenomenologic. The naturalistic paradigm grew during the period in history known as postmodernism and as a reaction to positivism and was predominately influenced by the ideas and writings of Immanuel Kant and Max Weber, (Polit & Hungler, 1995).

A fundamental ontological assumption of this paradigm is that reality is diverse and is a result of individual construction. Reality is assumed to be relative or to exist within a context which results in a variety of constructions. It is further assumed that the absolute truth or falsity of these constructions cannot be determined, and thus, this is not a prerequisite of inquiry.

Methodological approaches arising from a naturalistic paradigm involve are characterized by the following features. They involve induction, are holistic, involve interpretations that are based upon subjects' experiences, utilize flexible and context-bound designs, and strive not for objectivity but to interact with subjects, and realize that results are affected by these interactions.

While those who work with quantitative approaches mainly use numbers, qualitative researchers work mostly with non-numerical data, such as those derived from interviews or observations. Another difference is that where quantitative researchers seek evidence to support or refute existing hypotheses, qualitative designs do not begin with presuppositions or hypotheses but instead allow these to emerge from the data by noticing patterns and recurring events (Huysamen, 1997).

Other strengths and characteristics of qualitative approaches are that they are particularly applicable for idiographic interventions and individual persons, preserve
contexts of events rather than manipulate variables, are concerned with essential qualities rather than amounts, accept social construction of reality for researcher and subject, emphasize multiple realities, research methods are flexible and adjust along with topics and questions under investigation, and value the interpretations, opinions, and perceptions of the investigator (Marsella, 2000).

In sum, quantitative and qualitative methods are based on quite different paradigms and as a result are able to illuminate different aspects of the same phenomenon. When utilized in the same study they may strengthen research design and increase the validity of results. The strengths of quantitative and qualitative methods are summarized below in Table 2.
Table 2. Strengths of Quantitative and Qualitative Instruments and Methods

<table>
<thead>
<tr>
<th><strong>Quantitative Instruments and Methods</strong></th>
<th><strong>Qualitative Instruments and Methods</strong></th>
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<tbody>
<tr>
<td>1. Useful for nomothetic approaches and population generalizations;</td>
<td>1. Useful for idiographic approaches and individual clients;</td>
</tr>
<tr>
<td>2. Generates numerical data capable of being combined, scored, and analyzed mathematically. Concerned with amount;</td>
<td>2. Preserves real life context of events being studied. Concerned with essence or nature of things not amount;</td>
</tr>
<tr>
<td>3. Generates “objective” data because of numerical status;</td>
<td>3. Preserves naturalistic context rather than controlling or manipulating variables;</td>
</tr>
<tr>
<td>4. Reduces errors associated with “interpretation” because of variations in perceptions among scorers;</td>
<td>4. Seeks meanings, interpretations, symbols;</td>
</tr>
<tr>
<td>5. Permits development of large data bases with common scoring procedures and methods;</td>
<td>5. Acknowledges social construction of reality for both researcher and subject. Emphasizes multiple realities;</td>
</tr>
<tr>
<td>6. Generates population norms for comparison purposes;</td>
<td>6. Emphasizes credibility, transferability, dependability, and confirmability of data;</td>
</tr>
<tr>
<td>7. Limits costs of test administrations, scoring, and interpretation;</td>
<td>7. Adjusts research methods and approaches to specific topics under study. Strong concern for ethnocentricism, sexism, ageism;</td>
</tr>
<tr>
<td>8. Standardizes administration, scoring, and interpretation;</td>
<td>8. Values opinions, interpretations, and perceptions of researcher.</td>
</tr>
<tr>
<td>9. Emphasizes internal validity and external validity indices and reliability (i.e., consistency) of measures.</td>
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</table>

As discussed above, the shift in paradigms from an empirical one to one that considers subjective material and qualitative method of research has coincided with a shift from a strictly medical model to one of rehabilitation and recovery. Both paradigms depend upon the contributions of psychiatric patients/consumers and would not have occurred without the social and political influence of a group of individual who themselves experience psychiatric disabilities.

The following section will highlight the influence and contributions of patient narrative information throughout history.

**Contribution of Patient Accounts**

Throughout history, individuals' accounts of their experiences and symptoms of mental illness have provided the foundation of our understanding of these disorders (Strauss, 1989) and have provided a rich source of data about experiential aspects of mental illness (Hudson-Jones, 1997). Historically, autobiographical accounts are the only source of information concerning subjective aspects of mental illness. As such, they provide essential information about variations in individual experiences and reactions to treatments not obtainable from large controlled studies.

First-person narratives published in the English language go back to the fifteenth century and have always been a source of interest but recently have become increasingly utilized by those in the mental health professions as teaching and research sources. These accounts, also known as first-person narratives contribute a unique archival record of the phenomenology of psychiatric disorder, and trace changes in treatment, diagnosis and public reactions to mental illness over a period of several centuries (Sommer, Clifford, & Norcross, 1998). For example, Sommer et al. (1998) in a review of these narratives reported that accounts of visual hallucinations
occurred when the reporting individual had been under a condition of sensory deprivation such as in restraints or in isolation.

Sommer, et al., (1998) reported that 48 autobiographies had been published just since 1980 by individuals diagnosed with schizophrenia or mood disorders who had either spent time in a psychiatric hospital, or were being treated in a community mental health program. Of the many things these authors noted in their review of those who had been hospitalized was, that over the years increasingly fewer books are critical of the treatment they received and several more recent publications are positive about this treatment, there are far fewer reports of staff brutality and more of increased respect for client/patient civil rights (Sommer, et al., 1998).

These memoirs are also important research tools and can be analyzed both quantitatively and qualitatively. They are accounts of illness from "the inside looking out" (Sommer, Clifford, & Norcross 1998,p. 1261), and therefore offer a viewpoint that the writer decides is salient, as opposed to an outside researcher, clinician or observer. They offer descriptions of various treatments patients have endured over the years including, exorcism, purging, leeches, insulin coma therapy, ECT, pharmacological treatments (Sommer, et al., 1998). These accounts are neither unbiased, objective nor representative, but their subjectivity may be considered their greatest strength and greatest weakness (Sommer, et al., 1998). The increasing recognition of the value of these narratives is also reflected in the fact that several psychiatric journals including *Schizophrenia Bulletin*, now include a first-person account in each issue of the journal.

**Historical Narratives**

A common theme in many accounts is a struggle by the victim of the illness to make sense of psychosis (Hudson-Jones, 1997). Throughout historical accounts, the search for and attribution of meaning has varied with social and historical contexts. For
example, the earliest narratives of psychotic episodes attributed psychotic symptoms to religious or spiritual experiences.

The *Book of Margery Kempe* (c 1436), is considered the first autobiographical account in the English language, of a psychotic episode. Kempe describes her first experience of mental illness, which today might be diagnosed postpartum psychosis, as “visions of devils tempting her to commit wicked deeds and to forsake her faith” (Hudson-Jones, 1997, p. 1).

The religious fervor and internalization by mentally ill individuals of the times was also reflected in autobiographies of the thoughts and experiences of those afflicted. Both Margery Kempe (c. 1436) and George Tross (born in 1631) have provided such accounts. Kempe described her experience as “visions of devils tempting her to commit wicked deeds and to forsake her faith” (Hudson-Jones, 1997, p. 1). Another example is provided in the following excerpt in which Tross describes an overwhelming religious guilt:

I was seiz'd with a great Fear and Trembling. A voice demanded: “Who art thou?” Convinced it must be God, he contritely replied, “I am a very great Sinner, Lord!” and fell to his knees and prayed. The voice proceeded: “Yet more humble; yet more humble.” He removed his stockings, to pray upon his bare knees. The voice continued. He pulled off his hose and doublet. Warned he still was not low enough, he found a hole in the floor and crept within, praying while covering himself in dirt. The voice then commanded him to cut off his hair, and at this point he anticipated it would next tell him to slit his throat. Spiritual illumination now dawned: the voice was not God’s but the Devil’s! Knowing he had “greatly offended”, he finally heard a call: “Thou Wretch! Thou has
committed the Sin against the Holy Ghost." Falling into despair--the sin against the Holy Ghost which was reputed to be unpardonable--he wanted to curse God and die, and his head exploded with a babel of clamouring voices, making a "Torment of my Conscience." (in Porter, 2002, p. 22-23)

Narratives attributing psychotic episodes to demonic possession persisted well into the early 19th century, despite the fact that cultural beliefs were shifting to secular explanations of illness as a defect of mental reasoning. This shift in understanding led to development of asylums. Initially such institutions provided only custodial care and segregation from society. However, by the end of the 18th century, new philosophies of humane care led to some improvements in many asylums. The development of a variety of treatments followed. Narrative accounts chronicled the effects of such treatments on recipients (Hudson-Jones, 1997).

Thus the focus of narratives shifted from religious persecution to accounts of psychiatric treatments of the day. Many such treatments were eventually discontinued, sometimes in response to personal accounts of former patients (Hudson-Jones, 1997). Autobiographical accounts have also provided information about the symptoms of mental illness as the following examples demonstrate.

**The Experience of Psychosis.** The experience of psychosis is a singularly life-altering event. Psychotic symptoms may occur in many different diagnostic categories including schizophrenia, paranoid disorder, major depression, bipolar disorder, and other disorders. The psychotic experience may differ among the various disorders. However, psychosis shares fundamental characteristics across disorders which include major disturbances in sense of self, cognition, emotions, relationships, and behaviors (Hatfield & Lefley, 1993).
The magnitude of the life disruption that is caused by psychosis can be respected when one considers the role that sameness and predictability play in our sense of safety and coherence. Indeed throughout life, individuals depend on this sense of equilibrium and stability of inner and outer environments in order to function as human beings. Antonovsky (1979) has stated this quite eloquently in the following: "the irreducible element in well-being is a sense of coherence, an enduring though dynamic feeling of confidence that one's internal and external environment are predictable and that things will work out as well as can be expected" (Antonovsky (1979), in Hatfield & Lefley, 1993, p. 123).

By disrupting the sameness and predictability of internal and external environments, psychotic experiences have a profound effect on the affected individual's sense of self. The person learns to identify with the psychotic experience and loses touch with that sense of self that existed before the onset of the illness. Those who have studied this phenomenon have said that schizophrenia and other psychotic disorders can be considered as "I am illnesses" because they so profoundly affect the identity of the person (Estroff, 1989). Level of chronicity has been associated with loss of a sense of self, identity and social roles (Estroff, 1989). Disturbance of identity is a defining feature in the DSM-IV when considering a diagnosis of schizophrenia (American Psychiatric Association, 1990).

A complete understanding of the phenomenon of psychosis is not be possible without an examination of the narrative accounts of individuals who have experienced these symptoms.

Changes in Self Perception.

Many accounts describe patients' experiences with this most frightening and disorienting of experiences. The following account illustrates the struggle to make
sense of what is an abrupt change in personality, thoughts and feelings that are new
and disorienting to the individual.

Something has happened to me-I do not know what. All that was my
former self has crumbled and fallen together and a creature has
emerged of whom I know nothing. She is a stranger to me and has an
egoism that makes the egoism I had look like skimmed milk and she
thinks thoughts that are heresies. Her name is insanity. She is the
daughter of madness-and according to the doctor, they each had their
genesis in my own brain. (Lara Jefferson, in Kaplan, 1964, p. 6)

In this dramatic account, the patient has personified her symptoms as a “creature” and
a “stranger” in a seeming attempt to separate the new, threatening experience from her
previously stable core and sense of self.

Others have described this challenge to self as literally being lost and in so
many words have described this. In the following description, Jane Hillyer describes
her experience of psychosis, perhaps related to depression as...

A feeling of being lost, lost utterly with no sense of place or time, no idea
as to who voices belonged to, no clear realization of my identity, lost in
mind and body and soul, lost to light and form and color: a distinct, acid
nausea of self-revulsion-all of these were in the feeling that swept over
me. (in Kaplan, 1964, p.160)

In both these examples, the sense of self has been threatened with resulting feelings
of alienation and estrangement.

In a psychotic state, a person’s identity can also become confused with that of
others. In the following example from Torrey (2002), a patient with schizophrenia
recounts his experience of believing that he can observe himself in different bodies:
I was myself in different bodies. . . . The night nurse came in and sat under
the shaded lamp in a quiet ward. I recognized her as me, and I watched
for some time quite fascinated; I had never had an outside view of myself
before. In the morning several of the patients having breakfast were me. I
recognized them by the way they held their knives and forks. (p. 34)

These examples illustrate the diversity of experience. They all describe the distortion
of self that occurs with psychosis but they are extremely divergent. In the first two
examples, the experience is obviously dysphoric while in the last, there is apparently
no element of fear present. In fact, the patient appears to be fascinated by the
experience and seems to enjoy observing himself in this distorted way.

Changes in Thought.

By definition, schizophrenia is a disorder of thought. Although these
disturbances are also seen in other disorders such as bipolar disorder, they are a
hallmark of the schizophrenias (Hatfield & Lefley, 1993). Disturbances of thought can
take many forms and include the impression that the mind is overwhelmed with too
many thoughts to process, that the connections between thoughts no longer exist or
that thoughts cannot be accessed at all (Hatfield & Lefley, 1993). In the following
excerpt a person diagnosed with schizophrenia describes this experience and the
corresponding struggle to regain a sense of control:

All sorts of thoughts seem to come to me, as if someone is speaking
them inside my head. When in any company it appears to be worse
(probably some form of self-consciousness). I don't want the thoughts
to come but I keep on hearing them (as it were) and it requires a lot of
will power sometimes to stop myself from thinking (in the form of words)
the most absurd and embarrassing things. (Hatfield & Lefley, p. 44)
The following is an example of this process as it occurs. Many of the narrative accounts involve retrospectives; in the following account, the individual is apparently in the midst of a psychotic experience and is attempting to write his thoughts but is unable to connect them. What results is a series of thought beginnings without any coherent connections and also contains many misspellings and incomplete sentences.

We are deprived because we are not able to make up our mind on some thing. Such as our jobs. The one things we would be best at. The book of Job is about a man who love all man human being. Love is a hard word to describe. Because we love so many thing. Which one do you love the best though. We should love God the most of all then ajust the rest of our life to what we want to be and what our Gold of life is. (Anonymous, in Kaplan, 1964, p. 187).

As mentioned earlier, a recurring theme in narrative throughout history is the attempt on the part of the person experiencing psychosis, to make sense of this. The following excerpt demonstrates this as the interpretation of voices becomes a complete preoccupation. The following excerpt is written by John Perceval and is from his narrative published in 1838. He kept a detailed diary of his experiences with his illness and of his treatment at the time. This diary was published in two volumes in 1838 and 1840, and again in 1961, in an edited version by Gregory Bateson (1964).

Hearing voices.

In the following excerpts of quotations from Perceval's Diary (Bateson, 1961), John Perceval eloquently describes the experience of hearing voices and his attempts and struggles to make sense of this experience and to gain a sense of control over his thoughts and feelings.

...I began to hear voices, at first only close to my ear, afterwards in my
These voices I obeyed or endeavoured to obey, and believed almost implicitly; especially after my mind was entirely deranged; I understood them to be the words of the Lord or of his Spirits... Those voices commanded me to do, and made me believe a number of false and terrible things. I threw myself out of bed — I tried to twist my neck, I struggled with my keepers... I recollect that even at the height of my delusions I refused to obey these voices on several occasions... I knew I had been deceived — and when any voice came to order me to do any thing, I conceived it my duty to wait and hear if that order was explained, and followed by another — and indeed I often rejected the voice altogether: and thus I became of a sudden, from a dangerous lunatic, a mere imbecile, half-witted though wretched being: and this was the first stage of my recovery. (John Perceval, in Bateson (1961), p. 265-267)

**Treatment.** The journals, diaries, and other autobiographical accounts have also provided fascinating although sometimes horrifying accounts of the treatment endured by psychiatric patients throughout history. A sampling of some of these accounts is provided below. The example below is from one of the most influential narratives in history, that of Clifford Beers. He describes the experience of the wearing "the muff," a device that was supposedly utilized to calm patients but was more often used with a disciplinary goal:

The putting on of the muff was the most humiliating incident of my life. The shaving of my legs and the wearing of the court plaster brand of infamy had been humiliating, but those experiences had not overwhelmed my very heart as did this bitter ordeal. I resisted weakly, and, after the muff was adjusted and locked, for the first time since my mental collapse I wept.
remember distinctly why I wept. The key that locked the muff unlocked in
imagination the door of the home in New Haven which I believed I had
disgraced- and seemed for a time to unlock my heart. Anguish beat my
mind into a momentary sanity, and with a wholly sane emotion I keenly felt
my imagined disgrace. (Beers, 1908, p. 40)

The following is an account of the experience of being placed in an insulin coma, a
somatogenic technique that was still widely practiced as late as the 1950’s.

The part of the treatments which I loathed the most was when I was revived
to consciousness. Seldom could I identify my own hands and feet as
belonging to my body. I felt completely disintegrated, literally all to pieces.
Seconds and minutes seemed like centuries while I desperately struggled to
restore my identity. Being strapped to the bed when I craved to get up was
equally frustrating. Most of the times my memory was erased, and my mind
blurred as far as rational thought was involved. When this happened, I was
frightened and helpless beyond description. (West, 1978, p. 102)

Stigma. In the following, a 53-year-old, happily married, professionally
successful sociology professor recounts his deep depression and hospitalization and
the challenges these posed to his sense of self and identity:

In spite of years of study of social psychology, all my professional
sophistication vanished now. “Insane” was only the worst of the
frightening words that flashed through my disordered mind.
“Institutionalized,” “psychiatric ward,” “mentally ill,” “deviant” are only a
few of the others that I can remember. Not only did I know that, in terms
of what we sociologists call “labeling theory,” my friends would hereafter
perceive me differently; I was already experiencing the pain of a new self-definition. Just the day before I had gotten my driver's license renewed. One of the questions on the application had been: "Have you ever been hospitalized for mental illness?" Never again would I be able to answer "No" to this question.

The realization was devastating. (Killian, 1978, p. 142-143).

The above examples provide only a very small sample of the hundreds of published first person accounts of various experiences of mental illness. For the interested reader, Table 3 below provides a more complete, but by no means comprehensive list, of resources.

Table 3. Bibliography of First Person Accounts of Mental Illness

Historical

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**Table 3. (Continued) Bibliography of First Person Accounts of Mental Illness**

**Autobiographical**

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# Table 3. (Continued) Bibliography of First Person Accounts of Mental Illness

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## Collections of Narratives

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### Family Accounts

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Table 3. (Continued) Bibliographies of First Person Accounts of Mental Illness

Family Accounts, continued

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Published Bibliographies

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Internet Sources (just a few of thousands), from: www.library.adelaide.edu.au/guide/med/menthealth/biog.html

1. 1st Person: a magazine which publishes only first-person accounts, opinions and poetry from people who have had a mental illness.
2. Autobiography page
3. Bipolar Disorder Writings
4. Depression: Personal Pages
5. The Experience of Schizophrenia
6. Personal Definitions of Depression


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Research Utilizing Patient Accounts

In recent years several investigators have recognized the untapped potential in utilizing patient accounts of individuals who have experienced various aspects of living with mental illnesses. These investigators have mainly utilized qualitative methods in order to describe as closely as possible the experience of mental illness and various struggles associated with trying to cope and live with psychiatric disabilities, and to identify common themes and patterns in data sets. Areas that have been examined include insight, quality of life, the relationship between illness and sense of self, and the concept of recovery from the perspective of individuals with psychiatric illness.

The Concept of Insight

For a concept that is so widely used in clinical practice, there is surprisingly little agreement about the meaning of insight. There is also no commonly accepted definition. Although psychoanalytically oriented clinicians differentiate between intellectual and emotional insight, the general current usage of the word refers to whether a person with a psychiatric disorder believes he or she has a disorder. Specifically, insight has been referred to as “the patient’s capacity to acknowledge some awareness of having an emotional illness” (Greenfeld, et al., 1989, p. 246).

Furthermore, it has traditionally been conceptualized as a unitary construct involving the polarities of “good” and “poor” insight. However, many individuals are able to acknowledge some aspects of their illness but not others. For example, they may be able to attribute a global meaning to their illness while showing poor symptoms awareness. Thus, insight is better seen as a complex dimensional and continuous construct (Amador et al., 1993).

It is widely agreed that insight is critical for many aspects of recovery including engagement in treatment for progress and for prognosis (Greenfeld et al., 1989).
the area of psychotic disorders however, understanding of insight is limited presumably
due to a longstanding assumption that psychosis precludes self-understanding
(Greenfeld et al., 1989).

Several factors have brought about an awareness that the concept of insight
needed to be broadened and more carefully defined. These include: 1. the limited
utility of the traditional concept; 2. the failure to include a range of views involved in a
patient's understanding; 3. the overall lack of agreement among mental health
professionals regarding the concept of insight; and 4. the global agreement among
professionals that the presence of insight is essential to recovery and prognosis.
(Greenfeld et al., 1989).

These issues were addressed in a study that aimed to broaden and clarify the
concept of insight. Using qualitative methods Greenfeld et al. (1989) interviewed
patients in various stages of recovery from psychotic illness. The subjects were
encouraged to speak freely about their understanding and experiences surrounding
their psychiatric illness.

Responses were found to be grouped into five major areas: views about
symptoms, thoughts about the existence of an illness, etiology of the illness, views
about vulnerability to relapse, and opinions about the value of treatment. Thus,
according to these authors, insight can be understood to be a much larger and broader
concept that traditionally held. From the point of view of patients undergoing various
stages of recovery, a number of distinct and largely independent dimensions are
involved in the process of understanding and incorporating the experience of a mental
illness. The results also indicated that a person may have insight into some aspects of
her/his illness and not others and that insight probably occurs in stages. This is
certainly a more clinically useful concept and can be more readily addressed in
treatment. The findings also belie the previously held belief that patients who experience psychosis are not capable of self-understanding. During the active stages of psychosis this may be hard to discern however.

**Quality of Life**

The measure of quality of life has become a popular focus for research in recent years. Although many have defined this construct few have considered its meaning to individuals who suffer from psychiatric disabilities (Corring, 2002). Most of the research has been conducted with individuals who do not have a major mental illness. According to Wolf (1996), there are very few studies that have investigated the construct of quality of life from the viewpoint of those who suffer from serious psychiatric illness. Others have argued that quality of life is so subjective a concept that the only way to address it is to utilize a self-report strategy and qualitative methods of analysis (Simmons, 1996).

In an exploratory study of the quality of life of psychiatric patients, Corring (2002) addressed these shortcomings. She interviewed 18 adults with a history of psychiatric illness and their family members. Focus groups met and discussed open-ended questions pertaining to individual's needs to obtain an acceptable quality of life. The Interview proceedings were audio-taped and transcribed verbatim. The transcripts were then perused several times by the researchers then assigned preliminary codes. Themes and subthemes emerged, and quotations from the narratives were used to illustrate the themes.

Several themes emerged and identified by the patients as necessary to insure good quality of life. They include: peer support and a feeling of belonging; the need to feel worthwhile; financial security; need for advocacy, need for a positive support system of family and friends, need for public education to reduce discrimination and
stigma; need for help with childcare; need to feel a sense of belonging to the community in which one lives; decent, affordable living space; maintaining a positive attitude; and not being rushed by others to recover too quickly.

The author's use of focus groups of individuals with histories of mental illness allowed her to discover the themes underlying their experiences. The themes that emerged are similar to others identified in similar qualitative studies of psychiatric patients (Corring, 2002). It is unfortunate that the author did not provide more detail regarding the subjects' demographic and diagnostic characteristics. She merely informs the reader that the subjects have a psychiatric history. Otherwise the study is an important contribution to the ongoing body of knowledge of phenomenology of experience of and recovery from psychiatric illnesses.

**Understanding of Illness and Sense of Self**

A highly relevant study, to the present research question pertaining to understanding of illness, was an investigation conducted by Estroff et al (1991). This study used predominately qualitative methods in the form of text analysis but also used quantitative methods and is a good example of a study that used the most appropriate methods to address the research questions. This study examined accounts of mental illness as they relate to sense of self in 169 psychiatric patients diagnosed with severe and persistent disorders. The authors were interested in sense of self because of the realization that mental illness is simultaneously an intensely private and public experience. Individuals respond to altered experiences of self and to ideas and actions of others which are sometimes in agreement and sometimes in conflict.

Previous work on the illness-identity subject yielded two types of self-talk: normalizing and illness-identity statements. A goal of a normalizing statement is to reframe the experience of illness so that it becomes non-pathological or normal,
something that most people go through. Illness identity statements, on the other hand, include language that indicates agreement with the experience of mental illness and is exemplified by usage of the words "I have" or "I am" followed by a disorder. They also commonly include mention of various symptoms.

Labeling has been supposed to influence the course of serious mental illness in that some researchers have made an assumption that labeling or self-labeling as chronic or seriously mentally ill creates a passivity in the individual (Scheff, 1984). Estroff et al., (1991) pointed out that this assumption was made without knowing what meaning the words "mentally ill" have to patients. Estroff et al., (1991) cite an influential study by Doherty (1975) in which self-labeling was investigated among a group of psychiatric patients over a 29-day period. This study involved three separate interviews with this group of 53 patients in a psychiatric hospital. Patients were asked if they agreed that they have a mental illness.

One-half of participants had answered in the affirmative and one-half had denied this. Half of this sample had changed their labels over the course of the investigation. This finding relates also to the review above of the study that investigated the concept of insight from the patients' point of view. Are patients who refuse to self-label or who do not agree with the clinician's diagnosis and interpretation of the patient's condition lacking insight, and is this a risk factor for later relapse? With the patients' changing their minds completely over a mere 29-day period, the authors look to the sense of meaning assigned to the label of being mentally ill rather than the agreement or lack thereof with that label.

Estroff et al., (1991) chose to further investigate the concept of understanding and the impact of labeling on the individual's sense of self. Specifically, they aimed to "seek empirical evidence of how and if [self-labeling] is related to illness
experience and course" (Estroff, et al., 1991, p. 340). The subjects in their investigation were 169 patients who had received various diagnoses indicating serious and chronic psychiatric disturbances. Furthermore, the investigators chose subjects who were "early in their psychiatric careers and likely to apply for financial benefits. "We reasoned that a person’s self-labeling stance and ideas about illness might influence his willingness to occupy a chronic sick role and thus contribute to different outcomes over time" (p. 341).

The procedure involved a total of five interviews at intervals of six months over a two-year period. Interviewees were asked in a semi-structured interview about their feelings and reactions about mental illness, medication, and the overall influence of mental illness on their lives. Responses from this interview were either audio-taped or written verbatim then subjected to a text analysis. Other sections of the investigation involved questioning subjects about psychiatric symptoms and socio-demographic information and were analyzed with descriptive and other quantitative methods. The text analysis involved identification of recurring themes and clusters within the text utilizing an inductive coding scheme.

In discussing the results of this investigation, the authors identified five types of illness-identity statements made by subjects: medical/clinical explanations, emotional-developmental themes, social-situational explanations, denial themes, and religious-spiritual explanations. Medical-clinical themes included language involving biological, brain or other material bodily functions. This theme also included use of the words "symptom" or "illness" or the name of a particular diagnosis. Substance abuse explanations were also included within this theme. The second theme identified by the authors involved attributing mental illness to various emotional or developmental factors, and mentioned factors such as various feeling states or childhood experiences
as an explanation for the present illness. The third theme identified was illness attributed to various social factors such as not having enough money or unemployment, substandard housing, etc.

A fourth theme identified involved a predominance of spiritual or religious explanations to account for the subjects' problems. The fifth theme involved statements involving denial of illness predominating. Other protocols involved mixed themes where two of the above themes predominated equally. The authors found that sociocultural factors influenced the accounts and self-labeling among their study participants more than did clinical factors such as formal diagnosis.

**Subjective Accounts of Recovery**

As discussed above, the concept of recovery from serious mental illness is relatively recent and until recently has been dominated by the viewpoints of mental health professionals. Medications and other treatments are resulting in better control of psychotic symptoms and long term outcome studies are illustrating that the outcome for these disorders is much more favorable than previously believed. This, in combination with other factors such as the consumer movement, has resulted in a new interest in the factors that influence recovery from mental illness.

In a review of the literature and personal accounts, Young and Ensing (1999) identified six predominant recovery themes: insight, rebuilding a sense of self, a sense of hope, empowerment, developing individualized coping mechanisms, and social support. As discussed above, insight involves awareness and understanding of the experience of mental illness but is now realized to be far more complex than previously held notions. Insight has been identified by both diagnosed individuals themselves and by those who try to help them as essential to and perhaps a first step in recovery.
Rebuilding a sense of self and the regaining a feeling of hope are interrelated and are prominent themes in recovery. Mental illness disrupts the equilibrium and deepest levels of identity (Hatfield & Lefley, 1993). The process of recreating a sense of self involves the possibility of failure and requires the taking of risks therefore also requires a sense of hope. As Davidson and Strauss (1992) remind us “discovering a more active self appears to offer the person a sense of hope that s/he will improve and would seem to provide the first opening to the road to recovery” (p. 136).

The notion of empowerment is also a main theme. As it applies to individual recovery Young and Ensing state that “it is characterized by increased self-confidence, self-reliance, sense of personal control, and self-esteem. Other components of empowerment appear to be a reduced sense of stigma regarding having a mental illness and a willingness to take personal risks that promote the recovery process” (p. 220). Another related essential theme is that of developing individual coping mechanisms. This in turn increases feelings of empowerment and a sense of hope. Some of the more commonly mentioned ways in which consumers have found to cope with their illness include: self-monitoring, establishing a behavioral routine, increasing activity, prayer, and seeking support from others (Young & Ensing, 1999).

The theme of social support has also been recognized as important to recovery. Research in this area has identified the relationship between higher levels of social support and lower psychological distress (Greenley, 1984). Others have found a reduction in hospitalization rates in community mental health programs that utilize a consumer involvement, increased social contacts and network therapy (Anthony & Blanch, 1989).

Young and Ensing (1999) explored recovery from the perspective of individuals with psychiatric disabilities developed a model based on their results. Eighteen
individuals with psychiatric disabilities were interviewed using semi-structured format and asking open-ended questions including the meaning of recovery, how individuals could tell that they were making progress, positive and negative factors that have influenced the recovery process, personal goals and expectations, and challenges. Using grounded theory techniques the authors developed a model of recovery and concluded that recovery is a process that involves a series of stages including:

1. "overcoming stuckness" (p. 223) which includes acknowledging and accepting illness, motivation to change, and finding hope; 2. developing a sense of self-empowerment which involved taking responsibility for one’s own recovery process; 3. redefining of the self, including gaining insight about the relationship between self and illness; 4. returning to basic functioning including self-care, increasing activities, and connecting with other people; 5. Improving quality of life was defined as a later stage of recovery and included striving to reach personal goals, risk taking, and finding meaning and purpose.

The authors concluded that their recovery model is supported by the existing recovery literature but highlights certain aspects of recovery that are not frequently mentioned in the literature, specifically, their finding of the salience of a return to basic functioning. Also the role of spirituality in providing hope and meaning to life was identified as essential to the recovery of the individuals in their study.

This is an important study that has greatly contributed to the literature on recovery. It is unfortunate that the authors did not provide more information about their subjects' psychiatric background. The diagnoses provided were self-reported and the authors did not provide any additional diagnostic information except to inform the reader that they had diagnosed with a severe mental disorder and were living independently in the community.
Others who have studied subjective aspects of recovery have identified similar themes. Smith (2000), in an analysis of ten interviews found that the initial stages of recovery involved acceptance, desire to change and seeking help from others. Individuals in that study also identified the following factors as important in their recovery: appropriate medication, a support group, meaningful activities, a sense of control and independence, a determination to maintain the recovery process, and an optimistic viewpoint about the present and the future (Smith, 2000).

In an ongoing longitudinal study of a cohort in Ohio begun in 1990, Cusick and Carstens (2001) identified the following factors as important to recovery: appropriate mental health care including medication, self-initiated activities, relationships with others, and spirituality. The consumers interviewed by these authors identified the development of an enhanced sense of self as essential to their recovery.

Davidson and Strauss (1992) also found that development of a sense of self, aids in many aspects of recovery including understanding and insight, coping with symptoms, and increasing a sense of confidence and empowerment. They further suggest that understanding the role of the sense of self in psychotic disorders may help to tie together diverse research findings concerning factors influencing the course and outcome of psychotic disorders. Others (Petite & Triolo, 1999) have also described the process of recovering a sense of identity and meaning during the recovery process.

Davidson (2003) has utilized phenomenological methods to identify processes and struggles involved in recovery from mental illness. He and his research team have analyzed over 100 interviews with a diverse group of individuals with varying severities of symptoms and lengths of illness. Davidson et al., (2003) has identified the following themes that interviewees have reported are helpful in their processes of recovery:
acceptance from others, engagement in meaningful activity, a sense of mastery and control, affirmation, a sense of spirituality, and maintaining a sense of hope.

In sum, recovery process studies to date have utilized a variety of research methods with a diverse group of individuals, yet have revealed many common themes among those interviewed. These investigations have usually focused on certain aspects of the recovery process within a given study and often include varying stages of illness in the same study.

The present study utilized an instrument that includes many recovery process issues and included only individuals who have experienced mental illness for an extended length of time. i.e., 15-year follow-up.

The Present Study

The purpose of the present study was to learn about the ways in which individuals understand, make sense of, and cope with the experience of mental illness. Unlike many recovery process studies to date, this investigation involved a 15-year follow-up of first-episode psychotic individuals, offering a rare opportunity to examine a learning history and repertoire of coping mechanisms and experiences. Although outcome measures were not examined in this study, the semi-structured questionnaire utilized is based on the recovery literature. The specific questions that were addressed in the present study included:

1. What are the ways in which individuals with serious mental illness describe the understanding they have developed about their disorders?

2. Specifically, what words and ideas do they use to describe a retrospective and current understanding of their illness?
3. What factors do individuals identify as having influenced understanding of their illness over time?

4. What are perceptions of how the illness has affected their interpersonal relationships?

5. What are the individuals' experiences with social relationships and social reciprocity?

6. What are the ways in which individuals report they cope with stress?

7. What do individuals perceive as the overall impact that having a mental illness has had on their lives and relationships?

8. Have these individuals experienced psychiatric coercion and what impact do they report?

9. What has helped these individuals deal with their illness over time?

10. How do these individuals view their futures?
CHAPTER TWO

METHODS

The present study focused on the accounts of individuals who had experienced initial psychotic episodes in Hawai‘i between 1978 and 1984 and who had participated in the WHO-Honolulu Determinants of Outcome of Severe Mental Disorders (DOSMD) short-term follow-up study. These same individuals again participated in the present study, a 15-year follow-up study in Hawai‘i between 1993 and 1999 entitled the long-term Course and Outcome of Schizophrenia and Severe Mental Disorders (LTCOS).

This research examined the responses of these individuals as they reflected on their long-term experience with their mental illness and related life events. This study only considered data collected during the follow-up period during 1993 and 1999, therefore only methods of the LTCOS study are described in detail. However, as mentioned previously, current study subjects also participated in an earlier investigation entitled Determinants of Outcome of Severe Mental Disorders (DOSMD). Because this is the same study cohort and many of the methodological considerations overlap, only pertinent background material is provided below.

**Background of the Present Study**

The present research is a part of a multi-national research program coordinated by the World Health Organization (WHO) to identify cultural and psychosocial factors in recovery from mental illness. The Determinants of Outcome of Severe Mental Disorders (DOSMD) study was the second of three multi-national (WHO) collaborative studies and addressed methodological shortcomings of its predecessor, the International Pilot Study of Schizophrenia (IPSS) and reexamined some of its results. A major change was to only include subjects who were first-time help-seekers.
The project resumed in 1978 and included 12 research centers in 10 countries. Each participant was contacted every four years for follow-up interviews until 1984. These interviews were then discontinued until the centers began locating and interviewing these original participants for the LTCOS portion of the research project.

Selection of Honolulu as a Study Site

Honolulu, Hawaiʻi was selected as a research center because of its ethnic and cultural diversity. When the DOSMD study was undertaken in 1978, the ethnic composition of Hawaiʻi’s population was as follows: 32% Japanese, 27.5% Caucasian, 14.1% Filipino, 13.2% Hawai’ian and part-Hawai’ian, 6.5% Chinese, 1.7% Korean, and 0.5% Samoan [Lum (1979), in Suarez (2001)]. A detailed description of DOSMD methods and of the present catchment area can be found in Suarez (2001).

Location of Subjects.

In order to locate as many of the original DOSMD subjects as possible, a variety of case-finding methods was used. Active case location continued during a six-year time period (1993 - 1999). Cases were located throughout the state of Hawaiʻi and some in the contiguous U.S. The methods used included perusal of public, private, state and federal records, clinical records of Hawaiʻi State Hospital, the Queen’s Medical Center, state-run community mental health centers on Oahu, and MFASIS (a database of Adult Mental Health Division of the Hawaiʻi State Department of Health). Other resources included historical and current phone listings, internet sites, the newspaper “morgue”, public-access criminal record computer terminals, and state and national birth, death, marriage, divorce, and voter registration records. Once located, subjects were contacted by appropriate means, usually by telephone or mail.
**Ethical Considerations.**

Initial contact to LTCOS subjects was made by either the WHO director or project coordinator. At the time of this contact, subjects were informed of the purposes of the worldwide investigation and offered 30 dollars compensation for their participation. Individuals who agreed to participate were then informed that the process would take approximately three hours of interviewing by a psychiatrist and behavioral scientist.

Subjects were asked for their signature on a participant consent form that fully described the purposes of the study and how the data would be used. Opportunity was given to discuss any questions or concerns regarding information in the form and regarding the investigation itself. The interview did not proceed until a subject had given this informed consent and signed the consent form.

Institutional approval to conduct research with human subjects was given to LTCOS project in 1993-94 by Queen’s Medical Center Research and Institutional Review Committee and the Hawai’i State Hospital Research Committee before beginning follow-up interviews.

Most interviews took place at University of Hawai’i at Manoa campus, NIMH/WHO study office, some at Queen’s hospital, study office, others in the subject’s home.

**Interview Procedures**

The Rochester Recovery Inquiry (RRI) is part of an extensive interview package that was administered to 61 subjects as part of a 15-year follow-up study of the cohort described above. Interviews included two sections consisting of clinical and psychosocial packages. This two-part interview lasted on average 2-3 hours. The clinical section was conducted by either a licensed psychologist or psychiatrist. This
section included the Present State Examination, Diagnostic and Prognostic Schedules, and Psychological Impairment Rating Scale.

The psychosocial section was administered by graduate students in the Clinical Studies Program and part of the WHO Hawai‘i headquarters research team. This section was designed to measure subject’s functioning within the past month in various social and independent living roles, occupational and leisure activities, social contacts, and general interests. In addition to the Disability Assessment Scale (DAS), information was collected from hospital and clinic records, interviews with mental health professionals in order to complete a history of social functioning and psychiatric history over the years since the last contact. The Rochester Recovery Inquiry (RRI) was the last portion of the psychosocial interview.

Training of Interviewers

As mentioned above, Interviewers were three graduate students in the Clinical Studies Program who were also part of the WHO Honolulu Field Research Center (HFRC). Training in administration of the RRI consisted of mastery of information in appropriate interview techniques according to World Health Organization criteria and instructions included within the RRI. Interviewees were trained by the principal investigator of the HFRC, Anthony Marsella. Initial training involved practice interviews with observation and feedback by Dr. Marsella. When interviewees had mastered initial observation sessions, they interviewed patients while being observed by the Dr. Marsella. They then interviewed patients independently but were observed periodically by Dr. Marsella throughout the course of the investigation.

Rochester Recovery Inquiry (RRI)

The Rochester Recovery Inventory (RRI), (Hopper, et al., 1995) is a 32-item semi-structured interview designed to explore recovery, coping, and impact of illness
from the subject's perspective. This instrument was constructed by a task force of recipients, researchers and clinicians, sponsored by the Center for the Study of Issues in Public Mental Health, Orangeburg and Albany, New York, and supported by NIMH grant P50MH51359 (1995). Specifically, the authors formed a taskforce for the purpose of developing a recovery instrument that would “tap multiple dimensions of living with severe mental illness not adequately addressed in existing questionnaires.”

This working group designed, pilot tested, and revised a prototype instrument tapping the following areas: the subject's own understanding of what his/her problem has been; social relations and reciprocity; modes of coping with recurring symptoms; impact of illness/stigma of various domains of everyday life and relationships; and experience with psychiatric coercion. The group named the instrument the Rochester Recovery Inquiry as the authors of the instrument had initially used it in a study in Rochester, New York as part of the World Health Organization (WHO) Rochester Site Cohort Follow-Up Study. The RRI was also added to the follow-up interview for a portion of the Honolulu cohort, as part of the WHO-Coordinated International Study of Schizophrenia (ISoS).

The interview is organized by topics which include: meaning and understanding of illness, impact of hospitalization and illness, interpersonal relationships and coping behaviors. Each interview ends with the question “Where do you expect to be 5 years from now?” Table 4 below, summarizes the specific questions in the RRI that address each recovery-process issue.
## Table 4. Interview Topics and Corresponding Questions

<table>
<thead>
<tr>
<th>Topics</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Understanding of Illness</td>
<td></td>
</tr>
<tr>
<td>A. Retrospective understanding</td>
<td>1. Please think back to the time when you were first hospitalized. Can you remember what you thought was going on at that time?</td>
</tr>
<tr>
<td>B. Current Understanding</td>
<td>2. How would you describe your illness today?</td>
</tr>
<tr>
<td>C. Awareness of factors influencing change in Understanding</td>
<td>3. What happened to change your view of your illness?</td>
</tr>
<tr>
<td>II. Perceived Social Impact of Illness</td>
<td></td>
</tr>
<tr>
<td>A. Perceived impact on how others behave</td>
<td>4. In general, how would you say your illness has affected how people behave toward you?</td>
</tr>
<tr>
<td>B. Perceived impact on self toward others</td>
<td>5. How would you say your illness has affected how you behave toward others?</td>
</tr>
<tr>
<td>III. Social support and reciprocity</td>
<td></td>
</tr>
<tr>
<td>A. Help and advice</td>
<td>6. Is there someone whom you can depend on for help and advice?</td>
</tr>
<tr>
<td>B. Someone to lean on</td>
<td>7. Who depends on you for help and advice?</td>
</tr>
<tr>
<td>C. To confide in</td>
<td>8. Whom you feel you can lean on?</td>
</tr>
<tr>
<td>D. Important decisions</td>
<td>9. Who leans on you?</td>
</tr>
<tr>
<td>E. Borrow, ask favors</td>
<td>10. In whom you can confide?</td>
</tr>
<tr>
<td></td>
<td>11. Who confides in you?</td>
</tr>
<tr>
<td></td>
<td>12. Whom you would trust to make important decisions on your behalf?</td>
</tr>
<tr>
<td></td>
<td>13. Who would trust you to make decisions on their behalf?</td>
</tr>
<tr>
<td></td>
<td>14. From whom you ask favors or borrow things?</td>
</tr>
<tr>
<td></td>
<td>15. Who asks favors or borrows from you?</td>
</tr>
</tbody>
</table>
Table 4. (Continued) Interview Topics and Corresponding Questions

<table>
<thead>
<tr>
<th>Topics</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>III. Social support and reciprocity</td>
<td>16. To whom you turn in emergencies things</td>
</tr>
<tr>
<td>F. For emergencies</td>
<td>17. Who turns to you in emergencies?</td>
</tr>
<tr>
<td>G. To do things with</td>
<td>18. Whom you do things with?</td>
</tr>
<tr>
<td></td>
<td>19. Who does things with you?</td>
</tr>
<tr>
<td></td>
<td>*</td>
</tr>
<tr>
<td>IV. Overall effect on life</td>
<td>22. How has having this illness affected</td>
</tr>
<tr>
<td></td>
<td>your life?</td>
</tr>
<tr>
<td>V. Overall effect on relationships</td>
<td>23. How would you say your relationships</td>
</tr>
<tr>
<td></td>
<td>with others have changed?</td>
</tr>
<tr>
<td>VI. Coping with stress</td>
<td>24. Is there someone you'd feel comfortable</td>
</tr>
<tr>
<td></td>
<td>being with in times of stress?</td>
</tr>
<tr>
<td></td>
<td>25. Would you like to have someone?</td>
</tr>
<tr>
<td></td>
<td>26. Is there someone who would come to</td>
</tr>
<tr>
<td></td>
<td>you if they were feeling stressed?</td>
</tr>
<tr>
<td></td>
<td>27. Is there some special place you go?</td>
</tr>
<tr>
<td></td>
<td>28. Are there special things you do?</td>
</tr>
<tr>
<td>VII. Psychiatric coercion</td>
<td>29. Some people we've spoken with told us</td>
</tr>
<tr>
<td></td>
<td>about experiences with physical force when</td>
</tr>
<tr>
<td></td>
<td>dealing with the mental health system.</td>
</tr>
<tr>
<td></td>
<td>Did this ever happen to you?</td>
</tr>
<tr>
<td></td>
<td>What impact, if any, did this experience</td>
</tr>
<tr>
<td></td>
<td>have on you?</td>
</tr>
<tr>
<td></td>
<td>30. Have you ever been the subject of a</td>
</tr>
<tr>
<td></td>
<td>legal court action in dealing with the</td>
</tr>
<tr>
<td></td>
<td>mental health system? What impact did this</td>
</tr>
<tr>
<td></td>
<td>have on you?</td>
</tr>
<tr>
<td>VIII. Things that have helped, advice to</td>
<td>31. Thinking back over the last fifteen</td>
</tr>
<tr>
<td>others</td>
<td>years and the things that have helped you</td>
</tr>
<tr>
<td></td>
<td>deal with your illness, what advice would</td>
</tr>
<tr>
<td></td>
<td>you give to someone who was having similar</td>
</tr>
<tr>
<td></td>
<td>difficulties?</td>
</tr>
<tr>
<td>IX. Future orientation</td>
<td>32. Where do you expect to be 5 years from</td>
</tr>
<tr>
<td></td>
<td>now?</td>
</tr>
</tbody>
</table>

* Questions 18-19, pertaining to child care, were excluded due to high number of items left blank.
In addition to the training discussed above, all interviewers who administered the RRI adhered to the following description and instructions:

The attached semi-structured interview is intended to explore some dimensions of recovery, coping and the impact of illness, as seen from the subject’s point of view. Suggested probes are meant to facilitate the process of remembering and reflecting. Some assist the subject to focus on specific aspects of the questions; others suggest areas of response that may not immediately come to mind; still others attempt to provide some concrete "staging" for what may otherwise sound hopelessly abstract. Interviewers should feel free to enhance or add to the probes. Note that the sections overlap to a certain extent, allowing the interviewer to refer to an earlier answer should the subject draw a blank on a specific question, or give an apparently contradictory response.

Subjects

Subjects were 61 participants in the WHO long term course and outcome of psychotic disorders study described above who completed the RRI, in addition to remaining clinical and psychosocial portions of the interview package. Of these 61 interview protocols, four were removed from the sample due to multiple unanswered questions. Therefore 57 completed interviews were retained for analysis. Table 5 summarizes basic descriptive information of these 57 subjects and Table 6 gives more detailed information for each subject.
Table 5. Description of Subjects (N = 57)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Total</th>
<th>Male</th>
<th>Female</th>
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</thead>
<tbody>
<tr>
<td>Schizophrenia</td>
<td>24</td>
<td>17</td>
<td>7</td>
</tr>
<tr>
<td>Affective Disorder</td>
<td>24</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>Atypical Psychosis</td>
<td>7</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Other Diagnosis</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

**Age**

\[ \bar{x} = 40.54 \]

Range = 30 – 62

<table>
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<tr>
<th></th>
<th>Male</th>
<th>Female</th>
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<tr>
<td>31 – 62</td>
<td>39.35</td>
<td>42.75</td>
</tr>
<tr>
<td>30 – 58</td>
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**Ethnicity**

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Total</th>
<th>Male</th>
<th>Female</th>
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</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>19</td>
<td>11</td>
<td>8</td>
</tr>
<tr>
<td>Japanese</td>
<td>14</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>Hawai'ian</td>
<td>11</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Filipino</td>
<td>5</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Chinese</td>
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<td>1</td>
<td>2</td>
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<tr>
<td>Other</td>
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( Native American, Palauan, Hispanic, Samoan, Vietnamese)
Table 6. Characteristics of Individual Subjects

<table>
<thead>
<tr>
<th>Case Number</th>
<th>Subject Number</th>
<th>Gender</th>
<th>Age</th>
<th>Diagnosis</th>
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<tr>
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<td>F</td>
<td>32</td>
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<td>Hawai'ian</td>
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<tr>
<td>075</td>
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<td>M</td>
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<tr>
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<td>079</td>
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<td>M</td>
<td>38</td>
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Table 6. (Continued) Characteristics of Individual Subjects

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<th>Case Number</th>
<th>Subject Number</th>
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<th>Age</th>
<th>Diagnosis</th>
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<td>097</td>
<td>57</td>
<td>M</td>
<td>32</td>
<td>schizoaffective disorder</td>
<td>Caucasian</td>
</tr>
</tbody>
</table>

Data Analysis

Subjects were interviewed and their comments were written down verbatim by researchers. Data were analyzed using qualitative methods with the goal of identifying common themes that most accurately addressed the interview questions. Each subject’s responses were typed with a word processor. A "hard" copy was then created for each protocol. Initially, these protocols were identified with only the subject’s random identification numbers. This was done to prevent possible bias in identifying categories and themes in responses. Only after the categories had been identified were the other identifying features of gender, ethnicity, and diagnosis added to the protocols.
**Analysis of Individual Narratives**

Data were analyzed following basic qualitative procedures described in Strauss and Corbin (1990) and in Worthen and McNeill (2002) and described below.

1. **Obtain a sense of the whole.** Each protocol was read at least twice and impressions and thoughts were recorded and set aside. This was done in order to get a sense of the whole narrative and to generate and become aware of thoughts and impressions that might bias later identification of themes and categories.

2. **Identify key words and phrases.** Each question in the instrument was considered individually. Responses were read and words and phrases that were relevant to the question were identified.

3. **Identify similarities among key words and phrases.** Similarities among these identified words and phrases were then identified. Similar words and phrases were then grouped together.

4. **Identify and name themes and categories.** Groupings of similar words and phrases were considered and categories were named that best represented each grouping of words and phrases. For example, words such as "illness," "mania," "voices," "paranoia," "I had schizophrenia," etc., became a category or theme of clinical/medical explanations for illness. The literature was also used as a guide in selecting appropriate categories (Strauss & Corbin, 1990).

5. **Place individual responses in categories.** Individual responses were then identified as belonging to one of the identified categories.
Frequencies were then tabulated to make statements about general patterns in the sample responses.

6. **Check accuracy of researcher decisions.** Two separate focus meetings with professional practicing clinical psychologists were conducted for the purpose of checking the accuracy and appropriateness of the identified themes and categories. Both these individuals have had extensive experience in the assessment and treatment of individuals with serious mental illness and both provided objective feedback. During the meeting, examples were provided for each category and responses were discussed in terms of their appropriateness. As a result of these meetings I changed several of my initial decisions regarding which category to place responses in. I also decided to look more closely at the importance of social factors in this group and the theme of taking responsibility. Consultation in combination with ongoing reference to the literature aided me in identifying themes that best represented the responses in the data set.

7. **Identify overall patterns in individual narratives.** After each response had been analyzed and tabulated, individual narratives were then read again in their entirety to gain an impression of overall adjustment and adaptation. The original initial impressions were brought forth in this process and overall impressions were attempted. After overall patterns were identified individual protocols were chosen to serve as examples of these patterns. Each of these was written in a narrative format including the questions in the narrative to
Methodological Challenges

By its nature, results of the proposed study are subjective and not generalizable to the entire population of seriously mentally ill. It may also be argued that the subjects who were able to participate in this interview were by this ability the more able and better functioning individuals. This is probably true to some degree. Several subjects refused to participate or were not able to due to extreme psychosis. As a result the data reflect the experiences of the subjects who have the ability and willingness to articulate their experiences verbally.

Another obvious limitation to the study is the attempt to describe experience as static where it is dynamic. This is a limitation and challenge of qualitative research generally and has no easy solution. The other obvious difficulty involves the interpretation of the words the subjects chose to describe their various experiences. How can one be sure that the researcher and the subject agree on the meaning of the words and that the researcher’s choice of interpretation agrees with the subject? Ideally, the researcher goes back to the subject to clarify the meaning as they understand it by scheduling a follow-up interview with the subject. This was not an option in the present study and seriously limits validity. It is possible that the interpretations describe in the results may not be in complete agreement to what the subject was experiencing or trying to describe at the time of the interview.

Reliability and Validity

Reliability and validity are determined differently in qualitative than in quantitative research. Traditionally, in a general sense, reliability refers to the degree
to which the same results would be obtained if the study were to be repeated, and
validity to the extent that the results accurately reflect the phenomenon being studied
(Morse & Richards, 2002). When these meanings are applied to qualitative research,
difficulties arise. For example, in qualitative studies, data are context-bound so
replication is often not possible and the degree to which a phenomenon represents
“reality” is also problematic due to the assumption of multiplicity of realities and social
reality construction in qualitative paradigms.

That being said, applicability, dependability, consistency, credibility of inquiry
and transferability of results remain goals of qualitative research and have been
suggested by some as more appropriate concepts as applied to qualitative methods
that reliability and validity (Lincoln & Guba, 1985). The terms reliability and validity
may still be used when discussing qualitative approaches but they have different
applications.

In qualitative methods, reliability refers to how accurately the research
techniques produce data. Reliability may be increased by use of more than one
method or data source. In the present study, several researchers independently
conducted semi-structured interviews which included the same questions asked of all
the participants. It is acceptable within the field of qualitative inquiry that all
interpretations are subjective. However, it is essential to determine the extent to which
one’s own biases and expectations are influencing the interpretation of the research
process. There are a number of ways to do this including keeping a journal of
thoughts, feelings and ideas as they occur and remaining mindful of the possible
biases these might cause. It is suggested that these subjective reactions be
‘bracketed’ from ongoing interpretations (Worther & McNeill, 2002). That is, they are
not ignored, they are merely set aside and acknowledged so that they do not interfere
with the ability to recognize new ideas and concepts that arise from the data. This was
done to some extent in the present study by recording and then setting aside initial
impressions.

Further ways to increase the solidity of qualitative work involve keeping a
record or history of each step of the process from literature review to coding to
interpretation and final write-up. A technique that is commonly used to increase validity
is to return to the original subjects after the researcher has assigned codes and
interpretations, and to ask the subjects if this is what they meant. If this is not possible,
another method is to have peers who are not involved in the study consult with the
researcher and give feedback on interpretations. In the present study, as discussed
above, I was able to independently consult with two clinical psychologists who work
daily with the seriously mentally ill but who were not involved in this dissertation
project.
CHAPTER THREE

RESULTS

The results are presented in the order in which corresponding questions were given to the informants and are grouped according to the concept they represent.

Overall results, representative of the sample as a whole, are presented initially followed by responses pertaining to differences among subgroups. Finally, impressions of overall individual narratives are presented. Verbatim examples of responses from interviews are presented throughout this section in order to exemplify each category and to provide clarification.

Understanding of Illness

Understanding and accounts of illness evolve over time and are influenced by a wide variety of social and cultural factors (Estroff, et al., 1991). The first three questions of the interview attempted to assess this evolution by representing the following components of understanding: a retrospective component, a current component, and a component representing a realization of factors contributing to any change in understanding over time. Results indicated that over time the majority of informants developed an understanding of their illness but these accounts of understanding varied widely in terms of individual experience and attributions.

Retrospective Understanding

The initial interview question asked subjects to reflect back to the first time they were in a psychiatric hospital and to recall what they thought was happening at that time. Responses indicated that informants developed a wide range of attributions and explanations to account for and make sense of their initial psychiatric experiences. After careful review of these responses, the following six themes emerged:
1. a confusion theme; 2. a clinical theme; 3. a theme represented by events and circumstances; 4. a theme represented by inner characteristics; 5. a religious theme; 6. a theme of nothing wrong. Table 7 shows the identified themes and corresponding percentages of responses.

**Table 7. Themes Representing Retrospective Understanding of Illness**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Percent Responding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confusion</td>
<td>26%</td>
</tr>
<tr>
<td>Clinical</td>
<td>16%</td>
</tr>
<tr>
<td>Inner Characteristics</td>
<td>16%</td>
</tr>
<tr>
<td>Nothing Wrong</td>
<td>14%</td>
</tr>
<tr>
<td>Events/Circumstances</td>
<td>12%</td>
</tr>
<tr>
<td>Religious</td>
<td>11%</td>
</tr>
</tbody>
</table>

**Confusion:**

The theme of confusion was identified and defined by recollections that included claims of not being able to remember what was going on, not knowing, or being unable to give a clear explanation or understanding of initial recollections of hospitalization and/or illness. A response was categorized as representing confusion if its predominant language included statements such as “I can’t remember,” “I didn’t know what was going on,” or included a very vague description with no explanation offered, such as “it was like a dream” or “I didn’t know where I was.”

This theme occurred with the greatest frequency and included twenty-six percent of the responses. Accounts ranged in complexity from containing only a few words to detailed descriptions of events and accompanying feelings. What they did share was an overall tone of confusion, dissociation, and an apparent inability to make sense out of the initial psychiatric experience or at least a difficulty verbalizing recollections.
The following is an example of a short response: “I didn’t know what was going on.” Other accounts involved a vague description of recollections with no clear understanding relayed, almost as if the subject was still struggling to make sense of initial impressions. An example of this type of more descriptive response was given by a woman who described her impressions and the way she was feeling and behaving at the time:

I wanted to get out. I was in a wheelchair when I woke up. I didn’t know where I was. My husband was on one side. I asked him, “Where am I?” They wouldn’t tell me where I was. I saw all these crazy people. I jumped out of my wheelchair and tried to get out. They wouldn’t let me out. I got mad. Next thing I know I was on top of this nurse. Later I tried to hang myself. I thought at the time my husband put me there to get rid of me for awhile. I told him I’d be good if he let me out.

Clinical

Another quite different theme included responses that utilized clinical or medical language to explain impressions of initial psychiatric experiences. Responses were categorized as clinical if they contained language associated with medical, clinical or psychiatric terms. If subjects described understanding their psychiatric experience in terms of symptoms, chemical imbalances, clinical disorders, or used terms such as “illness” or “disease” they were considered to be clinical responses. Subjects who mentioned alcohol or drug use in their responses also were included in this group. An example of such a response is: “I knew something was wrong, didn’t know what...weird thoughts, things weren’t right. I thought I had an illness. Everyone was against me. I
was doing things wrong, drinking... I thought it was schizophrenia, multiple personalities.” This type of response was given by 16% of the sample.

**Inner Characteristics**

A theme of inner characteristics was defined as an understanding or description of illness in terms of various emotions, feelings, and other internal or self-based concepts. Responses were included in this category if they involved language involving feelings or inner states. The following are representative examples of this type of response. “Just a lot of anger that I held in for so long. Just couldn’t hold it in any longer so it just came flooding out. Very angry about my past/parents... angry that I was hospitalized...” In this next example, self esteem and self-consciousness are the main elements. “...very self conscious...thought I wasn’t doing well at work...problems with concentration, self-involved, guilty feelings...not sure why it happened. I guess I’m not that confident in myself.” Sixteen percent of the sample explained their initial recollection of hospitalization and illness in terms of inner characteristics.

**Nothing Wrong**

Another group of informants reported, in their recollections, that they initially did not think anything was wrong with them. If the response involved such statements as “I remember thinking I shouldn’t be in a hospital” or if the prevailing theme was that the individual did not need help or did not have a problem it was placed in this category. The following are examples of this type of response. 1. “I felt I was being locked up when I didn’t need to be. Now I realize I couldn’t take care of myself. Then I thought I was okay.” 2. “I thought the doctors were out of their minds to say I was mentally ill.” Fourteen percent of the sample reported that their initial recollection of hospitalization and illness was that nothing was wrong with them.
Events and Circumstances

This category emerged from responses that shared a tendency to describe initial recollections in terms of external events and stressful circumstances, as exemplified by the following response. "I think I knew then that my illness was basically due to a very stress-producing relationship having to do with my marriage... I think it saved me to get out of the marriage." Another example is similar in relating the impression of the cumulative effects of stressful life events. "My family all got sick at the same time, alcoholism, addiction, abuse, violence. Mom got Parkinson’s disease, sister in a coma, younger brother in head-on in intensive care, all within two years. Even my girlfriend of five years left me." Twelve percent of the sample explained their initial recollections in these terms of events and circumstances.

Religious

Another group of subjects (11%) described their initial understanding in terms of religious experiences. Examples of language used in these responses included words such as “Satan,” “God,” “messiah,” and “angels.” The individual in the following example describes his total emersion in a religious idea and how it became the focal point of his understanding. “I had a fascination with prophecy. It started with my involvement in the church and within a matter of a few months I was off the deep end. I had too many and too high expectations of God. I created my own god. The hallucinations and euphoria were all just part of this prophecy I had created.”

Another subject reported that he thought that he had been possessed. “The devil took over...possessed...exorcism.” Another believed that he was the antichrist...”...thought I was antichrist, new messiah, I should kill myself because I was antichrist.” Finally, the individual in the next example describes the overwhelming effects of believing that he is the stage for a battle between good and evil. “I thought
there was a war between good and evil going on within me. I think evil was winning back then. At that time, I appeared to be an angel. I felt stuff was coming in to destroy me. I was naïve and timid at that time and I had no control. I just surrendered myself to it. I couldn't tell what was good and what was evil because it all came in at the same time.” The remaining responses (5%) either did not answer the question at all or involved responses that did not address the question.

**Present Understanding**

Another part of the concept of understanding included present accounts of problems or illness. The same themes that described responses to retrospective understanding were also apparent in descriptions of present understanding. Forty-two percent of informants described their present understanding in clinical or medical terms. The following examples illustrate the use of diagnostic terms in the explanations. “I would say now that I was bipolar. I have a chemical imbalance in my brain.” “I had a manic depressive breakdown.” Eighteen percent of informants referred to inner characteristics to describe their current understanding. Sixteen percent described their current understanding in terms of circumstances. Nine percent reported that they do not think they have a mental illness. Seven percent gave responses that included a combination of themes with no one theme predominating. Four percent each gave descriptions that involved a religious theme or a confusion theme.

A number of respondents maintained the same or similar explanations of their illness over time will be presented. Thirty-nine percent of subjects (n=22) reported a similar or same viewpoint of their illness when asked about how they view their illness presently. The themes that were maintained in these responses, in order of prevalence were: clinical (39%), inner characteristics (18%), circumstances (18%), not
having a problem (14%), and confusion (9%). One individual maintained a spiritual explanation for his illness and one response did not address the question so was considered a “no answer”.

The remaining 61% of responders reported a present understanding of their illness that was in a different category than their initial view. Of these, four individuals (11%) retained elements of their original themes in their responses but also included other themes and thus were considered to have a changed viewpoint. An example of such a viewpoint was provided by an individual whose retrospective understanding involved a spiritual theme exclusively but whose present understanding maintained a spiritual explanation but also included understanding in terms of inner characteristics and circumstances.

*Part of the problem was that I had a poor understanding of the bible and the Pentecostal Church was a little more than I could handle. Also I was a little bit perfectionistic, and this affected the way I prayed. But there were also a lot of suppressed emotional problems,... I was fooling around a lot, drinking and just cruising around. There was stress at home, because I was getting pressure from my parents to do something, join the army, go to college...*

Two of the other three combined responses involved a movement from an initial exclusively clinical explanation to a present understanding involving clinical, inner characteristics, and circumstances. The remaining combined response involved a movement from initial explanation in terms of inner characteristics to one involving clinical and spiritual components.

The remaining 31 interviews (54% of the total sample) involved a change in viewpoint from one single category or theme to another single theme. Many directions of change were described but the most common was a movement from an initial
explanation involving confusion to that of a present account using clinical terms. This particular type of change was reported by 29% of those who changed their viewpoint. In addition, the most commonly occurring endpoint among those who reported a change in understanding was a clinical explanation (55%). Other directions of change accounted for the remaining of this group and involved changes from circumstances to inner characteristics (10%), from confusion to circumstances (6%), spiritual to no problem (6%), inner characteristics to circumstances (6%), confusion to spiritual (3%), confusion to inner characteristics (3%), clinical to inner characteristics (3%), no answer to inner characteristics (3%), and a change from spiritual to inner characteristics (3%).

**What Happened to Change their View**

When subjects were asked about the elements that influenced a change in viewpoint about their illness, they mentioned a range of factors. These were mentioned alone and in combination and included in decreasing order of occurrence: psychiatrists and other mental health professionals (17%), influences from family and friends (14%), spiritual influences (11%), direct experience with the illness itself (6%), and self-understanding (3%).

Combination responses included knowledge plus experience with illness, experience and family/friends and psychiatrist, experience and self-understanding, knowledge and self-understanding, knowledge and mental health professional, family/friends and self-understanding. Each of these categories was represented by one individual or three percent of those who changed their viewpoint. One individual credited a meeting of his basic needs for his change in viewpoint stating, “I’m feeling less desperate from circumstances, getting a disability check and a roommate.” In addition, twenty percent of this group declined to provide a response to this question.
Examples from each of the above categories will now be provided. Responses crediting mental health professionals tended to be short and direct as in the following:

1. “Doctors educated me about the bad chemicals that come out with the Lithium;” and
2. “psychiatrist at [name deleted] clinic told me.” This next example communicates a sense of struggle in coming to terms with a diagnosis. “Dr. [name deleted] said that hearing voices was a sign of mental illness. Finally I admitted it was one too. At first I refused to believe it. Within a few weeks I believed it. I disagreed with the label at first. I realized he was being honest.”

Responses that mentioned family and/or friends as being influential in changing viewpoints involved receiving feedback or simply being motivated by wanting to be with family members. The following examples mention the receipt of some sort of feedback from friends and family members. “People around me, my cousins and friends told me.”

“My brother told me about an incident when I smoked marijuana with him and I began to act really weird. This happened right around the time I was hospitalized.” The next examples cite family members as motivating factors. “I didn’t like being like that. I wanted to be with my family.” “[I was] trying to get my son back, was trying to cooperate, he gave me a reason to live.”

Several subjects mentioned various types of spiritual factors as influencing their thoughts about their illness. The following three examples illustrate different aspects of spirituality and their impact. 1. “When I first started [deleted] Yoga process, when I was able to separate my mind from myself, when I realized I am not my mind;” 2. “It just happened gradually, I started praying, started to feel good about life;” 3. “When I think about my old life, I felt ashamed. Back then I didn’t feel ashamed. The church helped me change.”
Other subjects claimed that gaining knowledge about their illness was instrumental in changing their viewpoints. These responses were considered to be in a different category than those mentioning knowledge from mental health professionals because their language suggested some initiative and independent thinking as illustrated by the following examples. 1. "I read self-help books...as well as other 12-step literature because I thought I had an alcohol problem;" 2. "I researched about my mental illness and found out about my symptoms."

Self understanding was shown in general statements such as "...a learning process, it make me understand myself better. It was a good thing." Self-monitoring was also considered a type of self-understanding as the following statement shows. "I lost all my old friends. I understand how to handle, I know to get enough rest, or else voices, mania...take my medication, avoid overly stressful situations, or else that will bring on my voices, mania."

Direct experience with the illness was also an influence in changing viewpoints although it occurred more frequently in combination with other elements. The following excerpt is a mention of experience alone. "The second hospitalization... at first I denied it, but finally I accepted it. It hurt me." In the next examples, experience with the illness in combination with knowledge from reading is credited for changing a viewpoint. 1. "The last episode I had which was here on the mainland, I knew I needed medication. I had done some reading on it before then, but I still denied that that was me. After the last episode, I knew I needed medication;" 2. "Definitely, by books or hearsay, just learning about actual episode. For a long time, still feel to some degree, it really screwed me up. Maybe for the better, but it really screwed me up. Mentally, I've suffered a lot. I have to control my emotions, whereas someone who's never had this doesn't have to worry about it."

90
This next example mentions a combination of experience, family, and Doctor as influencing a change in viewpoint. "I have a lot more respect for my illness...That's a tough question. I had a manic episode and went to [homeless shelter], called police, went to my dad's and saw my Doctor. I trusted their judgment for the first time."

Themes representing present understanding are shown directly below in Table 8.

**Table 8. Themes Representing Current Understanding of Illness**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Percent Responding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical</td>
<td>42%</td>
</tr>
<tr>
<td>Inner Characteristics</td>
<td>18%</td>
</tr>
<tr>
<td>Events/Circumstances</td>
<td>16%</td>
</tr>
<tr>
<td>Nothing Wrong</td>
<td>9%</td>
</tr>
<tr>
<td>Combination</td>
<td>7%</td>
</tr>
<tr>
<td>Religious</td>
<td>4%</td>
</tr>
<tr>
<td>Confusion</td>
<td>4%</td>
</tr>
</tbody>
</table>

A comparison of present and retrospective understandings is depicted below in table 9.

**Table 9. Retrospective and Current Understanding of Illness**

<table>
<thead>
<tr>
<th>Theme</th>
<th>% Retrospective</th>
<th>% Current</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confusion</td>
<td>26</td>
<td>4</td>
</tr>
<tr>
<td>Clinical</td>
<td>16</td>
<td>42</td>
</tr>
<tr>
<td>Inner Characteristics</td>
<td>16</td>
<td>18</td>
</tr>
<tr>
<td>Nothing Wrong</td>
<td>14</td>
<td>9</td>
</tr>
<tr>
<td>Events/Circumstances</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
<td>Religious</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Combination</td>
<td>0</td>
<td>7</td>
</tr>
</tbody>
</table>

**Perceived Social Impact**

Social impact was assessed by asking subjects how their illness has affected how others behave toward them and how they behave toward others.
Perceived impact on how others behave

Subjects were asked the specific question “In general, how would you say your illness has affected how people behave toward you?” More than half of this sample (63%) reported that their mental illness has resulted in an overall negative impact on how others behave toward them. Responses in this category were further broken down into whether this impact was a result of perceived stigma, a result of characteristics of the illness itself or a combination of the two.

Stigma was perceived by 28% of the group while 12% perceived negative behavior from others to be the results of characteristics of the illness itself. The remaining 23% perceived a negative impact but did not specify this to be due to effects of illness or stigma. What characterized comments in these responses was a general sense of being rejected by others.

Responses were considered to involve perceived stigma if they included language that identified being treated differently due to having a mental illness. They included words such as “crazy,” “mental,” “label,” etc. The examples that follow clearly indicate perceived stigma in interactions with others. “They treated me differently because I was labeled mental, crazy. They underestimated me....” In this next example, the individual actually uses the term “stigma.” “I found out who was my friends. None of them ever came around and said 'hello' due to stigmatizing effects in gangs and rural community from involvement in mental health system.” In this next example, the individual shares the experience of being treated differently by family members. “People in my past have no idea how to take me. Extended family members are very hard to deal with. They show everything from sorrow [to] apprehension in dealing with me, a family member who might be ‘crazy’ and who was in the hospital. People, who have met me afterwards, I’m proud to say, hold me in very
high regard." Another individual attempts to "normalize" the language in this response. "They think I'm not normal like them. They think I'm mentally ill, but I'm emotionally disabled."

Other responses mentioned various aspects of the illness itself as resulting in negative reactions from others. 1. "Sometimes [people are] irritated with me. My mind spins out...uncomfortable to be around." 2. "People kept away from me. I was aggressive, belligerent, on drugs." 3. "I have a difficult time in my life. I'm mentally ill and I don't know the rules. I can't comply. I don't say, for example, "hello," I chat to myself or just stand there."

The remaining responses that suggested a negative impact did not specify illness or stigma as a factor but all included statements than involved feelings of being rejected by others. 1. "Two times [I was] kicked off the bus. I guess some people don't like me. I don't know why. Sometimes they snub me." 2. "[I was] ridiculed, laughed at, my humor fell flat, started around sixth grade."

The remaining subjects in the sample reported either no impact on others' behavior towards them (14%), or reported that their illness has had a positive impact on how others behave toward them (19%). Two individuals (3%) did not answer the question.

The responses that reported a positive impact included feelings cared for and supported by others as the following examples indicate. 1. "I've come to find out they're really nice and caring. They've either had it or had family with it." 2. "I really thought that people would shun me because I had been in a mental hospital. No one ever turned their back on me. My friends would come and visit me and were very supportive. I was surprised." 3. "It has made my relationships from the past stronger.
I became closer to them through sharing my problems, relying on them and respecting their opinions. Also through gaining their trust and knowing they care."

**Perceived Impact on Behavior towards Others**

When subjects were asked how their illness has affected how they behave toward others, their responses indicated two very different general patterns: 1. a general reaching out toward others, including increased sensitivity and compassion, and 2. a general pulling away from and increased caution around others, including having to monitor behaviors, being less patient with others or withdrawing altogether.

Close to a third of the sample (32%) gave responses that indicated that their illness has had an overall positive effect on how they behave toward others. These included an increase in compassion, being kinder to others. Examples of these responses are given by phrases such as “I’m more understanding and tolerant now of everyone,” and “I’ve become more open with others,” and “I enjoy people more than I did then.” Responses in the second group were characterized by an overall lack of comfort around others and included phrases such as “I have to watch what I do,” “I should stay away from everyone,” and “now I avoid people.” Forty percent of the sample gave responses that fell into this category. Twenty one percent of the sample reported that their illness has not had any effect on how they behave toward others. Four individuals gave responses that were too vague to categorize.

**Social Support and Reciprocity**

Social support has been defined as “attachments between and among individuals that promote mastery of emotions, offer guidance, provide feedback, validate identity, and foster competence” (Caplan, cited in Hatfield & Lefley, 1993, p. 80). In the present inquiry social support was represented by a series of questions
regarding social networks involving the give and take or reciprocity in everyday social interactions.

When all of below categories of social interactions were considered together with the question of how many informants reported at least one case of reaching out to someone, all but five individuals reported having at least one reciprocal social interaction. All the subjects reported that they had some sort of social contact with someone and most reported that they have people to turn to for help in various matters and that they have people to do things with. However, there was a large range in the number of such contacts reported, with one person reporting only a single contact with someone he barely knew, to others who endorsed the maximum situations addressed in the inquiry. Each social situation is considered individually below.

Is there Someone who You can Depend on for Help or Advice?

The majority of respondents (81%) reported that they have someone in their lives that they can turn to for help and advice. Most of these reported that they turn to family and friends for this purpose. Some turned to mental health professionals in addition to family and friends. A few individuals (10%) reported that they turn only to mental health professionals for this purpose. The remaining eleven percent of the subjects indicated that they do not have someone to depend on for help or advice.

Who Depends on You for Help or Advice?

A smaller proportion of the sample (67%) indicated that there is someone who turns to them for help and advice. Thirty-two percent said they have no one who turns to them for advice.

Reciprocity

Nearly the same proportion (63%) reported that they have reciprocity concerning someone who they both can depend on and who depends on them.
Sixteen percent indicated that they have someone they turn to but no one turns to them. Only a few individuals (5%) reported the opposite situation of not having anyone to turn to but that people turn to them for advice. Of those who reported that they do have reciprocity, over half (55%) reported that they have this with the same individuals.

**Is there Someone You can Lean on?**

A majority of responders (74%) reported that they have someone in their lives they can lean on. Twenty-three percent indicated that they do no have anyone they can lean on. Two individuals did not answer the question.

**Is there Someone who Leans on You?**

A slightly smaller proportion (65%) said that there is someone who leans on them. Nearly a third (32%) reported that they do not have someone who leans on them. Of those who did answer affirmatively to this question, all indicated that family, friends or a combination of these comprised these individuals who lean on them.

**Reciprocity**

Over half the sample (53%) reported that they have reciprocity on this area; they reported that they have someone to lean on and someone who leans on them. A third of the sample indicated that these are the same individuals. Nineteen percent reported having someone to lean on but that no one leans on them. Just over ten percent reported the opposite—that they have no one to lean on but someone who leans on them.

**Is there Someone in whom You can Confide?**

The responses were very similar to this question with a majority (75%) reporting that they have someone in their live in whom they can confide. The remaining twenty-five percent reported that they do not have someone in whom they can confide.
Is there Someone who Confides in You?

Responses were nearly identical to this question with only slightly fewer (72%) reporting there is someone who confides in them. Twenty-eight percent reported that no one confides in them.

Reciprocity

Roughly two thirds (67%) of the sample reported that they have reciprocity, having both people in whom they can confide and who confide in them. Nine percent indicated that they have someone to confide in but no one who confides in them. The remaining five percent indicated the opposite, that someone confides in them but they have no one to confide in.

Who would You Trust to make Important Decisions on your Behalf?

The majority of subjects (81%) reported that they do have someone in their lives in whom they can trust to make important decisions on their behalf. Fourteen percent said that they have no one in whom they trust to make such decisions. Five percent declined to answer the question.

Who would Trust You to make such Decisions on their Behalf?

Slightly more than half the sample (51%) reported having someone in their life that would trust them with these decisions. Slightly less than half (44%) indicated they do not have someone who would trust them to make such decisions.

Reciprocity

Less than half the subjects (40%) reported reciprocity in this regard. An equal proportion reported that they only have someone who they trust to make these decisions and ten percent said they only have someone who would trust them to make such decisions.
Is there Someone in Your Life from whom you Ask Favors or Borrow things?

Eighty-two percent of the sample reported that there is someone in their life from whom they can ask favors. Sixteen percent indicated they do not have such a person in their life. A few individuals (7%) declined to answer.

Is there Someone in Your Life who Asks Favors or Borrows things from you?

The results are nearly identical to this inquiry with most respondents (77%) reporting that someone borrows things from them and sixteen percent indicating they do no have this. Nine percent declined to answer.

Reciprocity

Sixty seven percent reported that they both have someone to borrow things from and someone who borrows things from them. Sixteen percent said they borrow from others but no one borrows from them and nineteen percent indicated that they don’t borrow from others but others borrow from them.

To whom do You Turn for Help in an Emergency?

Most of the subjects (89%) reported that they do have someone to turn to in the event of an emergency. Only a few (11%) indicated that they do not have someone to turn to.

Who Turns to You for Help in case of Emergency?

A smaller proportion (67%) reported that others would turn to them in an emergency. Twenty-six percent indicated that others would not turn to them in an emergency. Seven percent did not answer the question.

Reciprocity

Sixty three percent indicated that they have reciprocity with someone to turn to and someone who turns to them. In forty percent, these are the same people. Twenty-six percent indicated that they have someone to turn to but no one who turns to them
and two individuals (3%) said they have no one to turn to but people turn to them in an emergency.

**With whom do You Do Things?**

A majority of the sample (79%) reported that they have someone to do things with such as spend time with or go to a movie with. Sixteen percent indicated that they do not have anyone to spend time or socialize with. Three individuals did not answer the question.

**Who Does Things with You?**

Slightly fewer but still a majority (75%) reported that someone does things with them. Ten percent reported that they have no one who does things with them.

**Reciprocity**

Seventy-four percent indicated reciprocity in this area with both someone they do things with and someone who does things with them. In seventy percent the same people were mentioned. Twelve percent indicated they were isolated in this regard and had neither someone to do things with nor who does things with them.

**Perceived Overall Effects of Illness**

The next two questions pertained to general perceptions of how having a mental illness has affected the individual's life including a general question pertaining to “life” in general and one specifying effects on relationships.

**Ways in which having this illness have affected your life**

Nearly half of responders viewed their illness as resulting in either lost opportunities (26%) or in restriction of activities (21%). While there was some overlap in these categories, what set them apart was whether there was a mention of things that could have been or if the language primarily pertained to activities the individual could no longer engage in.
In the following example, the subject describes a series of changes in his life and his comments have a quality of grieving to them. "It changes your attitude about work, people, everything. It made me lose my job, my driver's license. I may have been able to get another job. Plus my concentration makes it hard to go back to school...I get bored, restless easily. I'd still be working, making good pay, financially independent, stabilized, and ready for a good retirement."

In this next example, the subject specifies the perceived deleterious effects of medication and hospitalization. "No, the medicine does. It slows you down. Hospitalization...difficulty thinking, money-wise, welfare...I'd be working, perhaps as a doctor, lawyer, businessman, definitely, I'd be married with kids, golfing..."

The following excerpt reflects the anger and discouragement loss of opportunity involves. "No work, fifty-fifty due to hearing voices and not being trusted on face value. Hearing voices makes me lazy...get sick of it. I'm a vegetable already. It affects everything." In the following quote this individual simply states that his illness..."makes me someone who is not an achiever, not have money or education. I don't know, it's that I'm not smart enough...I don't know."

The following examples illustrate the emphasis on restriction of activity and its effects on the individuals' lives. "I can't take a regular job, couldn't handle late hours, need to follow sleeping schedule, housework suffered, barely managed to hang-in." "I think if I weren't ill I'd do more things. I get kind of depressed and I have periods of low energy, apathy." "Yes, because I can't stay in the heat for a long time or in the cold either. I have to be in a comfortable place." "Just that when you have a lot of depression you aren't able to feel good about anything or notice yourself to do the things you want to do. I briefly tried cocaine, heroin, modern dance, acting 25 different things." "Because I've had to stay in the hospital for a number of years, I can't do
things I'd like to like camping and sporting events. Even if I'm out of the hospital, it may keep me from a few of the activities I would want to participate in.”

Close to one third (28%) of the sample reported that having a mental illness has not had an effect on their lives. Eleven percent declined to answer the question. A small percentage (14%) reported that having had a mental illness had resulted in a positive impact on their lives, resulting in a growth in self-reliance or self-understanding.

The following examples of perceived positive impact provide a stark contrast to the tone of the previous negative impact statements. The individual in the following example describes personal growth through struggle and hard work. “It made me a stronger individual, but it was a lot of work. I found that the ‘fixes’ aren’t out there in the world but in here within myself. You need to figure it out and take steps to change.” This next example indicates the emergence of gratitude “It did big-time. Made me wake up. Now I enjoy simple things like the leaves or the sunshine. I don’t take too much things for granted.”

In this next example, the individual considers the role of attitude in defining perceived impact. “How would my life be if it had never happened? Would I be as motivated? Earlier in my recovery, I had my little pity parties but I realized I could look at it as a blessing or a curse. I had to pick myself up. The bible says something about a period of tribulation. All things work out for the better. Sometimes terrible things happen for no reason, sometimes by design. I probably would have been into drugs, driving around, lazy and into a lot of trouble it this hadn’t happened…”

In the following example the subject describes the realization of the role of choice in adaptation. “I believe it has enhanced those things. It's given me an insight into my own personal boundaries and limits…insight into people and myself. If
anything it has been a big plus in my life. There is no way that type of experience
could not affect you...only through denial, I guess. It's a matter of how you choose to
let it affect you. You can turn poison into medicine.” Here, the experience is described
as humanizing: “It's been a blessing. It's telling me I'm not a freak of nature or of
society. It confirms to me that I'm a human being.”

**How relationships have changed**

The themes that emerged in response to this question, pertaining to how
relationships have changed over time, are very similar to the themes that emerged in
response to the previous question about how the illness has affected behavior toward
others. Again, the predominant themes that emerged from these responses were
those of caution and self-protection versus increasing social comfort and reaching out.

Subjects' responses were evenly divided with thirty-three percent indicating a
withdrawn/cautious pattern and thirty three percent a response of increased social
comfort and reaching out to others. Sixteen percent reported their relationships had
not changed since their initial hospitalization. Ten percent did not answer the question,
and nine percent provided responses that did not address the question specifically
enough to fall into a category.

Many informants, whose responses indicated a pattern of decreased social
comfort, mentioned that they have lost trust in others, as indicated in the following
examples. “Not trusting people easily...trust has to be earned and it takes awhile to
get to know people”. “I stick to myself. It might be a trust issue. It’s harder to trust
people.” “For a lot of reasons, I really tend to pick my friends well because I've been
burned in the past. I think I'm less trustful. I'm careful and a little more reserved.” “Not
trusting people easily...trust has to be earned and it takes awhile to get to know
people.”
Others mentioned a loss of initiative and fear of stigma. "They've changed a lot. I don't call them and they don't come to see me. It's harder to meet people now than before. I'm not really into making close friends with anyone." "I knew [friend with schizophrenia] from 10 years ago. Overall, not close friends, but it's always been like that. I try not to meet new people, I won't take initiative. I'd have to explain negative things...scared now they'd categorize me."

In contrast to the above comments, responses indicating a tendency to reach out have an optimistic tone and indicate in increased level of comfort around others. "[I'm] now friendlier with people, easier to get along with, more dependable." "[I] probably seek people out more but that may be because of my age though, not my illness. It may have been just a growing process, going to the mainland and going to college." Other comments indicate development of compassion and empathy toward others. "I think I'm more tolerant of people than I was before. I didn't have much empathy to peoples' sorrows. Now, however I'm not so quick to write people off." "I can make acquaintances, share things with people that before it would have taken me five years to accomplish." "Dramatically, prior to that, I was like a hermit, a complete captive. After that episode, I prospered. I have a good job, good money, and it's given me more knowledge. People come to me to ask questions, people trust me." "I think I've become more compassionate and understanding, not as critical of others so not as critical of myself."

**Stress and Coping**

Several items in the inventory pertained to the effects of stress on behavior and relationships. The first questions inquired about social reciprocity in times of stress, who the subjects felt comfortable being with during these times and who reached out to them. Over half of the respondents (61%) reported that they do have someone in their
lives they feel comfortable being with in times of stress. Thirty-seven percent indicated that they do not have such a person in their lives. One individual declined to answer the question.

Of those who answered in the affirmative, most (84%) indicated that they would reach out to family and/or friends in times of stress. Two individuals (5% of this subgroup) said they would feel comfortable reaching out to a mental health professional. Three individuals (8%) reported they would reach out to family members, friends, doctors and care home operators.

Of those who reported that they do not have someone to turn to when stressed, more than half (57%) indicated that they do not want someone to turn to, that they prefer to be alone in times of stress. However, the rest of this subgroup (43%) reported that they would like to have someone to turn to.

The subjects were also asked if there is someone who would turn to them if they were feeling stressed. More than half (68%) reported that various individuals do turn to them when they are stressed, all but two of these individuals indicated that those who come to them are friends or family. The remaining two answered in the affirmative but did not specify any particular individual. Twenty-five percent indicated no one comes to them when stressed and seven percent declined to answer.

Fewer than half of the respondents (47%) indicated reciprocity with regard to these relationships. That is, they indicated that they both have people they turn to and who also turn to them in times of stress.

Coping with Stress

Individuals were asked about what they do and where they go to help them cope with feelings of stress. These are listed below in Tables 10 and 11.
Table 10. Patient Reports of Activities that Help in Coping with Stress
(# of times mentioned)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Times Mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking/Take a walk</td>
<td>10</td>
</tr>
<tr>
<td>Read</td>
<td>7</td>
</tr>
<tr>
<td>Listen to music</td>
<td>7</td>
</tr>
<tr>
<td>Read the bible</td>
<td>6</td>
</tr>
<tr>
<td>Sleep</td>
<td>6</td>
</tr>
<tr>
<td>Lie on the beach</td>
<td>5</td>
</tr>
<tr>
<td>Watch television</td>
<td>5</td>
</tr>
<tr>
<td>Watch movies</td>
<td>4</td>
</tr>
<tr>
<td>Swim</td>
<td>4</td>
</tr>
<tr>
<td>Exercise</td>
<td>4</td>
</tr>
<tr>
<td>Meditate</td>
<td>3</td>
</tr>
<tr>
<td>Pray</td>
<td>3</td>
</tr>
<tr>
<td>Shop/go to a mall</td>
<td>3</td>
</tr>
<tr>
<td>Ride a bike</td>
<td>3</td>
</tr>
<tr>
<td>Go to church</td>
<td>2</td>
</tr>
<tr>
<td>Deep breathing</td>
<td>2</td>
</tr>
<tr>
<td>Go on the internet</td>
<td>2</td>
</tr>
<tr>
<td>Rest</td>
<td>2</td>
</tr>
<tr>
<td>Take a drive</td>
<td>2</td>
</tr>
<tr>
<td>Listen to radio</td>
<td>2</td>
</tr>
<tr>
<td>Take a shower</td>
<td>2</td>
</tr>
<tr>
<td>Play basketball</td>
<td>2</td>
</tr>
<tr>
<td>Play sports</td>
<td>2</td>
</tr>
<tr>
<td>Run</td>
<td>2</td>
</tr>
<tr>
<td>Surf</td>
<td>2</td>
</tr>
<tr>
<td>Talk to someone</td>
<td>2</td>
</tr>
<tr>
<td>Go to the temple</td>
<td>1</td>
</tr>
<tr>
<td>Creative visualization</td>
<td>1</td>
</tr>
<tr>
<td>Chant the Sutra</td>
<td>1</td>
</tr>
<tr>
<td>Chant God's name</td>
<td>1</td>
</tr>
<tr>
<td>Chanting</td>
<td>1</td>
</tr>
<tr>
<td>Talk to the gods</td>
<td>1</td>
</tr>
<tr>
<td>Stretching</td>
<td>1</td>
</tr>
<tr>
<td>Yoga</td>
<td>1</td>
</tr>
<tr>
<td>Reflect on nature</td>
<td>1</td>
</tr>
<tr>
<td>Get away from the situation and think</td>
<td>1</td>
</tr>
<tr>
<td>Write letters to family</td>
<td>1</td>
</tr>
<tr>
<td>Take medication and go to bed</td>
<td>1</td>
</tr>
<tr>
<td>Ride the bus</td>
<td>1</td>
</tr>
<tr>
<td>Cooking</td>
<td>1</td>
</tr>
<tr>
<td>Ride a motorcycle</td>
<td>1</td>
</tr>
<tr>
<td>Hike</td>
<td>1</td>
</tr>
<tr>
<td>Go to the gym</td>
<td>1</td>
</tr>
<tr>
<td>Call a friend</td>
<td>1</td>
</tr>
<tr>
<td>AA meetings</td>
<td>1</td>
</tr>
<tr>
<td>Use humor</td>
<td>1</td>
</tr>
<tr>
<td>Clean the yard</td>
<td>1</td>
</tr>
<tr>
<td>Wash clothes</td>
<td>1</td>
</tr>
<tr>
<td>Eat soup with friend</td>
<td>1</td>
</tr>
<tr>
<td>Move around</td>
<td>1</td>
</tr>
<tr>
<td>Go fishing</td>
<td>1</td>
</tr>
<tr>
<td>Relaxation training</td>
<td>1</td>
</tr>
<tr>
<td>Talk to the birds</td>
<td>1</td>
</tr>
<tr>
<td>Smoke cigarettes</td>
<td>1</td>
</tr>
<tr>
<td>Smoke cigars</td>
<td>1</td>
</tr>
<tr>
<td>Smoke marijuana</td>
<td>1</td>
</tr>
<tr>
<td>Drink a beer</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 11. Places that Help in Coping with Stress (# times mentioned)

<table>
<thead>
<tr>
<th>Place</th>
<th>Times Mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beach</td>
<td>19</td>
</tr>
<tr>
<td>Park</td>
<td>8</td>
</tr>
<tr>
<td>Bedroom</td>
<td>7</td>
</tr>
<tr>
<td>Temple or church</td>
<td>5</td>
</tr>
<tr>
<td>Home</td>
<td>5</td>
</tr>
<tr>
<td>Mountains</td>
<td>3</td>
</tr>
<tr>
<td>Library</td>
<td>2</td>
</tr>
<tr>
<td>Backyard</td>
<td>2</td>
</tr>
<tr>
<td>Shopping mall</td>
<td>2</td>
</tr>
<tr>
<td>Parents' house</td>
<td>2</td>
</tr>
<tr>
<td>Fast-food restaurant</td>
<td>2</td>
</tr>
<tr>
<td>Inside my heart</td>
<td>1</td>
</tr>
<tr>
<td>Anywhere alone</td>
<td>1</td>
</tr>
<tr>
<td>Alcoholics Anonymous (AA) meetings</td>
<td>1</td>
</tr>
<tr>
<td>Jacuzzi</td>
<td>1</td>
</tr>
</tbody>
</table>

In the discussion below, responses from these two questions were combined to define stress-relieving categories. The following categories of activities emerged from a review of the responses: quiet-reflective, quiet-passive, active-physical, and social. Responses either fell into one of these categories or contained a combination of categories.

Quiet-reflective activities included behaviors such as meditation, reflecting on the stressful situation while in a quiet environment, relaxation exercises, reading the bible, praying, and creative visualization. For example “I go to the beach, sit under a tree and just think, [or do] relaxation training.” Environment was important in reflective responses as in the following: “[I go to] temple and read the bible when depressed…chant Sutra.” The following response also mentions a serene environment. “[I go to] top of tantalus (mountain top), view Honolulu…get away from situation, calm myself down, think about the situation.” Another respondent finds relief from within himself. “Yeah, inside my heart. I chant God's name, meditate.” Quiet-reflective responses comprised eleven percent of the sample.

Responses were considered to be quiet-passive if they did not appear to involve reflection but merely passive behaviors such as watching television or going to
the mall. The following are responses that were considered to belong to the passive
category. 1. "[I go] to my room...take medicine, go to be;" 2. "home, play around,
sleep;" 3. [go to the] beach...[take a] hot shower;" 4. "No [particular place], read in
bed;" 5. "the shower, smoke cigars;" 5. "my bedroom, shopping mall, library, listen to
radio, sleep, wash clothes;" 6. "Take a drive, read, and watch TV. Drive;" 7. "to bed,
read, mindless TV." Twenty-eight percent of the sample reported that they engage in
this type of activity to relieve stress.

A few subjects (n=4, 7%) mentioned exclusively active behaviors in their
responses: 1. "Move around, go to the beach, swimming;" 2. "Las Vegas, travel, play
basketball, running, get rid of stress by being physical;" 3. "Out in the open, open air,
beach park, walking, swimming, being outdoors;" 4. "Throw board in water, pretend to
surf, being near, smelling the water."

Two individuals (3.5%) reported that they prefer social activities to relieve
stress. 1. "...haven't been able to squeeze that in...AA meetings, once or twice a day.
Use humor, make dumb jokes;" 2. "No [particular place]. I just go to certain people to
talk. My friend and I go to eat oxtail soup. It's a cleansing period for both of us. It's
like a brand new slate afterwards and we can laugh off the stress."

Many subjects (44%) included a combination of the above types of activities in
their responses. The most commonly occurring combination responses included
mixtures of active-physical with passive and reflective activities as the following
examples illustrate. 1. "...beach, movies, shopping, exercise (walk, run), meditation;"
2. "the internet, temples, parks, beach, churches, any spacious place with a hallowed
feeling...surfing, riding motorcycle;" 3. "[I go to the] beach, away from everyone, or to
a movie, half-hour walk three time a day, breathing, chanting, stretching, yoga,
Shiatsu;" 4. "Sit in back of house, go to park, run couple of laps, read bible, TV...;" 5.
“Regular places, fast food restaurants, mall, parks, take a walk, read bible, cooking
listen to music, T.V...” Other combinations of activities included reflective with
passive, reflective with social, and active with social.

Taken as a whole, the great majority of individuals (84%) reported that they
engage in quiet activities and did not mention socializing as a part of these activities.
Only a minority (9%) specified any social element to their stress relieving activities,
although playing sports such as basketball is a social activity, and attending movies
and shopping are also commonly social in nature.

**Experience of Force in dealing with the Mental Health System**

Unfortunately, for many individuals, part of living with mental illness includes the
experience and repercussions of undergoing some sort of force or control at the hands
of people working in the mental health profession. This often occurs in the context of a
psychiatric hospitalization. Subjects in the current study were asked about their
experiences with physical force in their dealings with the mental health system. More
than half of the subjects (53%) reported that they had experienced physical force in
some capacity from individuals representing the mental health system. All of these
reports of force occurred in a psychiatric hospital. Most of these reports recounted
episodes of being placed in physical restraints.

Although no one reported that this experience resulted in a lasting impact,
early all recollected various associated negative emotions ranging from humiliation to
anger. A few respondents commented that they “deserved” the treatment. Two
subjects reported that while they had not experienced force from mental health staff
members, they had suffered violence from other patients. One reported that she had
been raped by another patient; the other that a patient tried to suffocate her. The
following are examples of some of the comments subjects provided regarding their
experiences with mental health system force. “Yes, restraints used as dominance tool, now it’s different, make me not want to go back, sabotaged acceptance by psychiatric unit, went to [another hospital].” “[I was] wrestled down in emergency room and committed, was in solitary room for awhile until I’d take medication…scared the stuffing out of me.” “[In the psychiatric hospital] restraints [were used]. Staff does this to help you so maybe you can calm down and enjoy the activities offered.” “Yes, I don’t remember why though. I felt controlled - they tied me to the bed.” “A lot in [psychiatric ward], seclusion at [another psychiatric hospital], scary. Felt like I was a wild animal. I don’t need restraints. I can calm myself down. But I take the blame. I figure it’s my fault. But it’s wrong for staff to hit a patient.” “[It was] scary, I thought they were going to hurt me. Doesn’t bother me now.” “Yes, I was strapped on the bed because I had been in a manic episode. The orderlies loosened my straps so I could eat. Then I started acting really manic and threw myself on the bed. They jumped on top of me to hold me down but once they had me down, they hit me in the chest and stomach. It didn’t really have any impact.” “…restraints and seclusion…pissed me off. I hope they don’t do that to anyone else.” “They strapped me down when I wanted to leave the hospital, very humbling, I was powerless, but I forgot about it.” “[While at the State Hospital, I was] strapped down, urinating on self, accosted in shower. For awhile I had resentments, but to do something…After awhile I let it go. Now I laugh about it.”

Informants were also asked if they had ever been the subject of a legal court action in dealing with the mental health system and if this had an impact. Although no one reported that they had been the subject of a court action in dealing with the mental health system, several did mention various interactions with legal authorities. For example, the informant who responded that she had been raped related to the interviewer that there had been an investigation regarding this but that she did not
make any changes. Another reported that police were involved in commitment to a hospital. Others recalled various interactions with lawyers regarding commitment proceedings.

Specifically, nineteen percent of the sample mentioned some sort of the above-type interaction with the court system, mostly involving commitment proceedings. One reported that he had considered filing a suit for "emotional and verbal abuse by hospital staff." The others reported some sort of dealing with the court system but did not provide details, or declined to elaborate on the experience. Most reported that these interactions were either unsettling or caused them to "feel like a criminal." A few acknowledged that they needed the legal services or that such aid had been helpful. Others did not comment on any impact the experience had on them.

**Things that have Helped, Advice to Others**

The subjects in the present study had been living with various aspects of their illness and been in various stages of recovery for at least fifteen years. In that time period it is assumed that they had accumulated a knowledge base about the various treatments and attitudes, behaviors, etc., that have helped them to cope with their illness over the years. Subjects were asked specifically to comment on the things that they have found to be helpful in dealing with their illness and what advice they would give a person having similar difficulties. Results are presented below in Table 12.
Table 12. Things that have Helped, Advice to Others (# times mentioned)

<table>
<thead>
<tr>
<th>Advice to Others</th>
<th># Times Mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take medication</td>
<td>16</td>
</tr>
<tr>
<td>Talk to a Dr. or therapist</td>
<td>15</td>
</tr>
<tr>
<td>Talk to a social worker</td>
<td>1</td>
</tr>
<tr>
<td>Go to the mental health clinic</td>
<td>1</td>
</tr>
<tr>
<td>Trust the mental health staff</td>
<td>1</td>
</tr>
<tr>
<td>Find someone to talk to</td>
<td>2</td>
</tr>
<tr>
<td>Go to friends</td>
<td>2</td>
</tr>
<tr>
<td>Reach out for help</td>
<td>1</td>
</tr>
<tr>
<td>Find someone to trust</td>
<td>1</td>
</tr>
<tr>
<td>Go to your family and ask for help</td>
<td>1</td>
</tr>
<tr>
<td>Be with people</td>
<td>1</td>
</tr>
<tr>
<td>Rally around family and friends</td>
<td>1</td>
</tr>
<tr>
<td>Calm down and talk about it</td>
<td>1</td>
</tr>
<tr>
<td>Don’t isolate</td>
<td>1</td>
</tr>
<tr>
<td>Find others with the illness</td>
<td>1</td>
</tr>
<tr>
<td>Group therapy</td>
<td>1</td>
</tr>
<tr>
<td>Support groups</td>
<td>1</td>
</tr>
<tr>
<td>Eat nutritious foods</td>
<td>5</td>
</tr>
<tr>
<td>Take vitamins</td>
<td>1</td>
</tr>
<tr>
<td>Clean out your system</td>
<td>1</td>
</tr>
<tr>
<td>Get rest</td>
<td>1</td>
</tr>
<tr>
<td>Avoid stress</td>
<td>1</td>
</tr>
<tr>
<td>Take care of yourself</td>
<td>2</td>
</tr>
<tr>
<td>Don’t drink or take drugs</td>
<td>8</td>
</tr>
<tr>
<td>Exercise</td>
<td>3</td>
</tr>
<tr>
<td>Hike</td>
<td>1</td>
</tr>
<tr>
<td>Appreciate nature</td>
<td>1</td>
</tr>
<tr>
<td>Seek alternative medicines</td>
<td>1</td>
</tr>
<tr>
<td>Educate yourself about your illness</td>
<td>5</td>
</tr>
<tr>
<td>Try to make things better</td>
<td>1</td>
</tr>
<tr>
<td>Make goals/try to accomplish your goals</td>
<td>3</td>
</tr>
<tr>
<td>Get busy</td>
<td>1</td>
</tr>
<tr>
<td>Get a job/go to work</td>
<td>4</td>
</tr>
<tr>
<td>Keep yourself occupied</td>
<td>1</td>
</tr>
<tr>
<td>Challenge yourself</td>
<td>1</td>
</tr>
<tr>
<td>Don’t rush</td>
<td>1</td>
</tr>
<tr>
<td>Be more aware of symptoms</td>
<td>2</td>
</tr>
<tr>
<td>Perseverance</td>
<td>1</td>
</tr>
<tr>
<td>Have a good frame of mind</td>
<td>1</td>
</tr>
<tr>
<td>Believe in yourself</td>
<td>1</td>
</tr>
<tr>
<td>Stop it before it happens</td>
<td>1</td>
</tr>
<tr>
<td>Don’t fight it, accept it</td>
<td>1</td>
</tr>
<tr>
<td>Take time to make sense of it</td>
<td>1</td>
</tr>
<tr>
<td>Try not to be scared</td>
<td>1</td>
</tr>
<tr>
<td>Try to enjoy life</td>
<td>1</td>
</tr>
<tr>
<td>Try your best</td>
<td>4</td>
</tr>
<tr>
<td>Keep yourself strong</td>
<td>1</td>
</tr>
<tr>
<td>Keep a cool head</td>
<td>1</td>
</tr>
<tr>
<td>Be responsible for yourself</td>
<td>1</td>
</tr>
<tr>
<td>Take first step to improve self</td>
<td>1</td>
</tr>
<tr>
<td>Find God/pray to God</td>
<td>11</td>
</tr>
<tr>
<td>Go to church</td>
<td>8</td>
</tr>
<tr>
<td>Join a religion</td>
<td>1</td>
</tr>
<tr>
<td>Read the bible</td>
<td>2</td>
</tr>
<tr>
<td>Have faith</td>
<td>1</td>
</tr>
<tr>
<td>Affirmations</td>
<td>1</td>
</tr>
<tr>
<td>Seek spiritual treatment</td>
<td>1</td>
</tr>
<tr>
<td>Meditation</td>
<td>1</td>
</tr>
<tr>
<td>Chanting</td>
<td>1</td>
</tr>
</tbody>
</table>
Two levels of response became apparent while reviewing subjects' replies to this item. At a more concrete level, responses did organize into categories which are discussed below. At a higher level, responses involved differing levels of acknowledgment of self in the recovery process. For example, some appeared to involve a listing of medical advice such as "take your medicine," "get rest," and "avoid stress." Others reflected the individual's sense of themselves as an agent in their own recovery. While many of these responses also included a listing of advice, the main apparent theme was a realization of the role of self in the recovery process.

Responses varied in the clarity in which they relayed this sense of self. Some were vaguer but still gave a sense of a beginning of realizing that a recovery process has something to do with being aware of internal states, strengths and weaknesses or in recognizing spiritual strength, inner strength, or having figured individual aspects about their own recovery by initiative. The categories discussed below include 1. taking responsibility and initiative; 2. seeking and/or receiving help from others; 3. basic self-care.

**Taking responsibility and initiative**

Although the responses in this category also contained similar information as other responses they all had one element that set them apart. All the responses in this group suggested that the individual had searched for and found some answers on his/her own and realized that it plays a role in their own recovery process. Nearly one third (30%) of the responses fell into this category. The following example illustrates the elements of initiative and of figuring out what is needed on an individual level.

*Take that first step to better yourself. Especially look for that first job. It will give you the strong confidence you need. That's the biggest thing. A job gets you money to help get you other things. Also, you need some people to help*
you – social workers to find you jobs, etc. You need to find within yourself what you feel like doing and then get a job you like. You need people to show you the way. You need to have a desire to work or take into you the help that people offer. It can’t be forced.

The individual in this next example has found that becoming more assertive and future-oriented has been helpful. “I guess being more forceful in the way things are going, don’t linger on the past. Try to make things better, going forward, trying to accomplish your goals.”

This next person has found that developing a belief and confidence in herself has helped her cope with her illness. “Have the courage of you convictions. Listen to the little voice (intuition) deep down inside you. I never listened to those people that told me I would not get much better. Have a spiritual relationship with God.”

In the following example, the individual has found that a combination of time, reflection, and sharing with others has been helpful in dealing with the illness. “Primarily time, all these situations are different. For me, time worked more than anything else, that and the desire within myself to make sense of it all. Spend time alone and also with other people who have shared similar experiences. Get a good doctor who asks you questions and is interested in you. Find empathy.”

The individual in this next example struggles with apathy to find meaning in her life. “Maybe to...gosh...try one’s best, to try and enjoy life even though mental illness makes you lose your interest, keep busy if that’s what you want to do. Don’t leave out things that are interesting. There’s so much out there. Don’t lose your interest in life.”

The following example indicates the importance of self-challenge and keeping occupied. “Try to plan, make goals for yourself. Group therapy is good but it gets boring...the same thing for years it seemed. You have to challenge yourself. Also,
appreciate nature, hike. If you can't do that, be creative, do art. If you can't do that, then read. And if you can't read, just get out of the house and do something.”

The individual in this next example has found that being aware of and learning to cope with symptoms has been helpful in dealing with illness. “...To be more aware when it’s coming on. Don’t fight it, rather accept it. Fighting it makes it worse. Find some sort of way to escape it even for a little while, like a comedy movie or something. Find someone close to you that you can trust. A good sense of humor is key. Going to the beach and sitting on the shore helps.”

Finally, in this next example, the individual stresses the importance of recognizing individual responsibility. “Most important thing is coming to understand that you’re the source of the problem. Something within you is triggering it. You don’t have to even find out what it is, but take steps to get yourself out of it. Be responsible for yourself and stop pointing the finger at everyone and everything else. Exercise in order to make your mind and body whole. Take your medication.”

Help from Others

A second theme that emerged from responses was that of either seeking and/or receiving help and/or support from others. Subjects mentioned a range of people including mental health professionals, family, friends, and church members. Many responses mentioned other activities as well but the prominent idea was that seeking or getting help from others helped them to deal with their illness. The following examples emphasize the role of others as key factors in helping these individuals to cope with their illness over the years. 1. “Get some help. See a psychiatrist or get professional help. Sometimes it’s not enough to just have someone you can talk to. I feel lucky I had my family to help me;” 2. “Find a good therapist that you trust. Stay out with people if you can;” 3. “Buddhism, join a religion, have them support you. I’ve
gotten so much support from my religion. Go to your family and ask for help, love and care;” 4. “Try to rally around your family friends. Don’t isolate yourself. Get a good therapist. You can find them. If at first you don’t get a good one, keep trying;” 5. “Reach out for help, to family, or if that’s not enough, seek professional help. I could have prevented getting to the point where I was if I had asked for help earlier.”

Twenty-eight percent of the sample gave responses that fell into the seeking help category.

Basic Self Care

The key element in these responses was the listing of items of advice that all involved taking care of one’s self. They contained items mentioned in other categories but no one theme predominated. The following are examples of responses that fell into this category. 1. “Don’t take drugs or drink. Go to church and pray. Take your medication;” 2. “Pray to God, seek good friends, take your medication;” 3. Keep seeing your psychiatrist. Take your medicine;” 4. “I would really tell them to try and stay straight (no drugs or alcohol), to eat healthy, take vitamins and pray to God;” 5. “In the hospital, you can make it anyway you want, hard or easy. If you follow all the rules.”

Get as much rest as you can; 2. Take your medication; 3. Don’t get into situations that will bring on stress.” Twenty-six percent of responses fell into this category.

Some responses (11%) were too vague or contained too little information to constitute a theme but involved some sort of general advice regarding control of behavior or emotion. The following are examples: 1. Keep going, keep your thumbs up;” 2. “If it feel good tomorrow, do it today;” 3. “The only thing I can think of is to try to keep a cool head. If you get all mad, it’s not going to help you at all;” 4. “Cool them down for now-talk about it.” Three individuals declined to answer the question.
Although it was not prominent enough to constitute a main theme in this question, twenty-six percent of the members of this sample mentioned some role that spirituality has held for them over the years, in helping them to deal with their illness. Individuals frequently mentioned that “having faith,” “praying,” and “support from people at church” have been important in helping them deal with their illness over time.

**Future Orientation**

The final question of the interview was to ask subjects where they expected to be five years from that point in time. Most answered this questioned in terms of where they wanted to be using words such as “I hope” and “I want.” The most frequently mentioned hope or goal was for meaningful employment. Forty-three percent mentioned wanting various combinations of employment, meaningful relationships or marriage, family and to have a home. Some (9%) reported they only want to have a job and independent housing. Nineteen percent reported that they only hoped for a meaningful way to earn a living. A small group (11%) reported that they expect to be in the same circumstances they are in now in five years. The remaining individuals did not answer the question.

**Ethnicity, Gender and Diagnosis**

Gender and to a lesser extent, ethnic and diagnostic differences were noticed in the following areas: understanding of illness; perceived overall effects of illness; who is reached out to in times of stress; and reciprocity in social interactions.

**Understanding of Illness**

Initial understanding and changes in understanding varied between gender and to a lesser extent among ethnic groups and diagnoses in this cohort. More females (40%) than males (14%) described their initial recollection as being one of confusion. Males on the other hand were more inclined to recollect their initial experiences in
clinical terms. Thirty percent of the males and only five percent of the females described initial recollections using clinical explanations.

With the exception of spiritual explanations of initial recollections, other differences among initial recollections were small. No females gave spiritual explanations while describing initial recollections.

There were also some variations in recollections of initial experiences among diagnostic groups. Considering the two major diagnostic groups in the sample, schizophrenia and affective disorders, those with a diagnosis of schizophrenia had more of a tendency to give initial recollections using clinical terms (33%) than did those diagnosed with affective disorders (12%). Both groups were equally inclined to give initial accounts in terms of being confused, 25% for schizophrenics and 28% for affective disorders. Those with a diagnosis of Affective disorder were more likely to recall initial experiences in terms of inner characteristics (20%) than were those diagnosed with schizophrenia (8%). The number of subjects in remaining categories was too small to make meaningful comparisons.

Considering variation in initial accounts among ethnic groups, the tendency to recall initial experiences as spiritual in nature was more a tendency of those of Hawai’ian (27%) and Filipino (40%) and not Caucasian (5%) ethnic groups. However, the numbers of subjects in each of these subgroups was small and as discussed above without additional information it is not possible to discuss meaning or implication of ethnic differences. They are merely reported here as part of the overall results.

The largest differences were noticed when considering how many and who changed their initial viewpoint about their illness. A majority of the females (80%) but just a little over half the males (51%) had a categorically different present explanation
for their illness than initial explanation. In addition, more Caucasians (37%) than other ethnic groups changed their initial viewpoint.

**Overall Effects of Illness**

Responses showed fairly proportional distributions in most of the other interview questions until the responses pertaining to overall effects of illness on life were examined. Here there was a slight tendency for more males (11%) than females (4%) to report that their illness has affected their lives in positive ways. However, these proportions represent only a small number of individuals.

A larger difference was noted when examining reported effects on relationships. More of the males (41%) than females (20%) reported that overall, their illness had resulted in an improvement in their relationships and an increased comfort with others. Females, on the other hand, tended to report that their illness has resulted in an overall loss of trust in others and/or a tendency to less comfortable around other people. Over half the females (55%) reported that they have become more cautious, less trustful or otherwise have less comfort in their relationships with others. In contrast only 19% of the males reported a decrease in social comfort. Similarly, more males (22%) than females (5%) reported that their illness has not had any effect on their relationships with others.

**People turned to in times of stress**

The results indicate that, at least in this sample, the decision to turn to others in times of stress is related to ethnicity. Nearly all the individuals in the Hawaiian ethnic group (91%) turned to others, mainly family and friends, in times of stress. A majority of Japanese (71%) also reported they turn to family and friends when stressed. Caucasians were roughly evenly divided with a little more than half (53%) turning to others, mostly family and friends, and 47% either choosing to be alone or not having
anyone to turn to. Eighty percent of the Filipino group indicated that they have no one to turn to in times of stress. However, there were only five individuals in the Filipino group.

Social Reciprocity

A low level of reciprocity was defined as three or fewer social situations in which an individual had a give and take interaction with others. The range of such interactions was zero to three in this defined subgroup and a total of 20 individuals fell into this group. There were more males in this group than females and more individuals with a diagnosis of schizophrenia than affective disorder. In total, a little over forty percent of the males in the total sample had low levels of reciprocity while twenty-five percent of the females reported this. Fifty-eight percent of those in the total sample with a diagnosis of schizophrenia reported low reciprocity while those with a diagnosis of affective disorder comprised 20% of this group.

A Closer Look at Social Factors

A variety of social factors was reported by members of this cohort as influencing their illness experience. These ranged from receiving information from others and support from family and friends to perceiving discrimination from others. Two groups of informants responded quite differently to a major question pertaining to overall effects of illness on relationships with others. Thus, it seemed that responses to other questions pertaining to social interactions and perceptions about overall effects of illness might also differ between these two groups. Therefore a closer look at the protocols representing these two very different response sets seemed warranted.

To review, equal proportions of this sample responded in opposite ways when asked about the overall effect that mental illness has had on their relationships with others. Specifically, this question asked "looking back over the entire period, how
would you say your relationships with others have changed since your first hospitalization? Thirty-three percent of the sample indicated their relationships had been affected in a way that resulted in a tendency for them to be more cautious in their relationships or to withdraw from others. Another 33% responded in an opposite way reporting they now have more of a tendency to be more sensitive to others and to reach out to them more. The two response types are compared and contrasted below on a number of other factors assessed in the questionnaire including social reciprocity, gender, and ethnicity. For ease of discussion, the two groups are referred to below as “cautious” and “reaching out” respectively.

Social Reciprocity

There was a tendency for individuals, who reported both positive impact on their lives and a tendency to reach out to others, to also report higher levels of social reciprocity with the same people. Specifically, individuals who responded in this manner reported a mean reciprocity number of 5.25; out of a maximum possible number of seven situations; n=4; range=4-6; mode=6. Those who reported that the illness had a positive effect on their lives but resulted in a tendency to be cautious around others also reported higher levels of reciprocity with a mean of 4.25; range = 3-6; n= 4; mode=6.

Those who reported both a negative impact on life and a cautious response to others had a mean reciprocity score of 3.4; range= 0-6; n=10; mode=4. Individuals who reported a negative result on their lives but a reaching out to others had a mean reciprocity of 3.0; range=0-7; n=14; median=3.

Gender Differences

Cautious: Considering the sample as a whole, there were twice as many females in this response group than males. Specifically, 50% of the females in the
total sample indicated they had lower levels of comfort around others while 24% of the males from the total sample responded in this way. A close look at the language used among males and females reveals some interesting differences. The males tended to describe this effect on relationships using more general terms portraying concern about how others might perceive them. For example, "people hate my guts now;" "I'm scared they'd categorize me;" "my reputation has suffered." Other responses suggested general avoidance and withdrawal: "I'm more restrained, isolated," "and harder to meet people, not into making friends;" "I avoid them;" "I won't take initiative." Only one male in this group mentioned the words "caution" and "trust" in his response by saying "I'm more cautious... I didn't trust them".

In contrast, more than half the females in this group specified a loss of trust as the major effect the illness has had on their relationships with others. For example: "I stick to myself. It might be a trust issue. It's harder to trust people"; I think I'm much more cautious about relationships now since I attribute what happened to my relationship with my husband"; "not trusting people easily, trust has to be earned and it takes awhile to get to know people"; "for a lot of reasons, I really tend to pick my friends well because I've been burned in the past. I think I'm less trustful. I'm careful and a little more reserved"; "it made me more cautious, a little less trusting but more sensitive and shy, hardened me on the outside (cat behind the lion)." The remaining female responses mentioned general tendencies to be more withdrawn. For example: "I'm something of a recluse"; "it's hard to make friends"; "I don't like many people because I don't like too much noise. I like to be by myself"; "I still feel that I should stay away from everyone".
Reaching Out to Others

There were more males responding in this manner than females. Considering the sample as a whole, 25% of the males in the total sample answered in this manner while only 9% of females answered in this way. However, as in the cautious group, there were interesting differences in the language to express this tendency to be more comfortable around others. In general, females spoke in terms of changes in or development of qualities within themselves as being affected by their illness. Males tended to speak of these changes in terms of behavior toward or involving others. Very few males mentioned inner qualities.

The following are some excerpts from female responses to this question. "I'm more empathetic...because of what I went through...I can be more patient and understanding than I used to be"; "I'm nicer after my breakdown"; "I think I've become more compassionate and understanding, not as critical of others, so not as critical of myself"; "I'm a little more compassionate..."

Male responses, on the other hand, referred more to behaviors in relation to others as the following examples indicate. "Probably seek people out more..."; "I can make acquaintances, I share things with people..."; "...I was more outgoing, enjoying meeting people..."; "easier to get along with people now"; "easier to meet people, enjoy myself, less aggressive"; "now friendlier with people, easier to get along with, more dependable."

On the whole, the remaining differences between these two response styles are unremarkable and are not presented here. They are included in the appendix for the interested reader.
Individual Responses

While the analysis of responses across protocols informs us of shared patterns and themes, consideration of individual protocols in their entirety highlights the variability and individual nature of illness experience. The examples presented below were chosen on the basis of their differences in overall presentation and responses.

Each account is written in the form of a first person flowing narrative with the interview questions added as part of the text to increase readability. The informant’s own words are in italics. Each example has been given a title based on the overall impression of the narrative. In this first example, the informant gives an overall impression that he has come to terms with his illness though is cautious about preventing relapses. He continues to move forward with his life in pursuit of his goals despite uncertainty.

Acceptance of illness and moving forward with life

When I think back to the time when I was first hospitalized and what I remember about what I thought was happening at that time, I would say that I was manic. At the time though I didn’t think anything was wrong. I was very angry and had no power at the time. At other times, I had delusions of grandeur. I felt my whole world had collapsed when I got a diagnosis. I would describe my illness today as always present but under control. When I consider what happened to change my view about my illness I would say that I have a lot more respect for my illness. That’s a tough question…I had a manic episode and went to a homeless shelter, called police. I went to my dad’s and saw my psychiatrist. I trusted their judgment for the first time. Also my mom had it, so have others, so it can be dealt with.
When I consider the ways in which having a mental illness has affected how people behave toward me, I'd say I don't tell them unless I know them. Some people are sympathetic but I can't change biases. I'm comfortable keeping it hidden. What's important is what I can do now. I'm comfortable with it. When I think about the ways the illness has affected my behavior toward others I'd say I'm more aware of hardships that others go through, more sensitive to illness in our lives...more empathetic. I'm more sensitive to others. It's made me more sensitive.

When I consider my relations with other people, I have several people to whom I can depend on for help or advice. Not many people turn to me. I'm solitary. It's hard to be in a new place. I keep my life simple so I don't get ill. Only my immediate family leans on me, my mom, sister, and dad. I can't confide in my family but I can turn to the bipolar group. My friend in the group. He confides in me too. I can turn to a counselor for help in other areas and to my sister, brother or friend. When it comes to doing things with others like shopping or movies, I don' have anyone yet. I want to get my rest, I'm still in touch with friends in Hawai'i.

When I think about the ways having this illness has affected my life I'd say at first it was hard to do anything. I could only have a job for two or three months. I only socialized with other mentally ill people. Only recently I've been working. My goal is independence.

When it comes to coping with stress, I want to be alone. I like to go to a place on campus, day hospital, other hospitals. I try to rest, eliminate activities and manic thoughts. Call my friend from the support group.
I did have an experience with physical force in the mental health system but the restraints were justified. Overall, the hospitals were good. I have not ever been the subject of a legal court action in dealing with the mental health system.

Thinking back over the past fifteen years, the things that have helped me deal with my illness, and what advice I'd give to someone having similar difficulties I'd say, realize the danger signs of approaching manic episode. Describe the signs such as insomnia. If you forget things, take care of yourself. Remember to eat nutritious foods. When I consider the future and where I expect to be five years from now, I'd say in a full-time job consulting small businesses. Married, a normal life with social activities and friends and back in Hawai'i.

The individual in the above example is not without struggle and emotional pain but does not let this stop him from progressing in his goals. He obviously struggles with the need to carefully monitor his symptoms, but he balances this with some risk taking. He had left Hawai'i 6 months previous to the interview to attend college on the mainland where he knew no one.

Acceptance of Illness with Resignation

The individual in this next example describes himself as stable and under control but seems to have a restricted life that involves few risks.

When I think back to the time when I was first hospitalized and what I thought was going on at that time, I'd say that the devil took over, possessed, exorcism.

When I describe my illness today I'd tell people I'm stable. I have schizophrenia. My mind can wander off, I can't concentrate. When that happens I lie down in bed.
When I consider how this illness has affected how people behave toward me, I'd say *I was possessed by the devil to be cured, there was no effect.* When I think about how the illness has affected how I behave toward other people, I'd say *I can control myself, I feel okay.*

When I consider my relations with other people I can depend on for help or advice, I'd say *I really don't have anyone but my sister or roommates.* I'd turn to the E.R. or ambulance in an emergency but *it depends on the situation, who's available.* *No one turns to me.* When it comes to doing things like going to a movie, I'd say *no one, or sisters.* When it comes to people doing things with me I'd say *sisters.*

When it comes to coping with stress, I'd be *by myself but would like to have a girlfriend* to be with. *No one turns to me.* I like to go to the mall, beach or movies when I'm stressed.

Thinking back over the last fifteen years and what has helped me deal with my illness I'd say *keep seeing your psychiatrist and take your medicine.*

When it comes to future goals and where I expect to be in 5 years... I'd say *I expect to be here at [halfway house], by June, working in food services.*

**No identification with illness**

The individual in the narrative example below describes his change in viewpoint from believing he had been possessed by the devil, to having a mental illness to a present viewpoint that nothing is wrong.

When I think back to the time when I was first hospitalized and what I thought was going on I'd say *I was possessed by the devil. I thought that's not right. I must be crazy. I read about it and said that's me. I would describe my illness today by saying I don't thing I'm sick. I'm
normal. I used to be manic-depressive-schizophrenic...a chemical imbalance. I got depressed when my brother left for the army. I was the youngest in the family, the last one left. What changed my viewpoint was that I researched about my mental illness and found out about my symptoms.

When I consider how my illness has affected how people behave toward me I'd say they treated me differently because I was labeled mental, crazy. They underestimated me. They usually realize, hey this guy's smart, he can remember things. How has it affected how I behave toward others? I feel like they are going to use that against me. I feel a little ashamed. They make fun of me.

When I consider my relations with other people I mostly turn to my girlfriend for advice, and she also turns to me. My sister and brother would help me to make important decisions if I became incapable. My girlfriend and kids would trust me in this regard. My family and I can borrow things from each other or ask favors. My siblings and I can turn to each other in emergencies. My family, girlfriend, kids and I do things with each other.

When I consider the ways having this illness has affected my life I'd say it hasn't really affected my life. When I look back over the entire period and how my relationships with others have changed I'd say it's easier to get along with people now. When it comes to coping with stress, I'd rather be by myself. My girlfriend comes to me when she's stressed. When I feel stressed I like to go down to the beach, sit under a shady tree and just think, or maybe go to Kokohead and do relaxation...
I like to be by myself with a clear train of thought, to organize and resolve my problems, no outside distractions, like meditation.

When it comes to experiencing physical force in dealing with the mental health system, this happened a lot in the psychiatric ward. I experienced seclusions at the state hospital. It was scary. I felt like I was a wild animal. I don't need restraints. I can calm myself down. But I take the blame. I figure it's my fault. But it's wrong for staff to hit a patient. [This individual reported that hospital staff had hit him, knocked him out and put him in seclusion.]

When I think back over the last fifteen years, the things that have helped me deal with my illness, and the advice I'd give to others I'd say, take your time. Take it day by day. Don't rush. Some day you'll get back on your feet. Don't get in trouble. Keep yourself occupied, don't get stagnant. In considering where I expect to be in five years I'd say hopefully married and own a house with a family. Steady occupation.

Even though he had denied that mental illness had had any overall impact on his life, his other responses indicate that this individual had experienced and perceived both pain and humiliation as a psychiatric patient. His decision to no longer identify with the label of mental illness and his self-label of "normal" is not surprising and may be a healthy step to his personal adaptation to this experience in his life especially if his illness remains in remission.

Unclear Understanding of Illness

While the individual in the following example acknowledges certain symptoms he has difficulty describing why this is so. The overall tone throughout this account is
one of confusion and/or a sense of being overwhelmed with symptoms but not being able to make enough sense of them in order to take initiative in his recovery.

When I think back to the time when I was first hospitalized and what I thought was going on I'd say I don't know...couldn't figure it out. When I consider how I'd describe my illness today I'd say I don't know. I have no idea. I'm not a psychiatrist. The medication isn't working. I still hear voices.

When I consider how the illness has affected how people behave toward me I'd say since the voices haven't disappeared, people just go along with it. They don't care if it doesn't bother them. How has it affected how I behave toward others? I get angry sometimes...irritable. When I think about my relations with other people and whom I can depend on for help or advice I'd say they don't help. I'd ask my psychiatrist, meds don't work, I don't want to bother my mom. She can't do anything. No one turns to me for advice. I don't lean on anyone and no one leans on me. When you ask me if I have someone I can confide in I say no, I don't trust people these days. They don't trust me...even mom. No one confides in me. They figured me out. I'm a bad person. When it comes to making important decisions I leave that up to the psychiatrist. I have no one to borrow things or ask favors from but sometimes my brother borrows money from me. In an emergency my mom can figure it out. No one turns to me in emergencies. I have no one to do things with and no one who does things with me.

When I think about the ways having this illness has affected your life I'd say no work: 50/50 due to hearing voices and not being trusted.
on face value. Hearing voices makes me lazy. I get sick of it. I'm a vegetable already. It affects everyway. When I consider how my relationships with others have changed since my first hospitalization I'd say down, people hate my guts now. When it comes to coping with stress, I have no one to turn to.

Would I like to have someone like this in my life? It depends on what they're like, true, they would do anything, help me with mental illness, maybe get the inside scoop about my disease. No one turns to me when they're stressed. I don't have any special place where I like to go when I'm stressed. I try to help myself but it backfires, like thinking out my problem.

Did I ever experience physical force from the mental health system? Yes, solitary confinement and restraints...still the same, nothing happened, no impact now. Have I ever been the subject of a legal court action in dealing with the mental health system? Yes, it was scary because I didn't know what was going on. No impact now.

Thinking back over the last fifteen years, the things that have helped me and advice I'd give to others I'd say just hang in there and try your best. Take your medication but if medication doesn't work, talk to a psychiatrist. Just pray if things don't work out. When I consider where I expect to be in five years, I'd say I don't know. I might be dead, I'm not sure.

Exceptions

Finally, there were a few individual responses that seemed to be following a certain overall style but that also differed in major ways from others. In this first
example, the individual appears to be restricted in activities and to be passively resigned to her illness but she is remarkably positive in some of her comments and in that way shows an ability to retain a sense of hope for the future and a sense of initiative despite her struggles with chronic mental illness.

When I think back to the time when I was first hospitalized and what I thought was going on I'd say, well, to be quite honest, I thought the doctors were out of their minds to say I was mentally ill. I was a secretary at the time. My doctor said that hearing voices was a sign of mental illness. Finally I admitted it was one too. In describing my illness today I'd say schizophrenia is a dreadful thing, you hear voices have racing thoughts. When I consider what happened to change my view of my illness I'd say that at first I refused to believe it. Within a few weeks I believed it. I disagreed with the label at first. Then I realized that my doctor was being honest.

When I consider how my illness has affected how others behave toward me I'd say I have a difficult time in my life. I'm mentally ill and I don't know the rules. I can't comply. I don't say, for example, "hello," I chatter to myself or just stand there. I don't feel comfortable around other people. I don't respond. When I consider my relations with others and if I have anyone to depend on for advice I'd say I don't have anybody. I could go to my doctor or the front desk at my apartment. Is there someone who would come to me? None. I'm a paranoid schizophrenic. What more do I need? I'm settled I a safe place. Is there someone I can lean on? Only my doctor. I don't have anyone really. Is there someone who leans on me? No one. Is there someone in whom I can confide? No one. I don't have anybody but I don't need it. When it comes to someone to make important decisions on my behalf I'd say I'm fine, I don't
know. I'd have to be hospitalized. I might get in touch with my aunt, maybe. In the case of an emergency, if anything happened, I could come in to my doctor. He's a good person, a dependable doctor.

Thinking about the ways having this illness has affected my life well, I'd say I need a boss who'd be able to understand I'm not as quick as I used to be. Instead of an hour to type out a letter, it'd maybe take an hour and a half. I'm not as quick. I'm a little slower. When it comes to coping with stress and if there is some special place I go to or things that I do that help I'd say no.

Thinking back over the last fifteen years, the things that have helped me and advice I'd give to someone having similar difficulties I'd say maybe to, gosh, try one's best, to try and enjoy life even though mental illness makes you lose your interest. Keep busy if that's what you want to do. Don't leave out things that are interesting. There's so much out there. Don't lose your interest in life. Considering where I expect to be in five years, I'll be right here in Hawai'i, no big changes.

In this final example, the individual seems to be making progress in many areas in his life and to have a clear understanding of what has been helpful to him in this regard, despite his ongoing belief that he was possessed by the devil.

When I think back to the time when I was first hospitalized and what I thought was going on at that time I'd say that I thought there was a war between good and evil going on within me. I think evil was winning back then. At that time, I appeared to be an angel. I felt stuff was coming in to destroy me. I was naïve and timid at that time and I had no control. I just surrendered myself to it. I couldn't tell what was good and what was evil because it all came in at the same time. How would I describe my illness today? Well, I hadn't
slept for a week before that. I'm sure now that it was a demonic possession. I'm like a receiver and I pick up different spirits and vision. At that time, I was possessed by a devil of some sort. When I consider what happened to change my view about my illness I'd say the bible. I went back to the bible. I hadn't read it for awhile and because of that I didn't have any gates locked, so things could come in. I think it all went away because I went back to the bible.

When I think about how this illness has affected how people behave toward me I'd say it made them pick up their bibles. They knew that I wasn't that kind of person and they knew I was a good person. They saw that if it could happen to me, it could happen to them. So they started to go to church and read the bible. It's affected how I treat others to. Now I help them more. Everything is reverence now. People have a good trust of me; they come to ask me to solve their problems. Back then I was my own capsule, but now I help them.

Considering my relations with others have reciprocity with several people including my family, my minister, and friends. When I think about the ways having this illness has affected my life I'd say it hasn't. I've never put that stumbling block in front of me. If I did, I'd lapse back into what I was back then. When I consider how my relationships have changed I'd say dramatically. Prior to that I was like a hermit, a complete captive. After that episode, I prospered. I have a good job, good money and it's given me more knowledge. People come to me to ask questions; people trust me.

Considering what I do to cope with stress I'd say I would like to be with the family, or with my mom. I tried to deal with it myself. Some people come to me when they're stressed. Some neighbors ask me advice. The neighbors'
kids also; we help them find jobs and get a good start in life. When I think about what I do and where I go when I'm stressed I'd say I go to the backyard and pray or smoke pakalolo.

Thinking back over the last fifteen years, the things that have helped me deal with my illness and advice I'd give to someone having similar difficulties I'd say take that first step to better yourself. Especially look for that first job. It will give you the strong confidence you need. That's the biggest thing. A job gets you money to help you get other things. Also, you need some people to help you, social workers to find you jobs, etc., you need to find within yourself what you feel like doing and then get a job you like. You need people to show you the way. You need to have a desire to work or take into you the help that people offer. It can't be forced. Considering where I expect to be in five years, I expect to be still working at [deleted.] I would like to work there until I retire. Also I expect to have the same personal life, living with my family, etc.
This study sought to describe various long-term aspects of living with and recovering from serious mental illness from the viewpoint of individuals who had been diagnosed with these conditions 15 years prior to being interviewed. There are several advantages to including a subjective component in studies of long-term course and outcome of psychotic disorders. For one, assessment of issues associated with the recovery process from the subject’s point of view gives both researchers and clinicians more information about individual variation and may result in a broadening of the concept. Additionally, by including information from subjects’ point of view, incremental validity in longitudinal studies is increased by contributing another perspective and source of data. But most importantly, consideration of the individual’s experiential perspective contributes to greater empowerment, clarification, and participation in research and clinical interventions.

Results from this study highlighted both the individual nature of illness experiences and the similarities to results from other previous recovery process studies. Overall, the results reflected a wide variation in experience in all aspects of understanding and adjustment and suggest that psychosocial factors may play an increasingly important role for individuals who have been living with their illnesses for many years. Possible implications of major findings and their relationship to previous research are discussed below.

**Understanding and Making Sense of the Illness**

Subjects in the present study described the evolution of understanding about their psychiatric disorders in ways that were very similar to themes found by Estroff et al. (1991) in a study of accounts of illness and self. The study by Estroff et al. as the
present one, found a tendency for shifts in accounts of illness toward clinical explanations. Similar themes have also been described by Greene et al. (1989) and others (Carr, 1988). Taken together, the results of these studies suggest that when individuals are assessed in the earlier stages of their psychiatric journeys they tend to give more mixed and unclear accounts of their illness, although in the present case, subjects gave retrospective accounts. The general tendency seems to be that over time these accounts become increasingly clarified, perhaps reflecting the process of incorporation into the individuals' lives and psyches. Additionally, it appears that there are a finite set of explanations individual's utilize to help them to make sense of their illness experiences and that these attributes very likely reflect shared cultural explanations about mental problems and illness (Estroff, et al., 1991).

This incorporation is also suggested by the tendency for explanations to become less idiosyncratic over time, perhaps reflecting interactions with and internalization of ideas and thoughts of mental health professionals and the larger social networks of individuals. This is also supported by the results of the present study in which individuals largely credited information from mental health professionals and family and friends with changing their viewpoints about their illness.

Understanding and making sense of the experience of mental illness is complex and represents a number of factors and may serve several purposes for the individual. On a cognitive level, mental illnesses, especially psychotic disorders, result in major disruptions to subjective states that challenge the individual's equilibrium and drive the individual to seek a plausible explanation for the experience (Carr, 1988). On an emotional level, the explanation an individual decides upon may have a large impact on self-esteem and other aspects of emotional and social interactions.
Coming to terms with a diagnosis of psychiatric illness represents a major challenge to an individual's sense of self. It has been suggested by some (Estroff, 1989; Doherty, 1979) that the degree to which an individual identifies with the illness has a major impact on her/his level of functioning and potential for recovery. At the same time, insight or understanding is recognized by both mental health professionals and patients as essential to the process of recovery (Young & Ensing, 1999). A study that examined the effects of acceptance of a psychiatric label on functioning found that acceptance and understanding of a diagnosis in combination with an internal locus of control were related to more favorable outcomes (Warner, Taylor, Powers, & Hyman, 1989).

Results of the present study suggest that the process of understanding the experience of mental illness is a dynamic one often involving struggle, denial, and an initial refusal to accept diagnosis until experiencing subsequent episodes of the illness or being confronted by family and friends. Thus, the development of an understanding of one's illness appears to be a process that involves interacting with and experiencing the illness itself, in combination with incorporating information about the illness from various sources, that eventually results in an account of the experience that makes sense to the individual and reduces both emotional and cognitive impact.

There was a tendency for individuals in the present cohort to recollect initial psychiatric experiences in terms of confusion or report an inability to recollect events clearly. This response may represent an honest recollection of very initial impressions as subjects were encouraged to recall what they thought was going on at the time they were experiencing their first psychiatric hospitalization. As mentioned several times in this study, the experience of psychosis is a singularly disturbing one involving a loss of ego boundaries, confusion of identity and intense perceptual distortion. Taken
together, this represents an intensely stressful and potentially terrifying experience. It is not surprising then, that if individuals are able to tap into that experience 15 years later, they would describe it in terms of confusion and dissociation and not offer an explanation. As discussed above, arriving at an account of mental illness experience that makes sense is a process that involves a number of factors. Thought of in these terms, it is somewhat surprising that more individuals did not express their initial experiences in these terms of confusion.

Other factors may also explain the variation in response to this initial question. The individuals in the present cohort were asked to recall their initial psychiatric experience that occurred 15 years ago and most likely differed in their ability to do this. Individuals may also differ in their willingness to disclose initial impressions. There were more females than males who described their initial experiences in these terms. While the reason for this is unclear, gender differences in explaining mental illness have been found by others. For example, some have found that females are less apt to medicalize psychiatric problems (Prior, 1999). Females have also been found to experience more emotion in association with psychotic episodes (Haffner, 2000), and this may be translated into an overall sensation of being overwhelmed and unable to make sense of the experience.

There was also a gender difference in the tendency to define initial experiences in religious terms. All of the individuals who described recollections of initial psychiatric episodes in religious or spiritual terms were male and predominately Hawai’ian and Filipino ethnic backgrounds. This may reflect the tendency for males to display more typically positive symptoms of psychosis, while females have been found by some to display more atypical affective features with psychosis (Hafner, 2000). The
implication of the ethnic differences is unclear from the present results and, as
discussed below, ethnicity does not have much meaning without additional information.

While the majority of informants developed accounts of their illnesses, a small
minority was found to report a continuing confusion in this regard. The example
provided above in the full narrative presentations is such an individual. Although he
refers to hearing voices, "illness" and "disease," he does not offer a sensible account of
his illness when he is asked directly. Ongoing difficulties in arriving at such
explanations often present obstacles to recovery in such individuals as they struggle to
cope with the confusion of symptoms and mental illness. They also may signal
neurocognitive difficulties. Misattributions of symptoms and ongoing insight deficits
have been found to be associated with frontal lobe deficits (Smith, et al., 2000).

In sum, the present results in combination with other literature suggest that,
over time, individuals develop accounts of their illness experiences that reflect a
complex interaction between individual needs and sociocultural influences.

**Perceived Impact on Relationships**

A sizeable proportion of the present sample reported that others have treated
them differently and negatively due to various aspects of their mental illness or to the
label of mental illness *per se*. Thus, the experience of stigma is an important concern
for these individuals. This finding is unfortunately very consistent with many other
findings in the literature. The mentally ill as a group have experienced varying degrees
of stigma and discrimination throughout history and this has persisted into the present
day.

The experience of psychiatric coercion in the present study may also have
contributed to internalization of stigma among this cohort even though the majority
claimed this experience had no impact on them. On the basis of comments referring to
feeling scared, powerless, humiliated and "like a wild animal" all suggest the experience of disempowerment and stigma from the psychiatric establishment.

The experience of stigma among the mentally ill remains one of the greatest obstacles to optimum recovery. Internalization of the negative thoughts and beliefs about mental illness has been linked to feelings of loneliness, hopelessness, reduced self-esteem, lowered confidence, reduced cooperation with treatment efforts, and reluctance to acknowledge needing and accepting mental health treatment (Byrne, 1997).

There was a tendency in the present sample for individuals who reported experiencing stigma to also report an increased caution or social withdrawal. There were also many who reported stigma who also reported an overall tendency to reach out more to others. Thus, as suggested earlier (Warner, et al., 1997) the internalization of stigma and the degree to which it influences social interactions may depend on a number of factors including locus of control and the degree to which an individual identifies with the diagnosis or label of mental illness.

More females than males in the present study reported that their illness has resulted in an overall tendency to respond to others with increased caution. These results suggest that gender may also play a role in perceived social impact and interactions in relationships with others. General differences pertaining to relationships and emotional reactions in general may help to explain this tendency in the present data and the differences in language to describe social impact of illness. Females have been shown to have a stronger emotional response to interruptions or conflict in relationships (Shear, Feske, & Greeno, 2000). Mental illness presents many challenges, conflicts, and interruptions in relationships, and the females in the present

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study reported varying degrees of emotional pain and resulting caution as a result of relationships with others.

Women also tend to perceive more dependency and emotional reliance on others than do males and a stronger identification with the feelings of others (Rosenfield, 2000). Males and females also differ in goals of interpersonal relationships. Male relationships tend to focus on instrumental behaviors such as activities and interests, while women tend to focus on affective aspects of relationships, such as mutual understanding and emotional intimacy (Shear, Feske, & Greeno, 2000). In terms of responses to interpersonal problems, females with anxiety disorders tend to respond to this with increased sensitivity, worry and agoraphobic avoidance. Males with anxiety disorders were much less inclined to react this way (Shear, Feske, & Greeno, 2000. While individuals in the present sample had not been diagnosed with anxiety disorders, this observation may have some relevance in explaining the tendency for more women in the present sample to report increased sensitivity and caution in their interpersonal relationships.

Social Support and Reciprocity

In terms of social support and networks, the results of the present study are supported in part by previous research. Specifically, Hammer et al. (1978) reported that individuals with a diagnosis of schizophrenia tend to have smaller social networks and experience less reciprocity in their relationships than people with no diagnosis. This is consistent with the present finding that most of the individuals who reported very low levels of reciprocity had a diagnosis of schizophrenia.

While some have proposed that this tendency to not reciprocate and to have reduced numbers of social networks increases risk for schizophrenic relapse, others have suggested that two extremes of social conditions increase levels of symptoms
and risk of relapse. Specifically, under-stimulating social environments characterized
by limited social contact have been associated with apathy and social withdrawal while
over-stimulating social environments involving emotionally charged interactions and
social demands have been associated with emergence of florid psychotic symptoms
(Hammer, et al., 1978).

The challenge then for those with schizophrenic conditions is to find a balance
in social relationships and networks that fits in with their individual tendencies and
toleration for social stress. Increasingly, the tendency for a person diagnosed with
schizophrenia to withdraw in a social situation is seen as possibly adaptive and some
have referred to a “withdrawal style” of recovery in schizophrenia (Corin & Lauzon,
1992). Thus, the tendency among the present sample of individuals with schizophrenia
to withdraw in social situations and to report low levels of social networks involving
reciprocity may reflect an adaptive style of behavior especially among those who also
report an ability to self monitor their symptoms and who reported that this monitoring
has helped them to cope with their illness.

There were those in the present sample who reported a combination of social
withdrawal along with no clear idea of what has helped them to cope with their illness
and a continuing struggle to make sense of their symptoms. This reaction may be less
adaptive in that it seems to reflect a chronic source of stress and uncertainty with no
clear resolution. Fortunately, individuals with this pattern were few in number. Most in
the sample reported that they have learned various techniques to cope with their
illness. Furthermore, many individuals reported that in times of stress they prefer to be
alone. This finding was not related to diagnosis.

Individuals who reported the highest levels of social reciprocity with the same
people also reported that the illness had resulted in positive effects on their lives and a
reaching out to others. While this was not a strong relationship as there was a lot of variability in other response styles, it does suggest a relationship between optimism and social reciprocity. Strong social links in which individuals can both feel they can depend on others and be of service or feel needed may foster interpersonal security and feelings of hope and optimism. The benefits to recovery of both optimism/hope and social reciprocity have often been cited in the literature; see for example Young and Ensing (1999). The role that perceived impact of illness plays on attitudes and behavior is less known and would be interesting to explore in future research.

In sum, social factors appear to be important in terms of recovery choices among this cohort. Individuals mentioned the role of others in influencing their understanding of their illness, and most mentioned the role of family and friends in helping with daily coping. However as discussed below, many reported that they prefer to be alone when they are experiencing stress even though most reported that they do have someone to whom they can turn if they choose to. Finally, in terms of social networks, relatively few subjects were truly socially isolated. Many reported very small social circles but these often consisted of close ties to family and friends.

Coping with Stress

The individuals in the present study reported a wide range of behaviors to help them cope with stress. These were very similar in type to those found by Carr (1988) and by Young and Ensing (1999). Carr, in an exploratory study looking at the ways in which patients cope with various aspects of schizophrenia, not surprisingly, found that the type of activity engaged in depended upon the particular symptom the individual was dealing with at the time. For example, what the author termed passive diversion techniques, included passive reception of stimuli such as watching television or listening to music and were used mainly to cope with feelings of anxiety and
depression. On the other hand, this author also found that physical activity such as walking and swimming were often used to cope with feelings of psychomotor retardation and inhibition.

While the particular usefulness of stress relieving techniques was not explored in the present study, the categories and types of activities mentioned were very similar. These results are further indication that people with schizophrenia and other serious mental illnesses are quite adept and able to play an active role in the management of their own illness with its corresponding symptoms and stress.

**Things that have Helped, Advice to Others**

The results of this section support previous recovery process studies. There is strong similarity among many studies in this area (Carr, 1988; Cusick & Carstens, 2001; Smith, 2000; Young & Ensing, 1999). The present results in combination with other similar studies indicate that over time, individuals discover a variety of ways in which to cope with and help themselves to regain functioning and a sense of wellness in their recovery journeys. Furthermore, results of the present study add support to the model of recovery proposed by Young and Ensing (1999) which proposes that needs and coping mechanisms evolve as recovery progresses in stages. The initial stages of recovery involve the challenge of acknowledging and accepting what it means to have a psychiatric disability, finding sources of hope and inspiration, and finding motivation for change. The middle and later stages, according to the model, involve moving forward and regaining what has been lost.

Specifically though, the middle and later stages of recovery involve taking responsibility and initiative by learning more about the illness, self-monitoring, taking care of basic needs, and taking risks to develop individual potential and work toward future goals. Although there is a minority of subjects who report an overall difficulty in
adjusting to their illness and their lives, the majority of respondents reported that they have found a number of ways in which to cope with their illness over time. Many mentioned combinations of reaching out to others, self monitoring, and taking care of themselves as vital to their efforts to cope with their illness.

The Role of Spirituality in the Recovery Process

Although this topic was not addressed directly in the interviews, many individuals spontaneously mentioned that various aspects of spirituality have had an ongoing positive impact on their efforts to cope with various aspects of their illness. This tendency has also been noted in other studies (Young & Ensing 1999; Cusick & Carstens, 2001. Specifically, having a spiritual life was, in the present and other studies, addresses a number of needs for the individual in recovery. These include generating and maintaining a sense of hope and faith that stress and tough times can be endured, giving meaning to one's life in the face of adversity, and creating a sense of belonging, community, and support from others belonging to a church or organization.

In a brief review of the literature on the role of spirituality in psychosocial rehabilitation, Longo and Peterson (2002) mention the following factors as enhanced in individuals who had developed a sense of spirituality: coping, social support, self esteem, and a sense of hope. Fortunately this area is becoming increasingly investigated by researchers who for years had neglected its role in treatment and recovery due to, in part, misinterpretations of the meaning of spirituality, confusions over religion and spirituality, and a general reluctance to explore this topic with their clients (Longo & Peterson, 2002).
Clinical Implications

The present results have several clinical implications, including the consideration of individual differences in the recovery process, gender differences, shifting therapeutic needs as recovery progresses, the ability of the individual to play an active role in his or her own recovery, and the need to consider the potential impact of stigma in terms of self-esteem and interpersonal relations. Mental health professionals who work closely with individuals in recovery from psychotic illnesses must resist the temptation to quickly categorize, and take the time to assess the individual's struggles and experiences with various aspects and challenges that mental illnesses present.

The growing recovery process literature can serve as a therapeutic tool in which to aid professionals and their clients to better understand what a given individual is experiencing at a given time and what their needs are at that time. For example, if an individual is in the beginning stages of recovery and is still struggling to make sense of and accept his/her illness it may not be very helpful to suggest that he/she move forward to take risks and become more independent. Needs are centered on making sense out of chaos and until this can be done it may be difficult to move forward.

In the area of gender differences, the present results suggest that males and females may experience various aspects of adapting to their illnesses differently and utilize very different language to describe the social impact their illness has had on their lives. For example, females may have more emotional reaction to the impact that their illness has had on their relationships. It may useful to explore the emotional impact of relationship issues in therapy or in interactions with those recovering from these disorders.
The need for careful individual assessment cannot be overestimated. The recovery literature and the present results indicate that as individuals progress in the recovery process, their needs will also change. Although this may sound simplistic, many groups in hospitals place patients together and address them as if they are in a similar point in the recovery process when they might not be. While the development of a reliable, standardized recovery instrument is still being developed, this will never take the place of careful interview and observation.

The present results and existing literature emphasize the ability of individuals to take an active role in their recovery. The discovery of their own coping skills increases confidence and a general feeling of empowerment among these individuals. Therapists and others who work with these patients must avoid the temptation to become overly involved in doing things for them. Again the importance of assessment arises. Individuals with psychiatric disorders often arrive at much better, more useful coping mechanisms themselves than the ones a therapist might suggest. However, learning to self-monitor and arrive at individual strategies can become therapeutic goals that clinician and patient can work on together.

The impact of stigma continues to be a major barrier to optimal recovery for many individuals with psychiatric conditions. The internalization of stereotypes and labels can result in lowered self-esteem and decreased motivation, as previously discussed. It is therefore important that this impact be assessed and addressed in therapeutic interventions. Many have found that joining a self-help group or consumer group to be helpful in reducing the impact of stigma. These groups address many other aspects of recovery as well and may increase confidence, and hope through social support and shared identity. There are consumer support groups in all areas of
the country now and it may soon be considered neglect on the part of a therapist who
does not discuss this with clients.

In sum, results from the present study, in combination with the growing
literature on the recovery process, raise many challenges for clinicians. On the one
hand, the more we learn about the stages of recovery and corresponding needs the
better we can address our client’s changing concerns. On the other hand, we as
clinicians also need to learn to do what we can to increase empowerment and
independence in the clients with whom we work.

Limitations

This study has several limitations that were discussed previously but bear
repeating before results are discussed. Results from this study are not generalizable
to the population of seriously mentally ill as a whole. However, this was not a goal of
the investigation. While precautions were taken to reduce researcher bias, it is still
possible that the particular themes identified may not fully reflect what the subjects
were communicating. A major shortcoming in this regard is that subjects were not
consulted about their responses. Ideally, subjects are consulted after themes are
identified and asked if they agree with the researcher decision. The present results are
similar to those identified by others. This is combination with consultation and
agreement from unbiased professionals suggests that the results have validity. There
is a potential positive bias in the present study and in other studies of recovery from
serious mental illness. In general, the individuals who provide information upon which
recovery themes and models are based tend to be relatively stable as far as symptoms
are concerned. The information about how individuals cope with acute psychosis and
difficult times in their illness is mainly retrospective. The ability to articulate a clear
enough account of illness to be included in a study may itself be a sign of stability and
progress. Much less is known about the recovery efforts of those who are not able to provide clear verbal account of their experiences. It remains a challenge to researchers to find ways in which to include this group in future research on recovery and adaptation.

Out of 84 individuals who completed the other aspects of this comprehensive follow-up study only 61 agreed to participate in the recovery inquiry. It is possible that fatigue was a factor in their decision not to participate. It is also possible that this was an influence in the items left blank by those who did participate and in many of their very brief responses. The recovery inquiry was conducted at the very end of the psychiatric and psychosocial interviews. In future studies of this design, the open-ended interview should be conducted at a separate time than other sections or if this is not feasible, perhaps it should be sandwiched between the psychiatric and psychosocial portions of the interview package to reduce possible fatigue.

A Caveat about Ethnicity

Before the implications for future research are discussed, a word of caution is in order concerning the meaning of the concept of ethnicity. Although several seemingly intriguing ethnic differences were found in this study, their implications cannot be determined from the present results. The only information regarding ethnicity we have about the present subjects is that they are referred to as “Caucasian,” “Japanese,” “Hawai’ian,” etc. However, without additional information, these designations have little meaning.

Ethnocultural identity, or the degree to which an individual identifies with the traditions and lifestyle of a particular cultural group, has more meaning than his or her designated race or ethnicity (Marsella, 1990). While the ethnic constitution in the present cohort is diverse, there is no information available about the degree to which
individuals identify with these ethnic groups. It is unclear the degree to which the
individuals, for example, have adopted western cultural identity and therefore the
degree to which the ethnic differences observed in the study are due to other
influences. In other words, the present observations can only be seen as raising
questions about their possible meaning and remind us to be cautious in interpreting
such findings without additional information.

Implications for Future Research

Research utilizing patient accounts, whether in the form of responses to open­
ended inquiries such as the present study, or phenomenological analysis of longer
narratives, yields information about mental illness that cannot be obtained in any other
way. This type of research should be supported, not only for its empirical contributions,
but because it helps to counter prevailing attitudes that tend to objectify and discount
patient accounts. The growing literature that is based upon patient accounts is yielding
a strong consistency across studies indicating the validity of this type of data. The
discussion below focuses on the research implications of the main topics addressed in
the present study.

Understanding

Results from previous studies has established the pivotal role that
understanding and making sense of the illness experience has for later recovery
efforts. What is less clear is how particular types of explanation, such as those
delineated in the present study, impact adaptation and recovery efforts. It seems that a
medical or clinical understanding would be adaptive in that it is widely accepted and
would encourage communication with mental health professionals. It also may be that
an understanding that incorporates individual life experiences has adaptive value for
other reasons. However, the adaptive values of particular patterns of understanding have not been examined and should be investigated more thoroughly.

There are individuals who continue to struggle to make sense of their illness. There was a small number of such individuals in the present study. While this difficulty likely has an organic component, it seems that interventions could be designed that might help such individuals to clarify and adapt to their illness at early stages.

Research and clinical challenges are presented by individuals who continue to struggle to come to terms with their illness and symptoms. While neurocognitive factors have been found to play a role in ongoing struggles with insight, strength-focused training may improve other areas of functioning. Additionally, many individuals are able to acknowledge partial understanding of different aspects of their psychiatric condition as more recent studies of insight have demonstrated (Amador, et al., 1993). Thus, it may be possible to help individuals to build upon the areas of insight they may already possess rather than trying to impact understanding in a more global sense.

**Perceived Social Impact**

Individuals with mental illness are very sensitive to how others perceive them. Many in the present study reported that they had perceived stigma and other negative interactions with others. The particular ways in which these perceptions impact stress levels and self esteem should be investigated so that early intervention can be made.

**Social Support and Reciprocity**

The important role that social relationships play in recovery has been firmly established. In the present study, the majority of individuals reported having reciprocal relationships and people to reach out to. A large number also reported that they choose to be alone when they are feeling stressed. Thus, the role of choice in social interactions may be the most important factor in determining the particular adaptive
value of such interactions. It is apparently important to know support and companionship are available, but mentally ill individuals also need to withdraw from social interactions at certain times. This seemingly inconsistent pattern of relating to others may place stress on established relationships. The relationships that have endured have probably established certain agreements and rules that spare individual feelings while maintaining security. It would be interesting to examine the particular patterns of interactions that lead to and maintain successful relationships. It would also be interesting to examine more closely the apparent trend in the present study of perceived positive impact of illness with higher levels of reciprocity.

**Perceived Overall Impact of Illness**

Having serious mental illness severely impacts all areas of an individual's life and especially impacts career and vocational opportunities. Many of the informants in the present study reported lost opportunities and restriction of activities. The impact these perceptions have on self-esteem and motivation should be examined. Maintaining a sense of hope has been established as an essential part of the recovery process. How do individuals establish a sense of hope when they are faced with the perception and realization that they have lost opportunities or that their activities are restricted? The particular ways in which a sense of hope and optimism are established and maintained are important areas for future research.

**Stress and Coping**

Previous research in combination with the present results, suggest that individuals with mental illness learn a wide variety of coping mechanisms. They seem to be very aware of the effects of stress and have learned ways of protecting themselves from its impact. This is an area in which mental health consumers could participate in the design and implantation of research. For example, a group of

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consumers might serve as a focus group to design a program to help other consumers who might be having particular difficulties dealing with stress.

**Experience of Psychiatric Coercion**

While individuals in the present study denied any lasting impact from their experiences with psychiatric coercion, the language they used to describe these experiences suggested otherwise. Many psychiatric hospitals continue to use manual restraints and other physical means of controlling patients. The emotional impact of these practices should be carefully examined as well as developing more individualized ways of managing extreme behaviors.

**Things that Have Helped, Advice to Others**

Just as individuals learn a variety of ways to cope with stress, they also develop creative and individualized ways to deal with various aspects of their psychiatric disorders. Previous research has shown that various behaviors and attitudes are associated with particular stages of recovery (Young & Ensing, 1999). What is less clear is how these particular attitudes and behaviors are discovered or develop. How do individuals discover what works for them? What attitudes and circumstances encourage the development of adaptive coping styles? Can these be successfully taught? What is the role of the mental health consumer who has discovered adaptive coping behaviors? Can these individuals play a role in research and intervention programs at community mental health centers and psychiatric hospitals?

**Ethnicity and Gender Questions**

Potential ethnocultural identity issues provide intriguing questions for research. The information about individual variation in different aspects of mental illness provides an important element in a model of longitudinal course and outcome of psychotic
disorders. The ways in which individuals understand and interact with their illness, their environment and others, may provide or help us to understand the variations in outcome across different cultures. The patient-centered phenomenon of recovery may vary across different cultures. For example, increasing self reliance, self monitoring and taking responsibility for one's own recovery are valued by many who experience mental illness in a western culture.

Males and females in the present study used very different language when describing the social impact of their illness. The role of gender on recovery and adaptation to illness is an under-explored area. Future research should further explore the ways in which males and females perceive the impact of various aspects of their psychiatric disorders and other aspects of recovery so that treatment interventions may be designed to accommodate these differences.

Variation in responses may be clarified by considering the influence of personality features on recovery. Donat (2001) has suggested that personality traits continue to impact the course of psychiatric recovery after Axis I symptoms are stabilized and that these factors influence the quality of interpersonal relationships, recovery choices and influence the therapeutic relationship with care providers.

Finally, as discussed earlier, results from the present study in considered along with other investigation, reinforce the observation that individuals with mental illnesses develop a variety of ways to cope with various aspects of their illness. This raises the idea that research should explore healthy qualities such as hardiness, curiosity, and perseverance in those who suffer from mental illness rather than solely focusing on aspects of illness and symptom management.
Concluding Comments

In this section I will outline a number of conclusions based upon the particular history of research in this area as well as the content and process of the current study.

Conclusions based on History

1. Interest in patient accounts of their illness experiences has a long and complex history that is interwoven with the very history of psychiatry. Review of this history reveals a tension between mental health professionals who recognize and utilize these accounts for research and clinical purposes and those who deny their importance and application.

2. Periodic advances have been made especially by consideration of special cases such as Perceval's Narrative (Bateson, 1961), Clifford Beers A Mind that found Itself (1908), and the thoughtful consideration of individual experience found in analyses by Karl Jaspers (1963). Other mental health professionals have helped pave the way by recognizing the inherent value in listening to what the mentally ill person has to say. Such early writers included Kaplan (1964) and Sommer (1961) who has been compiling biographies for over 30 years.

3. Larger philosophical and scholarly movements such as postmodernism and the Existential-Humanistic development in Psychology have legitimized the academic pursuit of subjective accounts.

4. Sociopolitical and medical advances have resulted in symptom amelioration and empowerment among those with mental illness. The community mental health movement and the consumer movements have resulted in increased influence of consumers and family members in all areas of mental health practice including research.
5. Contemporary writing and research utilizing subjective accounts is a multidisciplinary endeavor including Anthropology, Clinical Psychology, Psychiatry, Nursing, and Social Work.

Conclusions based on the Present Study

1. It is both feasible and sensible to approach subjective accounts of mental illness from a variety of research paradigms including qualitative, phenomenological and quantitative. They are increasingly seen as complimentary and increasing the power of the total investigation.

2. Course and outcome of psychotic disorders have been linked to a variety of clinical and demographic variables. This investigation offered the opportunity to explore attitudes and experiences that have been previously linked to the recovery process. While the present study did not link the results to specific outcome variables, future research will explore how the present results are related to various outcome measures.

3. Finally, patient involvement in qualitative studies has therapeutic value in that it is empowering, and may help them to clarify their understanding of their illness and to reinforce their strengths. Although this particular effect was not addressed in the present study, others who have conducted qualitative, especially phenomenological research have commented on its therapeutic benefits (Davidson, 2003). In the present study, several of the participants spontaneously commented to the interviewers that they had found the research process beneficial.

In closing, the accounts of individuals who have experienced mental illness offer a unique source of information about the inner perspectives and adaptation to psychiatric disorders. In the present study a predominant theme throughout the interviews was one of understanding and making sense of various aspects of the
illness experience. Humans strive to make sense of all aspects of their lives and the experience of mental illness is no exception. It is also apparent from the present study and others that individuals benefit from increased responsibility and empowerment in their efforts to recover from mental illness. We can assist them in their efforts by listening closely to and respecting what they have to say and by respecting their capacities, abilities and strengths.
APPENDIX A

Rochester Recovery Inquiry

I'm going to ask you some questions about the times you've had psychiatric problems. I'm interested in learning how you understand what has happened to you.

1. Please think back to the time when you were first hospitalized. Can you remember what you thought was going on at that time? [Press for subject's understanding as it was then.]

2. How would you describe [your illness] today? [Probe for subject's own understanding. How would they explain it to a family member or friend, for example?]

[if discrepant:]

3. What happened to change your view of [your illness]? [Probe for when and how subject's view changed.]
APPENDIX A, Continued

[Note the words or phrases the respondent uses in relating both past experience with hospitalization and present understanding. Use her/his preferred term in the indicated brackets hereafter.]

Preferred term: __________________________

Many people who have experienced a psychiatric hospitalization report that it has had significant impact on their lives—both good and bad. I’d like to ask you about a few specific areas.

4. In general, how would you say [your illness] has affected how people behave toward you?
   [Probe: what is it about [the illness] that you feel is responsible for these effects? (Please not differences between effects attributed to disability and those attributed to stigma.)]

5. How would you say it has affected how you behave toward other people?
   [Probes: Has it affected, for example, your closeness to other people? If so, how? (Again, note disability vs. stigma effects.)]
Now I'd like to ask you some specific questions about your relations with other people.

First, I'd like to ask you some questions about people who are important to you. Is there someone, a friend, relative or someone else ... [Note: For all of these, specify names and relationships to subject. Probe for: anyone else?]

6. whom you can depend upon for help or advice in day-to-day life?

7. who depends on you for help or advice in day-to-day life?

8. whom you feel you can lean on?

9. who leans on you?

10. in whom you can confide?

11. who confides in you?
12. whom you would trust to make important decisions on your behalf, if you were to become incapable of making your own decisions?

13. who would trust you to make important decisions on their behalf?

Now, I'd like to ask about some everyday activities that may include not only those people we were just talking about, but neighbors and acquaintances as well. Is there someone in your life, someone you see regularly...
[Again, for all of these, specify names and relationships to subject. Probe for: anyone else?]

14. from whom you ask favors or borrow things, when you need to, such as...[examples: food, money, cigarettes, transportation]

15. who asks favors or borrows things from you?

16. whom you ask to help with child care, when you need it, such as...[example: watch children while you go shopping] [Note: Omit if not applicable.]

17. who asks you for help with their child care when they need it?
APPENDIX A, Continued

18. to whom you turn for help in case of an emergency, such as...[example: getting to the hospital to visit a relative]

19. who turns to you for help in case of an emergency?

20. whom you do things with, such as ... [examples: going shopping or to a movie, hanging out in town]

21. who does things with you?

Changes over time:

22. Think for a moment about the ways having [this illness] has affected your life. How would you say it has affected your ability to find work, or to undertake activities that you value, that others value? I'm thinking not only about paid work, but about other activities as well. [Probes: suggest volunteer work; self-help activities; schooling; household upkeep; childcare; involvement in group activities (music, church, sports.)]
APPENDIX A, Continued

23. Looking back over the entire period, how would you say your relationships with others have changed since your first hospitalization? [Probes: I'm thinking here of friendships, how easy it is to meet people, whether you've felt exploited by others, avoided by them, and so on.]

Now I'd like you to think about those times when you're feeling particularly stressed. I'd like to ask you how you handle those times. Specifically:

24. Is there someone you'd feel comfortable being with at times like that? [specify names and relationship to subject]

[if no, ask:] 25. Would you like to have someone like this in your life?

26. How about the reverse: Is there someone who would come to you if they were feeling particularly stressed? [specify names and relationship to subject]

27. Is there some special place you can go when you're feeling stressed? [specify what and where]
APPENDIX A, Continued

28. Are there special things that you do that help when you're feeling particularly stressed? [specify what those activities are]

Some of the people we've spoken with told us about experiences with physical force when dealing with the mental health system.

29. Did this ever happen to you? [if yes, describe, then ask:] What impact, if any, did this experience have on you?

30. Have you ever been the subject of a legal court action in dealing with the mental health system? [If yes, describe, then ask:] What impact, if any, did this experience have on you?

31. Thinking back over the last fifteen years, and the things that have helped you deal with [your illness], what advice would you give to someone who was having similar difficulties?

32. Thank you very much for your cooperation. Just to close the interview, may I ask: Where do you expect to be 5 years from now?
APPENDIX B
CATEGORIES AND REPRESENTATIVE WORDS AND PHRASES FOR RRI QUESTIONS

Question 1. “Think back to when you were first hospitalized. Can you remember what you thought was going on at that time?”

Category: Confusion

1. “I didn’t know what the f--- was happening.”
2. “I didn’t know... days were slipping away. I was losing it.”
3. “...drugged, like a zombie”
4. “it was very confusing. I can’t remember, I felt like I was going over the deep end.”
5. “I couldn’t come up with anything, accused of being schizophrenic. It was confusing, I didn’t know.”
6. “I wanted to get out. I didn’t know where I was”
7. “I don’t know. I think I was drinking.”
8. “Weird looking people...everything distorted, everyone looked inhuman. Maybe if I went to sleep things would look better, where am I? What am I doing here?”
9. “I remember being taken to [psychiatric hospital]. I thought my watch was controlled by the Japanese. I don’t really remember what I thought was happening.”
10. “People were after me. There was no escape.”
11. “[I] didn’t know what was going on.”
12. “[I] don’t know, couldn’t figure it out.”
13. “It was like I was in a dream. Later I just thought that I had lost my mind.”
14. “I don’t remember too good. [My] brother told me I take off the clothes and was walking around.”
15. “I don’t remember. I didn’t know.”

Category: Clinical

1. “I felt that I was suffering from severe depression. I was unable to function, lived in my bedroom, profound sadness.”
2. “…alcohol and things, hallucinations... girlfriend gave me something in a drink or something.”
3. “Under the influence of paint – total confusion, sniffing everyday, out of it.”
4. “Realized I had an illness, withdrawn.”
5. “I couldn’t eat... voices, insomnia, delusional.”
6. “…thought I had an illness.”
APPENDIX B, Continued

Question 1. (Continued) “Think back to when you were first hospitalized. Can you remember what you thought was going on at that time?”

Category: Clinical

7. “I didn’t have the energy, I was depressed.”
8. “It was my disease that made me sick.”
9. “I knew I was depressed.”

Category: Inner Characteristics

1. “Just a lot of anger that I held in for so long. I just couldn’t hold it in any longer so it just came flooding out.”
2. “I thought I was going crazy. I thought I was losing my mind. I felt sad. Some of the time I felt like dying.”
3. “It was a heavy episode, incredible experience. I dove into my mind, thought I was sad... Something was awakening in me...”
4. “I was very restless...I was feeling depressed”
5. “I never lived up to my potential. I was down on myself.”
6. “I was very self conscious of others, very self-involved...guilty feelings, not that confident in self.”
7. “...suicidal-type feelings, depressed feelings, out of control, boredom.”
8. “I was just plain disgusted with life.”
9. “I was looking for answers...trying to find myself. I thought the world was going to end...by my committing suicide.”

Category: Nothing Wrong

1. “I shouldn’t be in a hospital. They’re forcing me into the hospital and to take meds.”
2. “I didn’t thing anything was wrong with me.”
3. “They said something was wrong, but I wouldn’t admit something was wrong.”
4. “nothing [wrong]”
5. “I didn’t think anything was wrong.”
6. “I thought the doctors were out of their minds to say I was mentally ill.”
7. “…I remember thinking that nothing was wrong with me.”
8. “Felt I was being locked up when I didn’t need to be.”
APPENDIX B, Continued

Question 1. (Continued) “Think back to when you were first hospitalized. Can you remember what you thought was going on at that time?”

Category: Events and Circumstances

1. “Everything fell apart. [My] girlfriend left... heartbreak.”
2. “…hopeless, homeless, money-less, threatened suicide for admission, to find a place to live.”
3. “…My father was supposed to go to jail which was very hard on me. We were close and I didn’t know how to handle it, it was so out of my control. It was my way of reacting and everything came crashing down.”
4. “I think I knew that my illness was basically due to a very stress-producing relationship…”
5. “[My] family all got sick at the same time, alcoholism, addiction, abuse, violence... all within two years... Even my girlfriend of 5 years left.”
6. “We lived with father and his new wife. I didn’t like her. That was a problem.”
7. “A lot of confusion, trying to be more in control, trying to run away from my husband... felt crowded... He was trying to control my life.”

Category: Religious

1. “I thought there was a war between good and evil going on within me... At that time, I appeared to be an angel...”
2. “…I was Satan, enormous threat to the world, caused all suffering to humanity, was immortal...”
3. “…I had a fascination with prophecy. It started with my involvement in religion... I had too many and too high expectations of God. I created my own god... The hallucinations and euphoria were all just part of this prophecy I had created...”
4. “Thought I was possessed by the devil.”
5. “Thought I was the antichrist, new messiah...”
APPENDIX B, Continued

Question 2. “How Would you Describe your Illness Today?”

Category: Clinical

1. “Drugs [led to] paranoia [which led to] suicide [attempt].”
2. “It was because I didn’t have enough Lithium to counteract the abnormal thoughts in my brain.”
3. “Made a mistake taking drugs... no make sense getting sick (going hospital) every time.”
4. “I had a manic depressive breakdown.”
5. “…Paranoia, just once in awhile, voices... I guess I’m schizophrenic…”
6. “I’ll always have some PTSD such as increased startle response…”
7. “I think I’m sick at that time. I think I’m doing better... because I take medicine.”
8. “I would say now that I was bipolar. I have a chemical imbalance in my brain.”
9. “I had a nervous breakdown. I was real nervous and paranoid.”
10. “I’d tell people I was sick – hallucinations, hearing and seeing things.”
11. “Still have the illness but it’s under control as long as I stay away from drugs.”
12. “The sickness is routine. It’s gotten less but I still need meds…”
13. “…Thought it was schizophrenia, multiple personalities.”
14. “Calming down, hyperactive... voices.”
15. “Right now I would say voices I guess, depression.”
16. “I had been experimenting with marijuana and I think that precipitated it. That and that I was feeling somewhat depressed.”
17. “It’s good I went because I got medicine. I’m schizophrenic.”
18. “…A Lithium deficiency…”
19. “A mental illness.”
20. “Marijuana and diet pills affected me. I wasn’t sleeping.”
21. “Schizophrenia is a dreadful thing, you hear voices, racing thoughts.”
22. “Always present but under control... I was manic.”
23. “…Mental disability…”
24. “Stable, have schizophrenia, can wander off, can’t concentrate.”
APPENDIX B, Continued

Question 2. (Continued) "How Would you Describe your Illness Today?"

Category: Inner Characteristics

1. "Thinking a lot about things that had happened, feeling hopeless."
2. "When there is something I cannot handle I get down."
4. "...It felt like I had no control over things...felt like hell. I used to think that people were judging me. I was very self conscious and self critical..."
5. "...A nuisance, wouldn't want to be responsible for a lot of people...I never know when I'm going to cave in."
6. "More strong minded."
7. "...I [thought] I can beat up anyone. I looked down on white people. I got into lots of fights...started smoking pakalolo to look tough."
8. "Today I'm tired...awake but tired."
9. "Absent minded, forgetful, doubtful, hard on myself."
10. "Back then I felt like I was a victim, now I realize that I have a responsibility in how I feel..."

Category: Events and Circumstances

1. "I'm okay but I get plenty stressed with family and work."
2. "A result of a lot of conditioning...The illusion that nothing was wrong started breaking down. It was triggered by my desire to find my biological father. My mom placed guilt trips on me..."
3. "I was involved with gangs...grew up too fast...didn't enjoy life. A lot of friends committed suicide..."
4. "Now my wife passed away...but then I didn't have an excuse..."
5. "Events triggered it..."
6. "Stress-producing relationship..."
7. "I wasn't prepared for all of that at once...How much can you handle...Loss of girlfriend compounded the situation."
8. "I always did what my husband and family told me to do. I think I was being punished for not doing something right, for upsetting my husband..."
9. "I was trying too hard and doing too much..."
APPENDIX B, Continued

Question 2. (Continued) “How Would you Describe your Illness Today?”

Category: No Problem

1. “I don’t think I’m sick. I’m normal. I used to be manic depressive, schizophrenic, a chemical imbalance.”
2. “...What illness? I’m addicted to psychotropic meds...”
3. “I sniffed paint and that caused illness [but there is] no proof of mental illness.”
4. “I don’t think I ever had an illness besides drugs and things...”
5. “Nothing is wrong with me...”

Category: Combination responses

1. “Some ways it’s worse but medication keeps the mind steady. I’d be worse today without meds. Spiritually I’m better off. Bear the bad things, medication side effects, etc..”
2. “...It was probably the high school pressure, stress. Your emotions go high and then low. Depressed...manic. Might be psychological, might be physical...”
3. “My parents getting divorced, partly inherited, partly the way I was raised. Part of it was partying too much.”
4. “...Poor understanding of the bible, perfectionistic, suppressed emotional problems, drinking, stress at home, pressure from parents...”

Category: Religious

1. “I’m sure now that it was a demonic possession...”
2. “I’m cutting myself short if I don’t sit in church...not having faith in God.”

Category: Confusion

1. “I don’t know, I have no idea...”
2. “I don’t know, it’s a different episode every time.”
APPENDIX B, Continued


Category: Psychiatrists and Other Mental Health Professionals

1. "... I needed the psychiatrist's help..."
2. "The Dr. told me I was manic depressive..."
3. "...Family therapist helped... resources therapist helped explain illness to [my] husband."
4. "...Dr. said hearing voices was a sign of mental illness... I disagreed at first... I realized he was being honest."
5. "Dr.’s educated me about the bad chemicals that come out with the Lithium."
6. "... My substance abuse counselor said I'm not doing anything wrong... It's the way I was brought up..."

Category: Family and Friends

1. "People around me, my cousins and friends told me."
2. "I used to be into decadence... [my] boyfriend said it's cigarettes or me..."
3. "My brother told me about an incident when I smoked marijuana with him and I began to act really weird. This was happened right around the time I was hospitalized."
4. "I didn't like being like that. I wanted to be with my family."
5. "Trying to get my son back, was trying to cooperate, he gave me a reason to live."

Category: Spiritual

1. "... More balanced view of religion... there may be more to life than what we see."
2. "... I started praying..."
3. "... The church helped me change..."
4. "... When I first started yoga process, when I was able to separate my mind from myself, when I realized I am not my mind."

Category: Knowledge

1. "I educated myself by taking psychology classes, doing some introspection. I worked on myself."
2. "... Read self-help books..."
3. "I researched about my mental illness and found out about my symptoms."
APPENDIX B, Continued

Question 3. (Continued) “What Happened to Change Your View of Your Illness?”

Category: Direct experience with illness

1. "The second hospitalization, at first I denied it, but finally I accepted it...."
2. "My friend died of overdose. If I overdose, no one is going to take care of me."

Category: Self Understanding

1. "A learning process, it made me understand myself better. It was a good thing."

Category: Combination responses

1. "...By books or hearsay. Just learning about actual episode...."
2. "...I had a manic episode, went to homeless shelter...went to my dad's and saw dr. I trusted their judgment for the first time...."
3. "Libraries, psychologist, diet, science books."
4. "My ex-wife was instrumental in changing my view...Also my decision to give up painting had a lot to do with my recovery. I was trying to satisfy others' expectations of me, yet I did not have a real desire to paint for myself."
5. "The last episode I had...I knew I needed medication. I had done some reading on it before then, but I still denied that was me. After the last episode, I knew I needed medication."
6. "...I understand how to handle. I know to get enough rest, or else voices, mania...take my medication, avoid overly stressful situations, or else that will bring on my voices, mania."
Question 4. “In General, How Would You Say Your Illness Has Affected How People Behave Toward You?”

Category: Perceived Stigma

1. "They treated me differently because I was labeled mental, crazy. They underestimated me...

2. “Friends on the outside gave up on me because of my mental problems...”

3. "They think I’m not normal like them. They think I’m mentally ill, but I’m emotionally disabled.”

4. "Yes, there’s another lolo...

5. "...I cannot be a normal person to them. Anytime I’m upset or have an opinion about something, they remind me that I’m sick or ill. I feel very stigmatized.”

6. "...They may figure the old man’s crazy.”

7. "...Other people don’t talk to me, they think I don’t have anything to say. Less social activity because of the schizophrenia..."

8. "It’s so hush-hush, people don’t talk about it...

9. "People in my past have no idea how to take me. Extended family members are very hard to deal with. They show everything from sorrow to apprehension in dealing with me, a family member who might be crazy and who was in the hospital...

10. "...My ex-husband tells me to be quiet about it...My ex-husband’s family says I’m crazy. My 16-year-old moved out, says I’m crazy.”

11. "...It was like people were thinking he’s not as strong as we thought he was. He’s one of ‘them’. Still I didn’t like feeling like an invalid, but that’s how people treated me, like I was in a wheelchair.”

12. "...I don’t trust people the way I used to. There is a lot of stigma out there re: mental illness...

13. "I’m amazed at times when people find out that I’m crazy. I often wonder how do they know.”

14. "I found out who was my friends. None of them even came around and said hello due to stigmatizing effects in gangs and rural community from involvement with the mental health system.”

15. “People think ‘Oh, you’ve got bipolar disorder, you crazy.’ Now I tell them I have a lithium deficiency since birth...

16. "...I can’t change biases. I’m comfortable keeping it hidden...”

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APPENDIX B, Continued

Question 4. (Continued) “In General, How Would You Say Your Illness Has Affected How People Behave Toward You?”

Category: General Rejection

1. “People turn their back.”
2. “...degenerate treatment...”
3. “…cousin at grandma’s funeral called me a fake...”
4. “It’s better not to make that a mind if they not liking you.”
5. “People hate my guts now.”
6. “Two times kicked off the bus. I guess some people don’t like me. I don’t know why. Sometimes they snub me.”
7. “Ridiculed, laughed at...”
8. “…I got trouble with people, can’t solve it, nobody want to listen.”
9. “People used to be frightened of me...”
10. “One sister doesn’t want to have anything to do with me. We had been really close, but now she won’t even talk to me...”
11. “…In the early days, people laughed, ran away, avoided me.”
12. “…At the time my friends saw what happened, didn’t know what the hell was going on and didn’t know what to do. During the episode they said “we can’t hang around you anymore, you’ve go to chill.”
13. “Father kicked me out of the house...”

Category: Negative effect from illness itself

1. “People...sometimes become irritated with me. My mind spins out, uncomfortable to be around.”
2. “They were staring at me and I was still paranoid, felt like I was being followed.”
3. “When I’m depressed they probably don’t like me as much or enjoy themselves as much...”
4. “First couple of years it did. My family just kept saying get better, get better. I got out of there.”
5. “I have a difficult time in my life. I’m mentally ill and I don’t know the rules. I can’t comply. I don’t say, for example, hello, I chatter to my self or just stand there.”
6. “People kept away from me. I was aggressive, belligerent, on drugs.”
7. “See the fear in you eyes. Strangers are afraid, fear may turn to hurt and paranoia may lead to hurting someone to protect self.”
APPENDIX B, Continued

Question 4. (Continued) “In General, How Would You Say Your Illness Has Affected How People Behave Toward You?”

Category: Positive Impact

1. “Good experience...being in hospital turned things around, grew, learned about others.”
2. “My husband’s family...was nicer to me...”
3. “My family only ones who knew about it. They’re more concerned about my health.”
4. “They’re a lot more assuring of me...”
5. “I’ve come to find out they’re really nice and caring. They’ve either had it or had family with it.”
6. “It has made my relationships from the past stronger. I became closer to them through sharing my problems, relying on them and respecting their opinions. Also through gaining their trust and knowing they care.”
7. “...They knew I was a good person...”
8. “…My ex-wife is thrilled to see me doing so well.”
9. “I really thought that people would shun me because I had been in a mental hospital. No one ever turned their back on me. My friends would come and visit me and were very supportive. I was surprised.”
10. “…It makes it seem like I’m more of a human being.”
11. “People in church treat me like a friend.”
APPENDIX B, Continued

Question 5: “How would you say your Illness has Affected how you Behave Toward Other People?”

**Category: Increased Caution, Decreased Comfort**

1. “Trust issues remain...people have to earn my trust.”
2. “I try to keep my mouth shut so that people won’t find out I’m crazy, but I can’t so I don’t go.”
3. “I didn’t trust them. I would be way more cautious than before.”
4. “I’m withdrawn from social activities and relationships. More work for me too, difficult to meet people, especially normal people. If I say I have schizophrenia, it’s something negative.”
5. “I kept away from them, was irritable. Now I avoid people...”
6. “…I should stay away from everyone.”
7. “Controlling my emotions certainly affects how other people react to me...”
8. “...Not easy to talk to people...”
9. “Self-conscious, deny it pretty well, pretend there is nothing wrong...”
10. “I guess I talk to people less than I used to.”
11. “I get angry sometimes, irritable.”
12. “Screwed me up, catch myself so I don’t irritate people, pain in the ass...”
13. “I didn’t trust people. I had a hard time dealing with people.”
14. “I just shut my mouth and do what I’m told. I don’t talk to anyone...”
15. “I don’t feel comfortable around people. I don’t respond.”
16. “I feel like they are going to use that against me. I feel a little ashamed. They make fun of me.”
17. “I think I’m more cautious about relationships now...I don’t put myself in situations where I’m around people who don’t understand...”
18. “I try really hard to be accepted and to do normal things...”
19. “...It’s harder to meet people...It makes it sometimes hard to think of anything besides the hallucinations...”
20. “...In terms of being patient with people, that hasn’t happened. I don’t have mercy for them. They haven’t been through mental illness. I have to watch what I do.”
21. “I’m not as positive. I can’t get more things done, run down.”
22. “It made me more cautious, a little less trusting...”
23. “...My wife and my mom...can monitor me well...They let me know and I watch my actions closely.”
Question 5. (Continued) “How would you say your illness has
Affected how you Behave Toward
Other People?”

Category: Overall positive effect, reaching out

1. “Made me realize people are different. Some people in the hospital cannot
make it on their own.”
2. “I’m more understanding and tolerant now of everyone, people with mental
illness and without.”
3. “... Friendlier with people, easier to get along with, more dependable.”
4. “Learn how to get close to people other than immediate family. Group
therapy helped me to see others, talk to others about their feelings.”
5. “…I’ve become more open with others…”
6. “…Understanding of people with mental illness... caring for people with
mental illness...”
7. “…wiser...”
8. “… I recognize borders and boundaries... I take time to listen to people and
encourage them to tell me their stories. I’m fascinated with people...”
9. “…I’m nicer after my breakdown...”
10. “Easier to get along...”
11. “I’m more aware of hardships that others go through, more sensitive to
illness in our lives, more empathetic. I’m more sensitive to others. It’s made
me more sensitive.”
12. “…I feel more compassionate and would like to help them more.”
13. “I feel I’m more compassionate. I’m able to understand and empathize with
people who also have emotional problems.”
14. “I trust them more...”
15. “More loving and caring...”
16. “Now I help people more...”
17. “Before my illness, I didn’t want to have anything to do with people. I enjoy
people more than I did then.”
18. “…I can be more understanding with people.”
APPENDIX B, Continued

Question 22. “Think for a moment about the Ways having this Illness has Affected your Life...

Category: Lost Opportunities

1. “Whenever I have tried to get jobs, I couldn’t remember where to go or the next stage, I get stressed out.”
2. “I haven’t worked for too long. No more training for experience. Yeah, my illness affected this.”
3. “It affected me in not going back to school. I kept asking myself, can I do it? Can I handle the extra stress?”
4. “...Otherwise would be working at Foodland on Maui.”
5. “It changes your attitude...It made me lose my job, my driver’s license. I may have been able to get another job...I’d still be working, making good pay, financially independent, stabilized, ready for a good retirement.”
6. “Makes me someone who is not an achiever, not have money or education...”
7. “I think because of my lack of self-confidence, I’m thinking it might be hard to find a full-time job someday.”
8. “No work...due to hearing voices and not being trusted on face value. Hearing voices makes me lazy...It affects everyway.”
9. “Ruined it, but not permanently.”
10. “...Twice rejected for jobs because I said I had a mental illness on the application...”
11. “Held me back in all areas, kept applying for jobs, but hard to get messages...”
12. “Made it impossible to find work...situation negative, especially concerning work, marriage...”
13. “...The medicine does, it slows you down. Hospitalization ...money-wise, welfare. I’d be working, perhaps as a doctor, lawyer, businessman definitely. I’d be married wit kids, golfing.”
14. “I think I get a better job than busboy. But now I think cashier enough for me.”
15. “...I’ve lost a few jobs.”
Question 22. (Continued) “Think for a moment about the Ways having this Illness has Affected your Life...”

Category: Restriction of Activities

1. “Just that when you have a lot of depression you aren’t able to feel good about anything or notice yourself to do the things you want to do.”
2. “At first it was hard to do anything. I could only have a job for two or three months. I only socialized with other mentally ill people...”
3. “Sometimes it interferes with the ability to do my job to the best of my ability. Self-doubt and depression sometimes get in the way.”
4. “... My doctor convinced me that I could work, so I did for awhile, before my ex-husband got me addicted to and dealing drugs.”
5. “Yes, because I can’t stay in the heat for a long time or in the cold either. I have to be in a comfortable place.”
6. “Used to surf... cannot surf anymore...”
7. “I guess if affected it because I get nervous a lot...”
8. “I can’t take a regular job, couldn’t handle late hours, need to follow sleeping schedule, housework suffered, barely managed to hang in.”
9. “The biggest way it affects my life is it dramatically undercuts my self-confidence. I never know when it’s going to turn my life upside down...I don’t enjoy things nearly as much...”
10. “…I need a boss who’d be able to understand I’m not as quick as I used to be...”
11. “I think if I weren’t ill I’d do more things. I get kind of depressed and I have periods of low energy, apathy.”
12. “…I can’t do things I’d like to like camping, and sporting events. Even if I’m out of the hospital, it may keep me from a few of the activities I would want to participate in.”
APPENDIX B, Continued

Question 22. (Continued) “Think for a moment about the ways having this illness has affected your life...”

Category: Positive Impact

1. “...It made me wake up. Now I enjoy simple things, like the leaves, or the sunshine. I don’t take too much things for granted...”
2. “…I realized I could look at it as a blessing or a curse. I had to pick myself up...I probably would have been into drugs...into a lot of trouble if this hadn’t happened...”
3. “Would still be doing drugs, going to nightclubs, playing music. Now want to go back to school, play music.”
4. “I believe it has enhance those things. It’s given me an insight into my own personal boundaries and limits, insight into people and myself. If anything it has been a big plus in my life. There is no way that this type of experience could not affect you, only through denial, I guess. It’s a matter of how you choose to let it affect you. You can turn poison into medicine.”
5. “It’s been a blessing. It’s telling me I’m not a freak of nature or of society. It confirms to me that I’m a human being...”
6. “…I put myself in positions where people depend on me...Sometimes I feel less motivated, but now I try to keep myself busy.”
7. “…It made me understand myself better. It was a good thing.”
8. “It made me a stronger individual, a more positive individual, but it was a lot of work...the fixes aren’t out there in the world but in here within myself...”
Question 23: “How would you say your Relationships With Others have Changed since your First Hospitalization?”

Category: Increased Caution

1. “...I really tend to pick my friends well because I've been burned in the past. I think I'm less trustful. I'm careful and a little more reserved.”
2. “Down, people hate my guts now.”
3. “Most of the time I get along but only on the surface. I walk away, it's hard to make friends.”
4. “...I try not to meet new people, I won't take initiative. I'd have to explain negative things, scared they'd categorize me.”
5. “I don't go up to strangers anymore... I avoided them.”
6. “More restrained, isolated...”
7. “Not trusting people easily. Trust has to be earned and it takes awhile to get to know people.”
8. “...I'm something of a recluse.”
9. “...I still feel that I should stay away from everyone.”
10. “I think I'm much more cautious about relationships now since I attribute what happened to my relationship with my husband.”
11. “It made me more cautious, a little less trusting but more sensitive and shy, hardened me on the outside, "cat behind a lion."”
12. “...I don't think they really trust me because I’m so anxious or nervous...”
13. “I don't like many people because I don't like too much noise. I like to be by myself.”
14. “It's made them harder... when I'm depressed I feel vastly inferior to others.”
15. “They've changed a lot. I don't call them and they don't come to see me. It's harder to meet people now than before. I'm not really into making close friends with anyone.”
16. “It's changed a real lot. I try to pick my mate. I look at the whole situation before I do anything.”
17. “I stick to myself. It might be a trust issue. It’s harder to trust people.”
APPENDIX B, Continued

Question 23. (Continued) “How would you say your
Relationships With Others have
Changed since your First
Hospitalization?”

Category: Reaching Out

1. “More loving and caring...”
2. “I was mean before because of too much stress, but I’m nicer after my breakdown...”
3. “...I’m not so uptight about my illness. My relationship with my sister... our relationship has improved...”
4. “Now friendlier with people, easier to get along with, more dependable.”
5. “Probably seek people out more...”
6. “I can make acquaintances, share things with people that before 1980 it would have taken me 5 years to accomplish.”
7. “I got better...I found I was more outgoing, enjoying meeting people...”
8. “…I guess I’m more empathetic to people’s family problems... I can be more patient and understanding than I used to be.”
9. “Better now, they’re more understanding...”
10. “Easier to get along with people now.”
11. “…I met a lot of people to help me along.”
12. “Easier to get along, mellower now.”
13. “I’m a little more compassionate...”
14. “…After that episode, I prospered. I have a good job, good money and it’s given me knowledge. People come to me to ask questions, people trust me.”
15. “…I realize I can get along and enjoy other people...”
16. “Easier to meet people, enjoy myself, less aggressive/avoidant...”
17. “...There are certain qualities in people that I search out such as openness, a sense of humor about oneself and a willingness to talk more about personal and spiritual matters.”
18. “I think I’ve become more compassionate and understanding. Now as critical of others, so not as critical of myself.”
19. “I think I’m a little more tolerant of people than I was before. I didn’t have much empathy to peoples’ sorrows. Now however, I’m not so quick to write people off.”

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APPENDIX C

RESULTS OF SOCIAL FACTORS

Ethnic Differences

There were more Caucasians reporting a pattern of caution with 42% reporting this. Hawaiians showed similar proportions (21%) to their numbers in the sample as a whole (19%). The Japanese, on the other hand, were somewhat under-represented in this group, with only 10% reporting a general pattern of caution. Japanese made up 25% of the total sample.

There were more Japanese represented in the reaching out group, on the other hand (47%), and to a lesser extent, Hawaiian (21%) and Caucasian (21%) ethnic groups. Caucasians comprised 33% of the total sample while Hawaiians made up 19% and Japanese 25%.

Perceived Overall Effects of Illness

Cautious

There was a slight tendency among those who responded in this way to also view the overall effects of their illness in terms of lost opportunities or restriction of activities (52%). Only 10% of this group viewed the overall effect of their illness in positive terms of self-growth. However, close to a third of this group (32%) reported that their illness has not had any effect on their lives.

Reaching Out

There was also a tendency among members of this group to perceive that their illness has resulted in lost opportunities or restriction of activities. Although fewer (47%) responded in this way than did members in the cautious group. However, a much larger proportion (37%) as compared to the cautious
group, reported the overall effects of illness in positive terms. Sixteen percent reported the illness has not had an effect on their lives.

Social Support

The differences between the two response types were fewer in terms of social support. There was more of a tendency for members among the cautious group to have low levels of reciprocity with others (32%) when compared to the reaching out group (11%). However two thirds of the informants in each group reported that they reach out to family and friends when under stress. An equal number (32%) in each group reported that they are alone when stressed, most by preference. Thus, the overall tendency to withdraw from others evidently does not always indicate social isolation.

Effect on how Other Behave

Members in the cautious group had more of a tendency to perceive stigma and other negative reactions from others (84%) that did members in the reaching out group. Although nearly half the informants in the reaching out group reported that they perceived these negative perceptions (47%). More individuals in the reaching out group reported that they perceived a sense of support and acceptance from others (37%). Only 10% of the cautious group perceived support others. More individuals in the reaching out group (16%) reported that heir illness had not affected how others behave toward them. Only one individual (5%) of the cautious group reported that their illness has not affected how others behave toward them.
What has Helped you Deal with your Illness

Members in the cautious group acknowledged basic self care with greatest frequency as what has helped them most in dealing with their illness (42%). Taking responsibility for oneself was a theme mentioned by 26% while seeking help from others was mentioned by 21%. The mention of the importance of spirituality was a difference among members of these groups, with 47% mentioning spirituality as important in helping them cope with their illness over time.

Members in the reaching out group mentioned the themes of self-responsibility and reaching out to others with equal frequency as what has helped them the most over time in dealing with their illness. These two themes were mentioned by 37% each. Basic self care was mentioned by 21% and spirituality was mentioned as important by only 10% of this group.
REFERENCES


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