LIVING WITH SCHIZOPHRENIA: REBUILDING A LIFE

A GROUNDED THEORY STUDY

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Abstract

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This qualitative study explored the subjective experience of living with schizophrenia. Specifically, it focuses on coping with the ongoing nature of this condition, and the consequences of being diagnosed and identified as being schizophrenic. This study was designed to explore the common features of the experience of living with schizophrenia, while at the same time offering my participants a chance to tell their own unique stories. In addition, sharing their personal narrative with me offered each participant an opportunity to talk about how he/she has come to an understanding of this experience, and the meaning it has had for each of them.

Open-ended, semi-structured interviews were conducted with seven participants, two women and five men, who have all been diagnosed with schizophrenia. Six of the participants have been diagnosed with Paranoid Schizophrenia, and one participant has been diagnosed with Undifferentiated Schizophrenia. The participants were chosen to reflect as broad a population as possible and they varied in age, ethnicity, cultural background, education, and socio-economic status. Data from the interviews were content analyzed according to the method of constant comparative analysis as developed by Glaser and Strauss (1967).

A primary finding is that the men and women who participated in this study, who are all struggling with the symptoms of a psychotic condition – schizophrenia – as well as from the complications of being identified as mentally ill, all actively think about and seek ways to live with their condition.

The findings are summarized in the following five categories: “Reclaiming a Sense of Self-Respect”; “Finding and Maintaining Values and Goals”; “Reconnecting with Others”; “Rejoining the World”; and “Finding Meaning in the Experience of Schizophrenia”. They describe a journey from loss and isolation to developing a renewed sense of self-esteem and for some, reconnecting with the larger community around them. These components are interrelated and can be assumed within an overarching theme: “The struggle to reestablish a viable way of being in the world: Living with Schizophrenia”.

The extant literature on schizophrenia does not entirely answer the question of how people diagnosed with schizophrenia find the internal resources needed to rebuild their lives and give meaning and value to this experience.

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CHAPTER ONE: INTRODUCTION

This qualitative study explored the subjective experience of living with schizophrenia. My research focused on how the participants describe living with this condition, how, philosophically, they interpret the condition itself, and how they gradually come to terms with the cultural stigma attached to such a diagnosis. Although their stories reflect their unique experiences, they also reveal commonalities that may be illuminating to those who provide services and support for this population. Arthur Kleinman's (1980, 1988) distinction between "disease" and "illness" provided a conceptual framework. In this study, it is the "illness" aspect of schizophrenia to which I attended.

Statement of the Problem and Background

I am the team leader of the Assertive Community Treatment (ACT) team with Telecare Changes, an intensive case management program for people diagnosed with severe mental illness, many of whom have been diagnosed as schizophrenic within the rubric of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR) (American Psychiatric Association, 2000). Our team consists of five case managers, a registered nurse, a psychiatrist, and me. We work as a team providing comprehensive services to our clients, all of whom are referred to us by Alameda County. We are responsible for assisting them with housing, medications, medical services, psychotherapy, and the provision of payee services, in which we are responsible for managing their money when they are unable to do so for themselves. Most of our clients receive Supplemental Security Income (SSI) and Medicaid. I am responsible for organizing and managing the work of the team, supervising the case managers and the registered nurse, and providing services along with the team.

Most of the clients who are diagnosed with schizophrenia in this program experience grave difficulties understanding what has happened to them. Also, they have difficulty coming to terms with the fact that although their symptoms wax and wane, they seldom, if ever, disappear completely. It is worth noting that these particular clients are within a context within which this phenomenon of ongoingness is given the attribution, "chronic". Additionally, a preponderance of the literature that describes phenomena of schizophrenia does so with the attribution, "chronic". While I recognize the context-bound nature of descriptors throughout this work, for readability and consistency in citing literature, I have employed the term "chronic" where necessary.

Harding, Zubin, and Strauss (1997), professors of psychiatry, who have done long-term studies of "chronicity" in schizophrenia, have questioned the use of this term to describe the ongoing experience of living with schizophrenia:

> Derived from the Greek word, *chronos,* the label 'chronic' denotes an illness of long duration or one of frequent recurrence. However, when chronic is paired with schizophrenia, as in "this person is a chronic schizophrenic," the connotation becomes an expectation of deterioration, defect, or deficit states (p.51).

They prefer to describe schizophrenia as a "prolonged" illness rather than a "chronic" illness. They assert that schizophrenia does not necessarily imply a course of deterioration over time, but a condition that renders the person with schizophrenia vulnerable to episodes of psychosis with periods of health in between (pp.61-62).

People who have been diagnosed with schizophrenia fear being called “crazy,” and feel stigmatized by their diagnosis. They feel overwhelmed by the idea that this is a diagnosis from which they may never be free. They wonder if they will have to take medicine for the rest of their lives; will they always be sick? They know that whatever euphemism is used to describe their condition, they are considered by society at large, and sometimes by their families, to be abnormal, weird, frightening, and different from “normal” people. One of our clients reports that her brother tells her he is embarrassed and ashamed to be seen with her in public, because she talks to her voices. He berates her for this, and she, in turn, feels shame, rejection, and self-contempt for her unacceptable behavior, although she also feels she has little control over this. She has lived with schizophrenia for almost twenty years, and yet the shame and hurt endures.

These persons often describe their experience as being a very lonely journey, alienated from friends and often from their families. They believe, and sometimes have been told by their families and the mental health professionals who work with them, that because schizophrenia is not curable, they will no longer be able to work. For them, this is a sentence to a life that is different from others, and marks them as people unable to be useful or productive members of society. They become marked by society, stigmatized, and their mental illness becomes the most salient aspect of their identity as defined by others. All the other aspects of who they are seem to become less important. Their courage and strengths are often overlooked. Many of my clients express honesty and integrity about who they are that is remarkable to me. Their schizophrenia is only one aspect of their identity.

As a result of this stigma, people with schizophrenia often cope by spending years denying its reality in their lives. Denying they have schizophrenia, they explain their hospitalizations as "mistakes." Their shame and denial contributes to their poor medication compliance, and this to their inability to cope with the demands of everyday living. This leads to a never-ending cycle of loss of self-confidence, self-esteem, and finally to loss of hope. They often retreat to grandiose delusions of being special or powerful in order to hide from the reality of the plight of their real lives, while grappling with the confusion and fear that their symptoms create. Their denial and confusion are yet another source of shame and fear, and one of the greatest obstacles they face in their recovery.

It is the work of the case management team to help our clients to overcome their shame and fear enough to learn to cope with a diagnosis which brings with it societal pity, aversion, dislike, fear - a life-long sentence to powerlessness, hopelessness and helplessness, stigma, and alienation from others.

In our work, we hope to be able to help our clients manage their symptoms in such a way that they can live meaningful and productive lives. In my experience, learning to live with schizophrenia appears to involve an acceptance of the presence of an ongoing condition in a person's life.

Acceptance may be what allows a person to find ways to live with and manage the limitations imposed by this condition, much like a person learns to live with diabetes or without a limb.

Unlike most ongoing conditions, schizophrenia is a disorder that may be difficult for the sufferer to understand. Our clients sometimes report that when they first went to the hospital, the world had changed in some terrifying and inexplicable way. One person reported that she was standing in her bedroom one night when the voices began "out of nowhere." They have not stopped since. She did not feel different from one minute to the other. It does not seem to her that she has changed, but that the world as she had known it has changed.

Schizophrenia can be described as a disorder of the mind. Bleuler coined the word "schizophrenia" in 1911 from two Greek words, "schizein" (to split) and "phren" (mind) to designate a group of disorders "characterized by a specific type of alteration of thinking, feeling, and relation to the external world which appears nowhere else in this particular fashion" (Spotnitz, 1999, pp. 16-17). For a person with schizophrenia, the sense of reality is affected. The person must learn not to trust his own eyes and ears, but to disavow what he sees and hears in favor of a "reality" as defined by others that is not his experience. This affects one's sense of self. There is the "sick self" that is not acceptable in the larger society, and the "knowing self" that recognizes that the symptoms the person experiences are not "normal" (Estroff, 1989). This creates a "splitting" of the sense of self and identity into what is real and acceptable and what is not real and unacceptable, (Lally, 1989, p. 260) and a struggle to find some way to cope with this situation. This includes learning to disregard voices that disparage them, command them to do self-destructive acts, or learn to ignore the frightening things they see.

Some of our clients have learned to cope with their severe psychotic symptoms, managing to stay out of the hospital for long periods of time, and to stay on their medications in spite of the side effects they may have had to endure. They seem to be able to integrate their schizophrenic experience into their identity as a person. They seem to have accepted the ongoing nature of their illness, in the sense that they are not just waiting for it to "go away", like a bad cold, and have chosen to live with it rather than to run from it. They no longer fear it, and some of our clients have even found a way to use their experience as an organizing principle of their self-concept. Some people have made remarkable progress at learning to live with this difficult and demoralizing condition.

Many people still view mental disorders as some kind of moral weakness or inferiority. This distinguishes schizophrenia from physical illnesses, even from other mental disorders that are more "acceptable." Our clients would rather describe themselves as "depressed," or to have "bipolar disorder," or even to be "drug addicts" than to be "schizophrenic." They associate this diagnosis with being "crazy," or "bad." People who can incorporate this fearful diagnosis into their self-concept can regain a productive and useful place in the world.

This research has been influenced by Arthur Kleinman's (1980, 1988) very useful distinction between the concepts of "illness" and "disease," in which illness refers to the subjective experience of the condition, its phenomenology, and the concept of "disease" necessarily includes an implicit reference to the patient-doctor relationship. The doctor must diagnose a patient with a disease. This diagnosis has important implications for the patient, since the diagnosis implies the severity, duration, and treatment of the disease. It also directs the type of relationship that the doctor who is doing the treating will have with the patient who is being treated. This relationship is influenced by culture and has an effect upon the experience of being diagnosed with a disease.

The term "condition" includes both the person's experience and the diagnosis – that is, the condition in which he/she finds himself/herself. This research concentrated on the subjective experience of schizophrenia ("illness"). The condition, in which people with schizophrenia find themselves, both intra-psychically and socially, is the context of their experience. Thus we may perceive that the "illness experience" becomes a part of the context that feeds back into the experience itself. This feed back loop suggests a possible process that I hope this study will illuminate.

Kleinman's (1988) distinction between "illness" and "disease" makes an important contribution toward very different orders of experience. His concept, "illness," refers to "how the sick person and the member of the family or wider social network perceive, live with, and respond to symptoms and disability" (p.1). "Illness," in this context, refers to the lived experience of the "disease." "Disease" is what practitioners have been trained to see through the theoretical lenses of their particular form of practice. Disease is “what the practitioner creates in the recasting of illness in terms of theories of disorder. Disease is the problem from the practitioner’s perspective” (p. 5). “Sickness” he defines as the “understanding of a disorder in its generic sense across a population in relation to macro social (economic, political, institutional) forces.” Sickness is described as “a reflection of political oppression, economic deprivation, and other social sources of human misery” (p. 6). Kleinman defines “chronic illnesses” as those illnesses whose course may oscillate between “periods of exacerbation, when symptoms worsen, to periods of quiescence, when disability is less disruptive,” but which never entirely disappear (p. 7). An ongoing illness becomes a part of the life history of a person, including social and psychological changes in the person’s life, which contribute in ways that have not clearly been defined to the alleviation or amplification of symptoms of the illness over the course of time (p. 8).

People diagnosed with schizophrenia, who have learned to cope with their symptoms, have gained some control over their response to these symptoms, and accepted that they have an ongoing condition. The meaning they give to this diagnosis seems to affect the progression of their illness, the quality of their lives, their relationships with other people, and their self-concept. This is what I have explored further.

The literature on schizophrenia is vast, covering etiology, treatment approaches, and medications to treat this condition. Using Kleinman’s concepts, much of this literature is from the perspective of the mental health practitioner, and studies the "disease" of schizophrenia (Strauss, 1989). It was my intent in this study to explore the "illness" of schizophrenia in Kleinman's sense. Thus first-person accounts by people who have lived with schizophrenia became an important body of literature to consider.

I began by exploring first-person accounts of schizophrenia, particularly with regard to how people interpreted what happened to them. Mark Vonnegut's account of his first psychotic break and subsequent hospitalizations in *The Eden Express* (1975) clearly depicts his gradual loss of reality, a loss of the boundaries of time, space, and knowing what was happening around him in a clear way. In the *Autobiography of a Schizophrenic Girl* (Sechehaye, 1951), Renee, the schizophrenic girl, describes her distortion of visual perception and onset of delusional thinking that gradually led to madness. These accounts relate the experience of psychosis, and movingly describe the confusion and fear that ensue. However, they do not deal, in any direct manner with the experience of living with the illness. Mary Barnes' account of her personal experience in *Journey through Madness* (Barnes and Berke, 1972) is a depiction of what it is like to live with the illness. *Welcome Silence*, by Carol S. North, M.D. (1987) is an autobiography of her experience with schizophrenia, and describes, in depth, the tyranny of both auditory and visual hallucinations. *The Quiet Room*, by Lori Schiller and Amanda Bennett (1996), is an especially vivid account of Lori's efforts to cope with her illness, and to accept its reality. It also includes the perspectives of her immediate family. *I Never Promised You a Rose Garden*, by

Hannah Green (1964), is a moving novel about a 16-year-old girl describing her struggle to give up the seduction of her madness, the power and uniqueness that it gives her.

Two qualitative Ph.D. dissertations (Powell, 1998; McNally, 1996) and one master's thesis (Phripp, 1995), all published within the last ten years, explore the experience of schizophrenia, using interviews with persons diagnosed with this condition. These studies focus on the nature of the subjective experience of the symptoms of schizophrenia, and the effect on the self, but do not deal with the experience and meaning of living with this condition.

In the last 14 years, the *Schizophrenia Bulletin* has begun to publish first person accounts of living with schizophrenia, although the accounts are few. The articles deal with various aspects of discovery of the diagnosis, treatment, and learning to accept and cope with this mental illness. Because schizophrenia affects one's ability to trust one's own perceptions, these accounts clearly indicate how hard it is to learn to live with an illness whose symptoms so profoundly affect the person's sense of self, and how difficult it is to relearn self-reliance, self-trust, and self-respect.

The literature that I have reviewed reveals that although the etiology and treatment of schizophrenia have been studied extensively, there is as yet a relatively small amount of research on the experience of living with schizophrenia from the first-person point of view. There appears to be even less research on the question of the illness experience – living with an ongoing illness of the mind and the ways by which a person comes to terms with this reality. I am interested in exploring what available internal resources and external influences are experienced by a person living with schizophrenia that contribute to or hinder the ability to cope with this ongoing illness and influence the course of the illness.

The Study Question

My primary research question is: How do people diagnosed with schizophrenia come to terms with this illness?

The sub-questions of this study are:

1. What was the initial response to being given the diagnosis of schizophrenia? How did the person experience this diagnosis?
2. How do people diagnosed with schizophrenia deal with the stigma attached to this diagnosis?
3. How do they experience their social surround?
4. How do they cope with the idea that schizophrenia is an ongoing condition? Does learning to cope with this experience appear to be associated with being able to rebuild one's life?
5. How does the experience of living with schizophrenia become an organizing psychological and emotional principle of the person?

These additional questions elucidated some of the elements of the process by which a person comes to terms or does not come to terms with having a condition that so profoundly affects his or her identity.

This qualitative study was based on self-report data obtained in semi-structured, in-depth interviews with persons with schizophrenia. The interviews were aimed at eliciting descriptions of the thoughts, feelings, and experiences of these persons as they have struggled to accommodate this diagnosis into their concept of who they are in the world. This study is phenomenological in that it focused on participants' subjective accounts of their experience. It is interpretive, as the intent of the study was to develop a conceptual understanding of psychosocial process. For this purpose the Grounded Theory approach to methods (the "constant comparative method") was used to analyze data (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

Since this was a qualitative study, there were no initial hypotheses to be tested. The researcher anticipated that the study would generate theory that is grounded in the data.

Assumptions of the Study

The study is based on the following assumptions:

1. Schizophrenia has a major impact on the life history of the person affected.
2. Schizophrenia is currently considered to be an ongoing condition (DSM-IV-TR).
3. People who have been diagnosed with schizophrenia are greatly affected by how people respond to them and to their symptoms.
4. People diagnosed with schizophrenia have a condition that affects the core sense of self, and self in relation to others, and to the world around them.

Significance of the Study

Until very recently, first person accounts of the experience of being schizophrenic were few. Much of the literature on schizophrenia has been directed at understanding the etiology and the treatment of this severe psychiatric disorder through medical interventions, institutionalization, and supportive services.

In addition, there is a large literature on the reactions to these measures which include proposals that emphasize non-medical interventions in the treatment of schizophrenia, including psychotherapy, milieu therapy, and psychoanalysis (Laing, 1967; Sullivan, 1962; Perry, 1972; Fromm-Reichmann, 1959; Spotnitz, 1999). During the 1960s and 1970s, many people with schizophrenia were given the opportunity to use these non-medical interventions, with some success.

However, newer and more effective anti-psychotic medications, which have become widely available during the last decade of the 1990s, are cheaper to prescribe and require less professional intervention, less time, and shorter inpatient stays than non-medical interventions. These new anti-psychotic medications are more effective at relieving psychotic symptoms than older medications, safer, and with fewer side effects. The use of these medications has influenced the decline in psychotherapeutic and psychoanalytic interventions in the treatment of this illness, particularly for people with few resources with which to pay for treatment.

Ironically, the effectiveness of these medications has permitted people with schizophrenia to find ways to communicate their experience more effectively to those of us who work with them. However, the interventions in the treatment of schizophrenia remain provider-oriented toward a provision of care that excludes client-directed treatment approaches. Those clients are still regarded poor judges of what treatment would help them in their recovery, and are seldom asked for their own thoughts about what treatments would be most helpful for them.

It was my intention to add to the small body of research in which the voices of those with schizophrenia are heard recounting their experiences of this illness: the ways in which they have learned to cope with the symptoms of their disorder, how the treatment they have received has affected this experience, and the meaning it has had in their lives. I hope that this study will provide other mental health providers and people diagnosed with schizophrenia a better understanding of how people learn to cope with an ongoing condition that affects the core of the self.

CHAPTER TWO: LITERATURE REVIEW

This research focused on the subjective experience of schizophrenia as an ongoing condition, often referred to in the literature as a chronic illness. This review will cover literature on the experience of chronic illness in general and of schizophrenia in particular. Literature on etiology and treatment of schizophrenia will be referred to only where directly relevant. Prior to reviewing these bodies of literature, I will set the context of my research with a brief review of two relevant theoretical frameworks.

I will begin with psychiatrist and anthropologist Arthur Kleinman on the conceptualization of disease and the experience of illness as constituted within a cultural framework. His research and theoretical approach influence my research as well as much of the current research and thinking about illness and disease.

Chronic illness has been described as a biographical disruption involving loss or change in sense of self, feelings of powerlessness, vulnerability, and dependence. The work of George Herbert Mead and his followers of the sociological school of "Symbolic Interactionism" have influenced much of the literature on the construction of personal identity in chronic illness. This perspective on identity, the experience of chronic illness, and the attached stigma influences my own approach. Therefore, I will present an overview of the symbolic interactionist perspective, including Erving Goffman's (1963) work on "stigma."

Kleinman: The Experience of Illness in the Context of Culture

Arthur Kleinman's (1980) conceptual distinction between "illness" and "disease" is crucial. "Illness" is the lived experience of the patient. "Disease" is the diagnosis of the physician (p. 5). As a psychiatrist and medical anthropologist, Kleinman studied the way people in Taiwan experience, talk about, and label their illnesses. He explored the differences and similarities between Western and Taiwanese ideas about illness and disease. His research indicated that ideas about illness and disease are culturally bound. Illness always occurs in a cultural context, and the meaning of the illness to the person, the family, and the health practitioner is influenced by the culture in which the illness occurs. This idea that illness is culture bound is important because it indicates that illness is a psychosocial phenomenon. Kleinman concludes that both illness and disease involve psychosocial and cultural factors and that these factors are the stuff of the disease itself in a psychological illness. It is the subjective experience of the behavioral and societal responses to the illness that, "provide it with meaning and constitute it as a symbolic form. Without illness, there is no significance attached to the disorder. That is why illness is always a cultural construction" (p. 78).

Kleinman's (1980) cross-cultural research not only reveals how cultural beliefs determine the way people interpret their experiences of illness, but also the kinds of treatment they seek and the types of treatment available. Based upon this research, he observes that treatment for sickness and disease in Western medicine has been strongly influenced by "ethnocentrism and scientism," which "follows the paradigm of biomedical science to emphasize in research only those variables compatible with biological reductionism and technological solutions, even if the problems are social ones" (p. 32).

Kleinman (1980) advocates that researchers who study disease and illness step away from their own culturally determined beliefs about disease and its treatment in order to see their own biases, and to see disease as a "cultural construction of a clinical reality," much of it based in culturally accepted norms of social, political and economic power (p. 45).

It is these cultural norms that determine how a person and his doctor will think about the patient's condition, and consequently how an illness will affect the patient's social identity. For example, there is tremendous stigma attached to mental disorders in Chinese culture. For this reason, in Chinese contexts, almost all mental disorders are described in terms of a physical illness; the patient assumes a medical sick role, and is allowed release from normal duties and responsibilities while his illness is being treated. Psychiatric illness is often called "neurasthenia", a term used to convey the idea of an organic disorder, thereby avoiding the shame which would be brought to the family's name with the diagnosis of mental illness. Within this context, the patient can then be treated as though he/she were physically ill (Kleinman, 1980, pp. 125-128).

In our culture, we tend to treat the patient in a privileged relationship between doctor and patient, the family being often excluded from the decisions made and treatment offered. Taiwanese health care primarily treats the whole family, recognizing that the family's interpretation of symptoms has as much influence on how the patient experiences them as the interpretation of the medical practitioner or healer. Kleinman's later narrative analysis of chronic illness in a western context (1988) reveals how family responses affect experiences of chronic illness in our own culture. Because illness is a psychosocial phenomenon, the ill person's sense of self is influenced by the responses of those around him/her. This process of interaction between one's internal sense of self and the self as defined by others is key to understanding the experience of the ill person. Symbolic Interactionism describes this process.

Symbolic Interactionism

Symbolic Interactionism defines the concept of "self" differently from the "self" as defined by theories influenced by psychoanalytic theories that focus primarily on the self as a way to describe one's intrapsychic experience or one's individual identity. Symbolic Interactionism focuses on the self as an interpsychic experience, one's social identity. The focus on the self as a process of interaction between internal and external experience is used by many of the researchers I reviewed to explore the meaning attached to the illness experience, and the stigma that ensues. This is a particular way of talking about the self that was unfamiliar to me, and is based on the work of George Herbert Mead (1934). Therefore, although he uses the word "self," it is defined in a particular way. The researchers I reviewed use the word "self" as defined by Mead.

The Construction of Personal Meaning

George Herbert Mead (1934) described "the self" as the "process of self-interaction with subjective and objective experiences" (p. 140). Human beings are social, and as such, each experience is both an external and internal event. We interpret each experience based on previous personal experience and the meanings given to that experience by those around us. This process defines the self. Mead's concept of self does not describe a structure such as "the ego," but a reflexive and ongoing process of interpretation of experience, and the meanings given to those experiences by the self. It is a continual interaction between the learned social/cultural meaning of the object such as a "chair" or a "cloud," and our own personal interpretation of this object or event based on our experiences with regard to this object in the past. Thus each object or event has a symbolic or agreed upon social meaning, layered with our experience, our interaction with this object or event – its meaning to us.

The experience of self, and its meaning to us, is characterized by the same process. Each experience I have is both an event and an event that I reflect on. The meaning of the experience to me will be the result of the interaction between its social and cultural meaning and my memory or consciousness of similar experiences in the past. The distinguishing characteristic of the self is that it can be an object to itself, it can reflect on itself. This self then is both subject and object to itself. It is both the actor and the observer. Mead uses the word "self-object" to describe this phenomenon (not to be confused with the meaning of "self-object" as used in self-psychology). The observer evaluates the action based on the criteria of others and the criteria of past experiences. In other words, the human being can be the object of his own action. He can communicate with himself as though he were another person, and reflect upon that communication. This is essentially a social experience, as that reflection will be based on previous experiences of communication with others. The "I" acts. I cook, I write, I read. "I" actions are reflective of the social expectations of the culture in which I live, and my previous experience of these activities. The "me" reflects on this experience, evaluates it, and gives meaning to it (Mead, 1934, pp. 135-175).

Sociologist Herbert Blumer (1969), building on the ideas of Mead, coined the term, "symbolic interactionism." Symbolic interactionism is distinguished from the traditional position of "realism" in philosophy, which regards objects as having an inherent meaning, emanating from the intrinsic makeup of a thing; and the traditional "psychological" perspective which regards meaning as arising "through a coalescence of psychological elements in the person." Instead, symbolic interactionism sees meaning "as arising in the process of interaction between people. The meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to the thing" (p. 4). Meanings are seen as "social products."

Blumer (1969) stressed that the interpretation of the meaning of an object or an event becomes the instrument for the "guidance and formulation of action." The interaction between self, object, and the symbolic meaning of the object will direct the choice of action with regard to that object. This includes the "self-object," using Mead's definition of this term. Interaction between the subjective self and the social self, or self as defined by others, can determine the action the person takes with regard to the self-object. My actions as a woman are defined by my interpretation of what it is to be a woman as defined by the cultural and social environment in which I live, as well as by my previous experiences of being a woman. This is what it means for me to be a woman. Thus, the meaning to me of the concept "woman" guides how I will act as a woman. It is a constant re-evaluative process, and, as such, is continually evolving.

Stigma: The Construction of Social and Cultural Meaning

Sociologist Erving Goffman, (1963, 1964) wrote extensively on the underlying rules of social interaction and the situation of persons who are unable to conform to these rules. Goffman analyzed the sources and psychosocial nature of stigma. Goffman described the social significance of stigma as a "spoiled identity," a social identity judged and defined by others. A person perceived to be not "normal" is stigmatized or "discredited" by others, and thus his "life chances" are reduced (1963, pp. 1-3).

To feel the stigma, the person must share the cultural belief system of those who label him. "Stigma" is thus a social and cultural construct shared by both the stigmatizers and those who are stigmatized. The person who carries or experiences stigma identifies himself as bad, loathsome, discreditable. Such judgment of the self leads to a sense of shame, self-derogation, and self-hate. However, the stigmatized public identity may be in direct conflict with the person's internal, or private, identity. There is then a conflict between the "virtual" identity and the "actual" identity – the identity as defined by others, and the identity as experienced by the self. Goffman (1963) observed that the social role can affect the personal identity: "This discrepancy, when known about or apparent, spoils his social identity; it has the effect of cutting him off from society and from himself so that he stands a discredited person facing an unaccepting world" (p.19). Although I may still see myself as a valuable person, my illness may reduce my value to others, and thus reduce my sense of value, my self-esteem, and my self-worth. My meaning to myself, my identity has been changed by my new role as a "sick" person.

A person diagnosed with a chronic illness faces ongoing stigmatization and subsequent loss of self esteem in a society which values physical beauty, youth, fitness, and the ability to "pull one's own weight" in terms of productivity and contribution to the working world. There is great pressure to "fit in" and to be able to conform to social and cultural norms. Those who are not able to fulfill this expectation run the risk of rejection by the larger community. Thus, people who have physical or mental impairments are at risk of being labeled as discredited, unacceptable, useless. This stigma may then be translated into public policy, and affect the treatment of those stigmatized by chronic illness.

Kathy Charmez (1983), in a sociological study using 73 in-depth interviews with 57 people diagnosed with a severely debilitating chronic illness – such as cardiovascular disease, diabetes, cancer, multiple sclerosis, and lupus erythematosus, as well as their health practitioners and family members – found that the ill persons suffered an undermining sense of the self, resulting in a "loss of self." Their inability to share the experience of illness with others results in a sense of isolation and distance, and an inability to maintain previous social roles, which results in "a crumbling away of their former self-images without simultaneous development of equally valued new ones" (p.168). This loss results in a diminished self-concept.

Charmez (1983) describes the spiraling consequences of the illness: loss of productive functions, financial strain, family strain, loss of personal freedom, loss of control, loss of the future, increased dependency on others. She observes that our self-concept as Americans is culturally bound to the Protestant work ethic with its emphasis on independence, privacy, hard work, and financial success. The person becomes worth less, diminished, de-valued in his own eyes and in the eyes of society. In addition, the victim may be blamed for his misfortune, as a moral failure to live up to societal expectations. In turn, the ill person may blame himself for his illness and loss of status, increasing the sense of personal failure. Charmez reports the experience of a young man who receives dialysis treatments, expressing the impact on his sense of self:

> This (dialysis machine) is an ego destroyer. You come, and you're depending on a machine to keep you going, and if you don't, then you don't go. I mean that's all there is to it...
>
> I know that sometimes I feel less than human, having to go through the process.... Traveling is very hard, getting away and just normal things that people do. And it makes me think from time to

> time that I'm less than human, and again I work my way out of that, but it is just a constant struggle to [do so]. (p. 173)

Charmez (1983) found that the unpredictable nature of the illness course results in uncertainty and fear: "The greater the loss or control and the amount of potential embarrassment from the unpredictable illness, the more likely that individual's self-concept suffers and he or she will restrict his or her life voluntarily" (p.175). An all-consuming retreat into the illness, and a restriction of concerns may result. The illness structures the ill person's world, shapes his self-concept, and "fosters an encompassing concern with self" (p.176).

Charmez (1983) found that the chronically ill person experiences being discredited by others, leading to stigma, shame, self-denigration, self-hate, and self-blame. The greater the magnitude of the stigma involved, the greater effect such discredit will have on the ill person's self-esteem.

Such findings are confirmed in another study, from a symbolic interactionist point of view, that focuses on "stigma" stemming from the social response to the ill person. Sociologist Graham Scrambler (1984), drawing on Goffman's work on the concept of stigma, interviewed 94 people diagnosed with epilepsy. He reports that the diagnosis of epilepsy is frequently accompanied by a sense of shame and fear of discovery of the illness by others. The presence of a chronic illness such as epilepsy can disrupt established social patterns of interaction with others and lead to a "deviant" way of living, when judged by social standards. Due to his illness, the person can no longer live "normally" – going to work, carrying "normal" responsibilities – or have "normal" relationships with those around him. This violation of social norms creates discomfort and anxiety for those around the ill person, since they can no longer relate to that person in the “ordinary” way. Thus the ill person can experience both “felt” and “enacted” stigma. Felt stigma is the shame associated with being labeled as a “sick” or “ill” person. Enacted stigma is the experience of being actively rejected by those who interpret one’s illness to mean that one is no longer a desirable person to be with, and should be isolated from others. The ill person may be judged as worth less, as one who does not contribute to society, or who is now dependent on others (pp. 205-216).

Scrambler (1984) describes chronic illness as an “ontological offense” – the person offends others by being an “imperfect being” whose deviance creates a violation of the “cultural norms governing routine social intercourse by causing…ambiguity in social interaction” (p.208). The illness may lead others to react with embarrassment, pity, fear, revulsion, helplessness, emotional discomfort, and rejection. Social intercourse becomes inhibited, awkward, and anxiety producing for both parties, increasing the sense of the ill person as different, apart, or alien.

This sense of difference, or being deviant, creates a sense of felt stigma, of shame, “a deep sense of ontological inferiority.” The ill person copes by resisting the transition from “normal” to “deviant,” by trying to pass as normal, or to make a “great effort to keep the stigma from looming large.” Fear of being labeled as deviant and the effort expended to conceal or hide the illness or disability exacts an immense toll on one’s identity, a “profound and lasting, if intermittent, source of unease, self-doubt and disruption in people's lives" (Scrambler, 1984, p. 217). The deviant role becomes part of the person's identity, creating what Scrambler calls a "subjective career," in which interpretation of events connected with the identity as an ill person have been made, and become the basis for the development of contingencies to deal with the future. Findings regarding the experience of chronic illness are remarkably consistent.

Chronic Illness

Most researchers into chronic illness use Kleinman's distinction between "illness" and "disease." Many are medical anthropologists who have expanded on Kleinman's work. Some medical practitioners have focused on the experience of chronic illness as a process.

The research reviewed here is primarily qualitative. These researchers present a good argument that qualitative approaches are the most effective way to understand the subjective experience of those who suffer from chronic illness. I have grouped the literature on chronic illness into three sections: illness in the context of culture, the experience of illness, and coping strategies and healing in chronic illness.

Researchers studying chronic illness, as well as those who suffer from such illness describe experiences of stigma, biographical disruption, loss of identity/self or a change in sense of self, a sense of powerlessness and vulnerability, and feelings of isolation and dependence. All of these experiences must be seen within their cultural context.

Illness in the Context of Culture

Kleinman (1988) defines "sickness" as "the understanding of a disorder in its generic sense across a population in relation to macro social (economic, political, institutional) forces...a reflection of political oppression, economic deprivation, and other social sources of human misery" (p. 6). Many authors refer to this aspect of illness. Medicine itself reflects the political environment in which it exists. Those who are ill are treated differently according to the social meaning or social judgment about a particular disorder, and the economic or social status of the patient (Anderson, Wiggins, Fajwani, Holbrook, Blue, & Ng, 1995; Bartz, 1999; Blank & Diderichsen, 1996; Bury, 1982; Jordan, Ong, & Croft, 2000; Sakalys, 2000).

How the patient understands his illness and his attitudes toward the illness are shaped in the context of the medical culture in which he lives. Kleinman (1988) has drawn attention to the difference between the way in which the medical practitioner views the patient's disease, and the way in which the patient views his illness (pp. 1-5). For example, the philosopher, S. Kay Toombs (1992), who lives with multiple sclerosis, describes in detail the separate worlds of physician and patient. He observes that the physician focuses on the symptoms in order to understand and treat the disease, whereas the patient focuses on the experience and meaning of the symptoms to his ongoing sense of his identity in the world. The physician is interested in scientific reality, the patient in experienced reality. The concept of time is also relative to each person's experience; severe pain slows time for the patient, but for the physician time may move quickly, too quickly to treat the patient effectively. The physician views the illness as an objective reality; the patient lives the illness as an immediate experience. The physician views the disease as a phenomenon; the patient understands it as a lived experience. This discrepancy between the world of the doctor, and the world of the patient makes it difficult for them to communicate a shared understanding of their experiences (pp. 10-27).

Mark Kidel (1988), a writer and filmmaker, whose experience of illness helped him to re-frame his life, observes that our culture is preoccupied with health and fitness. From his personal experience with serious illness, as well as his subsequent exploration of Western European and American beliefs about health and fitness, he observes that in our obsession with fitness, the body has become an object, which we seek to bend to our will. The body becomes the other, to be molded, and to be made into the image we desire. When the body fails to respond as we desire, we are encouraged to seek "professional" help. Our medical culture promises cure, and illness is regarded as the enemy, to be fought and conquered: "Consumer-style health is about restoring a product – 'good health' – as fast as possible. 'Cure' in this context is professionally defined and administered and is as 'external' to the patient as was the subjective experience of the illness in the first place" (p. 9). Thus, all symptoms and disorders are seen as physical facts, which are only secondarily connected to the "patient."

Kidel points out that this attitude encourages the physician's detachment from the lived experience of the patient and avoids the emotional components inherent in the diagnosis of an illness, especially one that is life threatening or chronic. The physician's disengagement from the patient's experience disempowers the patient and can contribute to the subjective experience of isolation, alienation of the body, alienation from others, shame, fear, and feelings of vulnerability (1988, p.11).

This view was echoed by Cecil G. Helman (1985), a medical anthropologist, in a qualitative research study using interviews with 42 people with either respiratory or gastrointestinal psychosomatic disorders. He found that patients reflected the various medical theories and judgments held by their health practitioners. Those who had been told that their illness has a psychosomatic component viewed themselves as "weak," and saw "emotion," "stress," or their "own personality" as contributing towards their ill health (p. 10).

Other studies have expanded on the impact of culture on the experience of chronic illness. Joan Anderson's (1996) qualitative research on health care policy in Canada, and Robert Castro's (1995) in-depth interviews of 74 inhabitants of a small, rural, very poor community in Mexico, show how differently the cultural and economic influences in people's lives determine how they experience illness and health. These two studies found that underprivileged patients from Third World countries respond to the diagnosis of a chronic condition differently from those who are more educated, affluent, or acculturated. They also found that the experience of illness and its treatment could be radically different from one section of the culture to another, as health care is also politically and economically determined. People living a marginal existence often experience a sense of exploitation, uncertainty, and violence. The causes of their illnesses are described as random events in an uncertain world, and pain itself was often described as an illness. Getting or staying well is experienced as strength or endurance.

Various layers of socio-cultural context impact the experience of illness. In the following section, I will review literature that focuses on the experience of chronic illness – its personal and social meaning. The cultural and social contexts continue to show their impact.

The Experience of Illness

Illness and chronic illness have both a personal and a social meaning. The personal meaning of illness can include a disruption in the everyday sense of self, and in the relationship with others. When chronic, it can be a biographical disruption of the expected trajectory of one's life, of one's identity, and thus affect how others relate to the ill person. I believe that this disruption of the sense of self is important to understanding how living with any chronic condition, including schizophrenia, contributes to the meaning people attach to their illness. I will begin with a definition of illness itself, that I believe accurately describes the experience of being ill. From there, I have chosen literature that describes the experience of chronic illness and its impact on the expected course of life and on the sense of self.

To begin, Kidel (1988) mentioned above, offers a definition of illness as being "out of sorts," "not feeling like myself" (p. 5). He observes that the person who is ill feels attacked by the body as in a "heart attack," a "gall bladder attack," an “asthma attack,” etc. Our everyday sense of self, normally taken for granted, is disrupted when we fall ill. Our first concern is to get well again. We want to return to our former state of business as usual, to be cured of whatever ails us so that we can get on with fulfilling our goals, living out our life plan, and feeling part of the world again.

In our competitive culture, illness has been associated with “vulnerability, fallibility and weakness,” which undermine our ability to carry out effectively our roles and goals. Illness is perceived, in this context, as a failure, a negative phenomenon, powerlessness. It is a manifestation of the unpredictable, “the dark forces which form an integral part of life, and cannot easily be brought under human control” (Kidel, 1988, p. 12). Health is associated with success, strength, and virtue. It is the manifestation of our current, though temporary, victory over death.

However, when the persistence of symptoms disrupts the structures of everyday life that underpin the expected course of life, leading to uncertainty about the future course of events and shredding the certainty of a cure, the illness becomes a chronic illness. A study, in which semi-structured interviews were used with 30 people diagnosed with rheumatoid arthritis and referred for the first time to an outpatient rheumatology clinic, led sociologist Michael Bury (1982) to describe chronic illness as a process of “biographical disruption.” The consequences of the illness may not be immediately apparent. Unlike a permanent injury, which happens suddenly, chronic illness may have an insidious onset, lending itself to a period of disregard or denial of the emerging symptoms while the person waits for the symptoms to go away. The person, seeking explanations for the persistence of symptoms, may resort to all sorts of cures, convinced that if the right cure could be found, the illness could be vanquished, like an enemy.

When the person is diagnosed with chronic disease, there often follows a period of disbelief, denial of the reality, or the permanence of the condition. Chronic illness, the experience of the disease by the person so afflicted, introduces that person to the world of suffering and pain, possibly death, which are normally seen only as distant possibilities or the plight of others. Expectations and plans for the future must be re-evaluated and changed.

Disruption in relationships with others follows as the presence of the disease decreases the availability of emotional and material resources previously available to the person. The course of the person's life history is permanently altered. Bury (1982) describes this as a "biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging. The relationship of 'internal and external reality' is upset" (p.171). The person may have the same internal identity, but his public identity has been permanently altered.

The experience of illness imposes upon the ill person an existential awareness of personal vulnerability, loss of control, and the terror of death. Illness impacts one's identity, and chronic illness changes one's sense of self in a permanent way. It is also a very lonely experience. The person who is ill experiences life differently, and often finds it difficult to communicate this experience to others on the basis of a shared set of experiences

S. Kay Toombs (1992), who writes about "living through illness," describes the individual meaning of illness as a shared world of meaning with others. Culture determines how the ill person understands his experience, although the experience is unique to that individual's personal life history.. Illness has both an intersubjective and an intrasubjective meaning (p. 8). "The loss of control that is intrinsic to the experience of illness is accompanied by an acute awareness of the unpredictability of the familiar world" (p. 20). It is this experience that separates the ill person from those around him, leaving him/her feeling isolated from others. Its impact on the person's identity in the world gives the illness its personal meaning. That lived, meaningful illness, with its experience of stigma, isolation, reduced functioning, role loss, loss of self-worth, becomes a "suffered illness." The significance of the illness creates suffering.

Alan Radley (1999), a medical sociologist whose paper will be reviewed below, uses the term "horror" to describe the terror experienced by a person being given the diagnosis of a life-threatening illness, of being forced to come face to face with the realization that one's previous identity in the ordinary world is lost forever. The "horror" and biographical disruption which Bury (1982) associates with chronic illness is vividly described by Radley, who tells of a woman's reaction to being given the diagnosis of ovarian cancer:

> I just make it down to the toilets, trailing the drip, hand on wound, surgical stockings on both legs. Away from those 20 or so

> strangers in the front of whom I have just been given the worst news I could imagine. I look at myself in the mirror. Is this what a person with cancer looks like? (p. 782)

Coping Strategies and Healing in Chronic Illness

Coping strategies and ways of healing and regaining a sense of self have been explored by researchers and described by sufferers. These strategies include objectification of the body as a way to distance the sense of self from the body's vulnerability, identity reconstruction incorporating the illness as part of the self, and the use of personal narratives to gain perspective and understanding on the personal meaning of the illness to the sufferer. I believe that these coping strategies are important to understanding how people live with a chronic illness and find recovery and healing in the process. Some of the literature I have chosen to review describes coping and healing in terms of a process. This conceptualization has influenced the way I think about how people live with a chronic illness such as schizophrenia. The coping strategies I found in the literature fell into three main categories: objectification of the body, identity reconstruction, and healing narratives.

Objectification of the Body

One way that people cope with a chronic illness is to "psychologize" the illness. Cecil Helman (1985) observed that patients coped by the "psychologicalization" of their conditions, "redefining physical symptoms as emotional or psychological in origin." Another way of coping was to "reify" the offending body parts, separating the diseased parts from the rest of the body and from the rest of the self, so as to preserve the sense of self-worth, of an idealized self. This also allowed them to experience their disease as outside of their control. Thus they no longer had to take responsibility for the illness, but could see it as an enemy to be fought. This attitude, Helman points out, is reinforced in the Western cultural tendency to see the body as separate from the self, from the spirit. Toombs (1992), similarly asserts that it is "objectification of the body" that allows a person to experience chronic illness as an "alien presence" in the body, thus reducing the ill person's sense of responsibility for the feelings of vulnerability, powerlessness, and loss of control. Other authors have observed this coping strategy (Castro, 1995; Kidel, 1988; Sakalys, 2000; Tatham, 1988).

Identity Reconstruction

Another way of coping with a chronic illness is to develop a new identity as an ill person. Graham Scrambler (1984) found that the deviant role could sometimes become the major aspect of the person's sense of self, leading to an identity as a deviant person, as a "debilitated" person. In this case the person copes with the stigma and loss of status by identifying as a victim, dependent on those around him. Others may develop "ego defenses," such as denial of the illness, seeking to hide it from others. Still others may adopt the strategy of acceptance of the illness and build an identity based on the cultural values and beliefs of the contemporary society in which they live. The latter become compliant with expectations of others, to ease tension and get along. For example, a blind person may allow others to treat him as though he were more dependent than he may be in order to ease their anxiety. A deaf person may resort to writing simply to avoid confusion and fear in hearing people. Some ill persons avow the deviance and then challenge the norms and values that attach stigma to the condition. For example, many of the wheelchair-bound have lobbied to have curbs and public transportation made accessible to them to normalize their condition.

Charmez (1999) revealed that chronic illness might offer the ill person an opportunity to "play out the myth of the hero who emerges victorious against all odds." In this way, suffering elevates the person's moral status as a person apart, a "hero who has emerged from battle" (p. 368). By facing the illness, the person may achieve some admiration from those around him/her. Adaptation in general was also found to be an important mode of living with impairment in Charmez's earlier (1995) study in which she identified altering life and self to accommodate to bodily losses and limits and resolving the lost unity between body and self as means of struggling with rather than against illness as primary themes.

This study (Charmez, 1995) on adaptation to chronic illness outlines three major stages: first, experience of the illness, and the personal defining of impairment through bodily assessments; second, identification of trade-offs as the person weighs losses and gains; and third, revision of the person's identity goals. Adaptation to illness involves the surrender to the ill self by relinquishing control over the illness and by flowing with the experience of it. This is an ongoing process; chronically ill people are forced to adapt repeatedly as they experience new losses.

Karen Yoshida (1993), a researcher at the University of Toronto, studied the impact of chronic illness on self and identity in in-depth interviews with 35 adults with traumatic spinal cord injuries (paraplegics), which she defines as chronic illness. This study describes a process by which people reconstruct a new identity that incorporates the illness as part of the total self, while the person continues to draw strength from the core aspects of the non-ill self. Yoshida does not see the process as linear or developmental but, instead, as a pendulum. I believe this is a useful way to conceive of a healing process, and for this reason, I will review this study in depth.

Using a symbolic interactionist perspective, Yoshida (1993) poses that a chronic illness, because of its impact on identity and sense of self, requires a reconstruction of that identity. Her research indicates that reconstruction of the self is a non-linear process, which she conceptualizes as a pendulum: a process that "swings back and forth...between the non-disabled and disabled aspects of self" (p. 217).

Yoshida (1993) identified five predominant identity views or outcomes: (a) the former self; (b) the supernormal self; (c) the disabled identity as total self; (d) the disabled identity as an aspect of the total self; (e) the middle self. Further, these identity views are influenced by five processes: (a) loss; (b) sustainment; (c) integration; (d) continuity; (e) development of the self.

Yoshida (1993) defines the "former self" as the person's identity before the injury, including both "core" elements and "peripheral" aspects of the self. "Core" elements of the self are enduring aspects of the self that "greatly define the individual," and are the basis for a sense of continuity. She observes that the younger the person was at the time of the injury the fewer core aspects of the self may have been established, making it harder for the person to draw upon these non-disabled aspects of the self in identity reconstruction. Peripheral aspects of the self are described as social roles (i.e., wife, mother), and career or work identities. Those whose life experiences have been more negative, and who are younger at the time of the injury, may move less freely across the arc of the pendulum.

A person's awareness of the continuous impact that his/her injury has on one's life can lead to anger and self-pity. Anger at others as well as at the self can lead to a negative identity in which the disabled self becomes the total self. Anger turned inward can lead to deep depression, self-rejection, and self-hate.

Yoshida (1993) identified an identity at the opposite end of the pendulum: the supernormal identity, which "refers to a person with a chronic condition who engages in activities that require a level of functioning more demanding than those who are able-bodied" (p.226). In an effort to reconstruct an identity, which is "personally valued and socially credited" in the world of others, these people seek to prove to themselves and to others, through these supernormal feats, that they still have self-worth.

Yoshida (1993) gives the example of a young paraplegic man, who continues to ride horses:

> ...like when I say, 'I'm going horseback riding.' 'You are doing what? Horseback riding? What are you doing horseback

> riding?'….well, I say, 'No big deal, I have horses, and I go riding.' And that type of thing. Ah, doing things that other people think I shouldn't be doing. Not that I do them because other people think I shouldn't be, but because I do it. And I want to do it. (p. 226)

As the pendulum swings back toward an acceptance of the disabled aspects of the self as permanent, the person may begin to see the disabled self as part of the total self. This involves some of what Charmez (1995) referred to as the "process of adaptation" to the chronicity of the condition. The person reassesses his/her options and possibilities with the reality of the limitations imposed by their chronic condition in mind.

Finally, Yoshida (1993) explains that the "middle self" occurs "when a respondent moves closer to the middle of the pendulum. This refers to individuals who act upon both the non-disabled and disabled aspects of self" (p. 229). It includes an acceptance of the permanence of the disability and an acceptance of the limitations imposed on the person by the disability. It also includes a "wider social concern for other persons with disabilities and other segments of society" (p. 230). From this vantage point, the person is now able to utilize and act upon both the non-disabled and disabled aspects of the self.

All of the movement on the pendulum toward the middle self is dependent on the strength of the identity of the core aspects of the non-disabled self. It includes recognition and working through of the loss of aspects of the non-disabled self, an acceptance of the injury as an ongoing event, a slow process of adaptation to the injury and the limitations it imposes on the person's every day life. Yoshida (1993) found an important element of the reconstruction of identity to be the sustainment given by significant others in the person's life. The support and acceptance of intimates is a vital part of maintaining the peripheral aspects of the self, which link the disabled person to the non-disabled world. The support of a family, the maintenance of important social roles, etc., all contribute to a sense of value, self-worth.

Integration is achieved as the person reclaims "lost aspects of the non-disabled self and an initial process of inclusion of the disabled self." Continuity "represents carrying through and acting upon valued aspects of the non-disabled self. The final experience is development of the total self"; and finally "development refers to the ongoing 'maturation' of the total self and to the continuing process of inclusion of the disabled self" (Yoshida, 1993, p. 232).

Yoshida's (1993) research indicates that although experiencing a permanent traumatic spinal cord injury is an identity-shattering event, the process of identity reconstruction, involving acceptance and adaptation, can be the source of life-enhancing maturation and growth, a source of strength for the individual. She believes that this process is applicable to other chronic conditions, describing the way in which most, if not all, people with chronic disabling conditions rebuild their identities.

Other researchers have also studied those elements that contribute to the reconstruction or maintenance of the integrity of the self in the face of chronic illness. Medical researchers, Morse and O'Brien (1995), in a qualitative study, examined the strategies by which people recover emotionally from the impact of serious traumatic injury or chronic illness. They identified four stages of development in the recovery process, from physical survival at the beginning to regaining the self at the last stage. The strategies employed varied with the stage of recovery. When physical survival was in jeopardy, the patient focused on physical strategies; in later stages, the patient seeks to preserve the self by "shutting down" emotionally; further on, the patient learns to "endure" the illness by passively accepting the treatments offered; and finally, the person begins the process of striving to regain the self by redefining the self as a disabled person. In a second study, Morse (1997) focused on self-comforting strategies that mediate the illness experience.

Nancy Leidy and Joan Haase (1999), researchers at the University of Arizona College of Nursing, in unstructured, tape-recorded interviews with 12 patients, studied the way persons with moderate to severe chronic obstructive pulmonary disease struggle to preserve their personal integrity. Personal integrity was defined as a "sense of wholeness" through finding purpose and meaning in every day activities. I have included this study in the literature review because it explores the way in which people with chronic illness remain connected to the non-ill aspects of the self and to others. This seems to me to be an important part of coping and healing in a chronic illness, and I hope to explore with my participants the ways in which they maintain a sense of personal worth within the limitations imposed on them by their illness.

Leidy and Haase (1999) identified the following themes related to the experience of finding purpose and meaning from daily activity: a desire to communicate one's sense of identity; a comparison of one's past identity in relation to present activities; conflicting emotions surrounding one's present ability to perform activities; the importance of maintaining meaningful relationships; and the loneliness of incapacity-induced separateness. These themes were unified into two concepts referring to maintaining personal integrity: "effectiveness" or "being able" and "connectedness" or "being with" (p. 69).

"Effectiveness," or "being able," as an important element of personal integrity, was often challenged by the physical changes participants experienced over time. These physical changes reduced the physical predictability, stability, stamina, and strength of the body, all of which are needed to maintain important role functions. Participants responded to these challenges through "emotional expression, goal setting and trying, and recalling the past to bolster a present sense of effectiveness" (Leidy & Haase, 1999, pp. 70-72).

"Connectedness," or "being with," was defined as a "sense of significant, shared, and meaningful relationships with other people, a spiritual being, nature, or aspects of one's inner self" (Leidy & Haase, 1999, p.72). The illness often created a sense of isolation and abandonment by others, which led to feelings of anger and anxiety, a loss of feelings of familiarity and comfort, of shared experiences, and the loss of understanding and trust in others. Those participants, who were able to find the energy to pursue important relationships with others or with God and to build new relationships, were able to maintain their sense of connectedness the most effectively.

Leidy and Haase (1999) concluded that the functional performance level (the capacity to remain engaged with life and be active) of a person with a chronic illness is probably influenced by some combination of psychosocial, physiologic, and symptomatic factors. Anxiety and depression were found to have an adverse effect on performance; and psychosocial resources such as self-esteem, self-efficacy, hardiness, well-being, optimism, and mastery to enhance performance levels.

E. Lindsey (1996), a medical researcher at the University of Victoria, investigated the meaning of "feeling healthy" for people living with chronic illness. Her findings were similar to those of Leidy and Haase (1999), cited above. Her qualitative study of eight participants living with a variety of chronic illnesses describes strategies they used to feel healthy within the limitations imposed by the illness. Lindsey characterizes them as: honoring the self; seeking and connecting with others; creating opportunities; celebrating life; transcending the self; and acquiring a state of grace.

Another theme found in the literature deals with illness as an existential experience, as an opportunity to see one's life from a different perspective. This too can be a way of healing in illness. Some years ago, I worked as a hospice social worker with people who had been diagnosed with a terminal illness. Many of them talked with me about how their illness had helped them to live more fully in the present and to focus on those aspects of life that are the most important: being with the people they loved; listening to a cat purr or a bird sing; and watching a sunrise or a sunset. Wealth, power, or success, so important to many people, no longer seemed important to them. Their illness came to have an important meaning for them in terms of understanding what is the most valuable in life.

For example, Radley (1999) (cited previously with regard to the experience of terror in the face of a serious diagnosis of illness) analyzed the narratives of persons diagnosed with life-threatening or terminal illness. He concludes that illness and the "horror" of the experience is an opportunity to find an existential "freedom," an aesthetic project of creating beauty out of ugliness and fear, of demonstrating to the world qualities that the ill person exemplifies. It offers an opportunity for the person with an ongoing illness to take true responsibility for his/her life, apart from the expectations and standards of others. Living with a serious illness is an existential way of "being in the world," finding one's own identity and place in the world apart from the more "normal" or "expected" ways of living in a particular culture. This can set someone free to become his/her true, authentic self. Radley proposes that the "sublime" can be touched through the "horror."

The theme of meaning within illness is described in the writing of Georg Groddeck (1923/1977), a psychosomatic physician. Groddeck puts it this way:

> Sickness and health appear to be opposites. They are not, any more than heat or cold are, for instance. Just as the latter are effects of different wavelengths, so illness and health are effects of one and the same life. Illness does not come from the outside; it is not an enemy, but a creation of the organism, the it – or we may

> call it vital force, the self, the organism – this It, about which we know nothing and of which we shall never recognize more than some of its outward forms, tries to express something by illness; to be ill has to mean something. (p. 197)

Kidel (1988), in the essay referred to previously, uses the Jungian concept "shadow" to refer to illness. As an advocate for holistic health and homeopathy, he believes that facing the illness, the shadow side of the self, is an opportunity for personal transformation through a deepening of awareness of the previously unexplored or unknown regions of the self. Facing and living with an illness forces us to look at and accept our vulnerabilities and our limitations. It forces us into a personal, and painful, authenticity. We are compelled to see others and ourselves as we really are, in a way that few experiences in our lives can force us to do. Kidel believes that most people maintain a false sense of invulnerability and a denial of death until they are forced to sense how fragile their well-being really is.

Kidel (1988) maintains that facing this painful reality shatters the belief that the body is separate from the self, and can lead to an imaginative opening up to the personal and symbolic meanings of the symptoms and the illness itself. For example, he suggests that a person with a heart condition might consider its implications from associations to the phrases "heartless," or "take heart." A person with arthritis might consider the origin of the word "stiffness" from "dead" to "strong," and so on. He suggests that to be aware of one's vulnerability to death is to become more fully aware of what it is to truly be alive.

Tatham (1988), whose essay on the meaning of illness was cited previously, shares this perspective. He proposes that illness provides an opportunity for a person to move to a higher state of integration, a higher state of being. Tatham regards illness as a part of an evolving, self-regulated system – a growing back to balance. The upheaval that occurs with the onset of a chronic illness in a person's life offers an opportunity for that person to reassess which values are the most important to that person. This insight can lead to a life more carefully and joyfully lived, accepting the vulnerability and fragility of life (pp. 22-33).

Healing Narratives

Kleinman (1988) interviewed persons diagnosed with a chronic illness, their physicians, and the people closest to them. The "personal narratives" of these patients and their families and physicians describe how they order the experience and what this experience means to them (p. 40). He observes that such personal narratives are integral to the legitimization of the patient's illness experience. In their narratives, patients express the symbolic and personal meaning of their illnesses and suffering either positively or negatively. These narratives can contribute to insight, empathy, and understanding of the suffering by those around the ill person, which may help them to support and assist that person to live more fully with the illness. This perspective has guided much of the qualitative research on chronic illness, and offers a means to explore the meaning each person makes of the illness experience. The literature included in this review describes, I believe, the ways in which chronically ill people are empowered by telling their stories in their own voices.

Some of the researchers (Bartz, 1999; Charmez, 1999; Kelly & Dickenson, 1997; Lang & Beine, 2000; Robertson-Malt, 1999; Radley, 1999; Sakalys, 2000; Thorne, 1999) whom I reviewed assert that the doctor-patient relationship is enhanced when the patient's unique experience is heard and validated. It is suggested that healing can take place through the relationship built on a narrative dialogue between caregiver and patient. In this way, a patient's experiences of alienation, isolation, rejection, and stigma can be reduced. Charmez (1999) asserts that this process reduces the suffering of the chronically ill person.

For example, Jurate Sakalys (2000), at the University of Colorado Health Sciences Center, examined the political role of autobiographical accounts of illness. Dr. Sakalys asserts that "illness narratives" serve the purpose of combating the patient's sense of illness engendered and/or exacerbated by the medical establishment that treats them. In other words, the "illness narratives" are a corrective to systemically induced iatrogenic illness. Sakalys's analysis of the narratives of ill people suggests that they may serve the political purpose of publicly expressing the patients' struggle to "preserve self-hood when social and professional environments suppress its expression" (p. 1471). Writing about the illness enables patients to reclaim their own voices. It is in this reclaiming, she says, that the seeds of healing and wholeness can be found.

In one example, Sakalys examines how first person accounts of illness can be a criticism of the medical culture in which the patient lives. This example also reveals the feeling of lost identity which evolves from the experience of being objectified:

> In this case, my name had not been changed, it had been defined. 'Lymphoma' was a medical flag, planted as a claim on the territory of my body. This colonization became worse. During chemotherapy a nurse...referred to me as the 'seminoma in 53' (my room number). By then the diagnosis was correct, but it had crowded out my name entirely. The hospital had created its own version of my identity. I became the disease. (2000, p. 1471)

Along with research findings are many other voices, both professional and lay, contending from personal experience that the narrative about their experience has a healing role. For instance, Arthur Frank (2000), a professor of sociology at the University of Calgary, and a cancer survivor, has written extensively on his experience of living with cancer. In a university lecture sponsored by the International Institute for Qualitative Methodology, Frank asserts that illness narratives are therapeutic and emancipatory, allowing some distance and some disengagement from his illness, as well as building healing relationships with others, and thus serve a "recuperative role." As a sociologist and as a survivor, he is an advocate for the use of narratives as a foundation for clinical understanding and practical ethics in the treatment of chronic illness.

A cautionary note is offered by sociologist Michele Crossley (1999), who studied the narratives of survivors of child sexual abuse and persons living with HIV. Crossley observes that although illness narratives offer a way of dealing with the experience of illness counteracting the "objectifying and deindividualising 'voice' of medical technology," they do occur within a cultural and social framework and reflect the standards and values of the society in which the ill person lives. For this reason, some narratives may run the risk of discourse that encourages passive adaptation and adjustment to social norms and values. If the storytellers are vulnerable and lacking in power, the encouragement of healing through forgiveness, love of the world, and love of others can offer an opportunity for further exploitation. In this way, illness narratives can become narratives of repression rather than narratives of liberation.

Crossley's (1999) research suggests that in considering the usefulness of narratives in the lives of ill or traumatized persons one must take into the account the cultural and social context of the person involved. Some narratives may reflect the denial of the illness, the anger and hostility or powerlessness of the patient or survivor., or may encourage an acceptance of abuse. She proposes that narratives can become a useful tool for healing or growth when they become part of a dialogue directed toward helping the person become empowered and freer through an ongoing, changing narrative.

Schizophrenia

The small body of literature specifically on schizophrenia as an ongoing condition concentrates on the disruption of a coherent sense of self. The subjective experience of loss of self is an important element in schizophrenia. Thus, the focus of this research has been on the subjective experience of schizophrenia, not on the etiology or treatment. I will review literature on etiology and treatment only as it pertains to my research. As with chronic illness, schizophrenia has both a personal and a social meaning. Researchers and writers who are interested in schizophrenia from a "whole person" perspective view schizophrenia as an illness of the mind rather than an illness of the brain. This is in keeping with the literature on chronic illness, where the emphasis is also on the whole person and on the experience of being ill over time.

As I mentioned in Chapter One, the use of the term "chronic" in describing the schizophrenic experience is pejorative (Harding, Zubin, & Strauss, 1997). However, much of the literature on schizophrenia describes it in this way. They assert that this term is iatrogenic and interferes with the person's ability to find hope in recovery. I will try therefore to minimize the use of this term in describing the literature on schizophrenia.

Like physical illnesses that are ongoing, schizophrenia brings stigma upon the sufferer. Stigma is culturally determined, and cross-cultural studies of schizophrenia indicate that in schizophrenia is understood and labeled differently in different cultures. The various understandings are not necessarily in concordance with the Western European conception of this condition. These cross-cultural studies may provide researchers and clinicians a new perspective on how to understand and treat this illness from a different perspective.

The researchers and clinicians I will review emphasize the importance of listening to the narratives of people living with schizophrenia as a way to understand their experience and the meaning that they have given to their illness. They believe that the person remains an active agent in his/her illness and ultimately determines the course the illness will take in his/her life. Thus, the stories that people with schizophrenia tell about their experience help others to understand how they cope with their illness. For this reason, I have included some examples of first person accounts by people living with schizophrenia that describe their experience and the strategies they use to understand their illness and cope with their symptoms. This section on schizophrenia will be presented within six primary categories: schizophrenia – fragmentation, regression and isolation; identity, self, and the structure of the schizophrenic mind; the impact of culture on the meaning of schizophrenia; experience of schizophrenia as an ongoing condition; coping strategies; and first person accounts.

Schizophrenia: Fragmentation, Regression, and Isolation

Some of the earlier theorists and thinkers who wrote about schizophrenia also conceived of schizophrenia as an experiential phenomenon – i.e., something that is being experienced by a person, a self. Each thinker reviewed here looked at certain aspects of the experience that he/she observed through clinical and/or research experience with persons suffering from psychosis. There are common features in the descriptions and most are structured by psychoanalytic thinking regarding conscious and unconscious experience. However, most of the thinkers and theorists I have reviewed understood psychosis to be the result of a profound failure in interpersonal relationships, resulting in loss of the self through fragmentation of ego structures, a retreat from reality, and regression to a more primitive mental state. From this perspective, they agreed that schizophrenia is an illness of the mind rather than an illness of the brain.

Harry Stack Sullivan (1953) regarded schizophrenia as a failure in interpersonal relationships, specifically in interpersonal communication, characterized by anxiety. The earlier and more intense is the anxiety in interpersonal relationships with others, the more serious are the consequences in living in the world with others (pp. xii – xv). Sullivan (1962) described schizophrenia as a "collapse of mental organization" to earlier, more primitive thought processes. This regression to "infantile or even prenatal mental functions" occurs in order to successfully reintegrate, by regression, "masses of life experience which had failed of structuralization into a functional unity" (pp. 12-20).

Frieda Fromm-Reichmann (1959) agreed with Sullivan's conception of schizophrenia as a fragmentation of the self, resulting in regression and withdrawal from reality. She believed that schizophrenia is the result of an overwhelming infantile trauma of abandonment and rejection, resulting in a fragile, vulnerable self. This poorly constructed self, in the face of difficult life events, then breaks down (pp. 93-94).

Based upon his long experience with treatment as well as his research on families and schizophrenia, R. D. Laing (1959) proposed that schizophrenia is an expression of a basic “ontological insecurity,” founded within the family matrix. In an effort to preserve the “real” self, the person retreats into a rigid withdrawal from the “false” self, as demanded by others. In this view, schizophrenia can be considered a retreat from the overwhelming demands of a particular kind of everyday world (pp. 42-56). In *The Politics of the Family* (1969), Laing elaborated on how the socio-political context impacts upon the family, which contributes to the development of schizophrenia. Like Sullivan, Laing believed that schizophrenia is an interpersonal, social, and culturally derived disorder of the self.

John Rosen (1953), a psychiatrist and Jungian analyst, described mental illness as a “process in which various unworkable defenses are abandoned in the desperate retreat from reality” (p. 4). In his view, if external or internal pressures in the person’s life become overwhelming, “the unconscious surges out, inundates the conscious, and the neurotic defenses give way to psychosis,” and “the patient’s blocked wishes appear in the form of delusions, hallucinations, and other irrationalities” (p. 6).

Other theorists echoed these conceptualizations of schizophrenia as a loss of the self through fragmentation of the ego structures that enable a person to cope with the vicissitudes of life. Humanists, such as Carl Rogers (1961) and Thomas Malone (1961), described schizophrenia as a terrorized response to a terrorizing experience within the family of origin, resulting in retreat from interpersonal relationships, from contact with others (pp. 133-135). Theodore Lidz (1973) agreed that the "schizophrenogenic" family was the primary cause of schizophrenia, particularly in the area of the "double bind," in which a profound failure of communication results in a profound failure in the relationship between the child and the parents. The child then seeks a "way out of his dilemma by falling back on earlier and more primitive forms of cognition as his emotional regression increases his turmoil…" (pp. 23-50). Regression in the service of survival, then, is schizophrenia.

Jules Henry (1973) an anthropologist who lived with several families with psychotic children, studied the way psychosis develops in the family, as well as the ways that children learn to resist the development of psychosis. He agreed with Lidz that the parental relationship with the child could be the most significant factor in the development of psychosis.

Carl Jung (1972) regarded schizophrenia as a destructive process of regression to "archaic thought-forms and behavior," but he did not attribute it solely to life experiences, developmental arrest, or psychic factors. He believed that schizophrenia might be an illness with both a psychological and an organic component (pp. 254-255).

Others, such as John Perry (1972), a Jungian psychiatrist who treated schizophrenic patients in a non-hospital setting, believed that schizophrenia was both a relational and social disorder of the ego, but that schizophrenia is "nature's way of setting things right." The acute turmoil and confusion of the psychotic episode can be understood as the "renewal process" toward living a "more fulfilled emotional life." It is the process whereby the "pre-psychotic" personality is reorganized, renewed (p.23).

Peter Giovacchini (1997), a psychiatrist and analyst, conceives of schizophrenia as a structural collapse of the mind and a regression to a more primitive mental state, which offers the possibility of reaching one's most fundamental creativity. In this way, schizophrenia can be described as a process of becoming one's most creative self, which he describes as potentially "exhilarating" (p. 239).

Hymen Spotnitz (1999), also a psychiatrist and analyst, describes schizophrenia as a completely reversible disorder. He asserts that "no one is born schizophrenic," and that "cases that appear to have been primarily determined by life experience are regarded as the easiest to reverse. Regardless of etiology, however, there is no evidence that the condition is not completely reversible" (p. 17). From this perspective, schizophrenia is an eminently treatable disorder and is amenable to both psychotherapy and to psychoanalysis (pp. 38-39).

Identity, Self, and the Structure of the Schizophrenic Mind

The theorists reviewed above describe the psychotic person as an active agent, struggling to survive the turmoil brought on by the psychosis. Leaning against the current of contemporary psychiatry, some researchers agree with these older conceptualizations of schizophrenia. Although they do not agree with these theorists that schizophrenia is the result only of a failure in interpersonal relationships, the researchers to be reviewed here seek to define schizophrenia from this perspective and to look at its impact on the person diagnosed with this self-disrupting illness. Many of these researchers write from a symbolic interactionist perspective, and much of the literature explores the impact of this illness on identity and the sense of self. This perspective matches my own experience with people living with schizophrenia, who continue to make meaning of their experience and find ways to cope with and heal within the limitations of their illness.

John Strauss (1989), a psychiatrist and researcher at Yale University, has done qualitative research on schizophrenia. He collaborated with other professionals, some of whom are also reviewed here, in an issue of the *Schizophrenia Bulletin* entirely dedicated to the exploration of the subjective experience of psychosis. In an article written for this issue, he notes that the early theoreticians, such as Kraepelin (1904) and Bleuler (1911), believed that a key feature, "perhaps the central feature of schizophrenia, was the loss of 'will,' goal-directedness, and cohesiveness of personality" (p. 182). Many people have described the schizophrenic experience as "falling apart," "losing control," and "cracking up." From Strauss's point of view, this remains an important aspect of understanding schizophrenia. Like the theoreticians cited previously, he views schizophrenia as more than a brain disorder, rather, it is an illness that affects one's sense of self, one's identity. He argues that the only way to truly understand schizophrenia is by learning, through qualitative research, about the subjective experience of this illness. This point of view is consistent with my view and gives weight to the argument that this kind of research is an important and effective way to understand schizophrenia as a chronic illness.

Horatio Fabrega (1989), a psychiatrist and anthropologist at the University of Pittsburgh, has worked with people with schizophrenia and has done cross-cultural qualitative research on the subjective experience of people with schizophrenia. In another article written in the same issue, he also describes how schizophrenia impacts the sense of self:

> Schizophrenia is a disorder that by definition affects individual perception and cognition, and compromises social identity and functioning. The changes wrought by schizophrenia affect the self in a broad context, encompassing such things as self-concepts, self-awareness, self-functioning, and self-career. Thus, schizophrenia erodes and undermines the organization and functioning of the self, and because of this, schizophrenia and self/subjectivity are integrally linked. (p. 277)

Fabrega (1989) goes on to say that schizophrenia impairs the "self-monitoring capacity and the individual's life trajectory." Through its impact on the self, schizophrenia "alters, in a tangible way, life career pathways in the interpersonal world as well as personal estimates of worth and accomplishment" (p. 278).

Sue Estroff, a medical sociologist at the University of North Carolina, has also done qualitative research on schizophrenia. In an article (1989) in the *Schizophrenia Bulletin*, cited above, she advocates a more humanistic approach to the understanding of schizophrenia. It has been my experience that many treatment providers treat schizophrenia as a medical disorder, believing that treatment of the whole person is irrelevant. I too believe that schizophrenia is more than a brain disorder; it is a disorder of the self. Estroff states that:

> Much of contemporary psychiatry, especially that dealing with the psychoses, seems to view the notion of self as irrelevant, if not a bit mystical. It is therefore particularly important to recall that the concept of 'self' has been central to the understanding of psychoses in the work of such pioneers as Kraepelin (1904) and Bleuler (1911) and more recently in the work of Sullivan (1962) and Kohut (1971). (p. 177)

Estroff (1989) defines schizophrenia as an "*I am illness*, one that is joined with social identity and perhaps with inner self, in language and terms of reference." This article was, to me, the most important article in the issue, as it most clearly expresses my view of schizophrenia. From her qualitative sociological research with people with schizophrenia, she asserts that, unlike other illnesses, having schizophrenia may also entail "becoming a schizophrenic." It includes not only the "experience of profound cognitive and emotional upheaval; it also results in a transformation of self as known inwardly, and of person or identity as known outwardly by others" (p. 189). It is this "disturbed sense of self" and "extreme perplexity about one's own identity" that is central to the diagnosis of schizophrenia.

Estroff (1989) points to two propositions about the relationship of self to sickness that are primary in our culture and can be applied to schizophrenia. One is the idea that sickness results in a change in sense of self, resulting in loss of a former self. This proposition is held by social scientists such as Erikson (1957), Charmez (1983), and Goffman (1963), who emphasize the transformation of the self and identity that results from serious mental illness, especially that which is prolonged (p. 193). On the other hand, concurrent with contemporary psychoanalytic thought is the idea that the absence of or loss of self constitutes illness – Kohut (1971) has proposed that there is no formed or cohering self in schizophrenia.

Estroff (1989) takes a middle view, with which I agree, suggesting that "self" is a complex process, and those losses or changes in sense of self and social identity do not necessarily equal a loss of self. First person accounts over time indicate that people with schizophrenia remain active agents in their illness, continuing to try to make sense of their symptoms, their lives, and their identities. This means that some facets of the self are more durable and able to provide protection and preservation of parts of the core self, making identity reconstruction possible.

From a symbolic interactionist perspective, Estroff (1989) identifies the two layers of person: the “private subject” and the “public person.” The private subject is the one who acts, including the “reflexive self” as defined by Mead (1934). This self-object is capable of self-observation, reflection, self-consciousness, and capable of engaging in a relationship with itself. It is this capacity that allows one to build a personal and social narrative about one’s lifetime. It is “the capacity that allows us to write autobiographies and to engage in psychotherapy” (p.190).

Estroff (1989) observes that accounts of schizophrenia by relatives and friends, as well as by those diagnosed with schizophrenia, sometimes describe “the tale of the new, strange, disturbed and disturbing, not-really-who-they-were-before-but still-somehow-the-same person” (p. 191). Like Kidel (1988), Estroff states that illness can be defined as “not being myself,” or “not feeling myself,” and the illness is in some way “not me.” When being “not myself” is myself, and others no longer see me as myself, the struggle for an inner sense of a coherent self and a coherent social identity may epitomize the schizophrenic experience.

Estroff (1989) observes that for a person with schizophrenia, the “core” self, the self that endures through time, by which we know, experience, and make meaning, is “thought to be perhaps the most altered, most vulnerable, most hidden or obscured” (p. 192).

Estroff (1989) recounts the experience of a person trying to express her sense of loss of the self:

> 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...She is not real – she is not I...she is I – and because I still have myself on my hands, even if I am a maniac, I must deal with me somehow. (p.189)

Estroff (1989) suggests that "self" is a complex process in which losses or changes in sense of self and social identity do not necessarily equal a loss of self, since first person accounts over time indicate that people with schizophrenia remain active agents in their illness, continuing to try to make sense of their symptoms, their lives, and their identities. This means that some facets of the self are more durable, able to provide protection and preservation of parts of the core self, making identity reconstruction possible. This seems to me to accurately describe schizophrenia as a lived illness rather than only a medical diagnosis to be treated with medication, as much of the contemporary literature contends.

William Pollack (1989), a psychologist at McLean Hospital in Maine, investigating the contribution of self-psychology to the understanding and treatment of schizophrenia, expands on some of these ideas in yet another article of the same issue of the *Schizophrenia Bulletin*. Drawing on his clinical work with people with schizophrenia, and using clinical vignettes, Pollack reminds us of Kohut's definition of psychosis as a "permanent or protracted breakup, enfeeblement, or serious distortion of the self" (p. 314). Without a cohesive internalized self-structure, "the self is vulnerable to disintegration anxiety, fragmentation, or a sense of chronic depressive boredom termed 'enfeeblement'" (p. 313). Pollack accepts this as the central feature of schizophrenia and suggests that the central struggle in schizophrenia is for "self-homeostasis." This concept is mirrored in "the theory of self-psychology, which recognizes the legitimate ongoing need for an empathic matrix of self/self-object connections for psychological sustenance, growth and security" (p. 320). In Pollack's view, Heinz Kohut's contribution to the understanding and treatment of schizophrenia is in his shift away from a focus on "hypothetical internal structures to a more experience-near concept of the primacy of the self," which focuses on "empathic introspection into psychotic subjectivity" (p. 320). Like Estroff, Pollack proposes that there remains an active agent struggling to regain a cohesive self.

Paul Dawson (1994), a research nurse at the Psychiatric Nursing Research Institute in Australia has investigated the "nature of the mental and the structuring role of the mind" in people with schizophrenia (p. 587). Based on his knowledge of psychosis, he examines the psychotic experience of people with schizophrenia within the philosophical frameworks of Kant, Heidegger, and Husserl. He asserts that delusional thinking can be understood as a "last ditch" attempt on the part of the psyche to make sense of this "dis-ordering" of experience (p. 590). The ordering of experience is the way in which the knower understands what is known. Dawson argues that reality, from the point of view of the philosophers discussed in this article, is a construction of the mind. Mental disorder then can be described as a "developmental disorder" of the "constituting self" and the "constituted world," and symptoms can be considered as a "positive response to the underlying disorder" (p. 595). This idea matches some of my own thinking about the meaning of delusions in schizophrenia and offers a powerful argument in favor of understanding delusions as more than just another symptom of the illness. It is why, I believe, so many of the people I work with tell me that they believe they are aliens, or that someone has put a microchip in their brains, or that they are being pursued by the CIA. These are all ways to explain the experience of their symptoms and add credence to the idea that the "active agent" of the self continues to try to make meaning of these experiences.

Dawson (1994) suggests that the bizarre expressions and delusions of a person with schizophrenia can be understood as the expression "of the felt ongoing process of knowing or experiencing by which this world is constituted" (p. 591). It is a route to understanding the profound manner in which the schizophrenic person's way of knowing differs from our own. As the boundaries between self and other become uncertain, and the ability to distinguish what is real from what is not real becomes more uncertain, the "ontological insecurity" that results compels the person to reconstitute reality. The resultant whole may be a bizarre reconstruction of reality. What is important is that the person in this process remains an active agent in the construction of his or her reality, attempting to repair the loss of an acceptable reality. Although Dawson does not directly make reference to symbolic interactionist theory, he asserts that humans are "teleological" or "goal-directed" beings, and that all behavior is purposeful, which is consistent with this framework (p. 595). Thus the production of delusions is seen as a reparative measure, and attempt to re-order reality.

The Impact of Culture on the Meaning of Schizophrenia

The person suffering from schizophrenia cannot be separated from the social context in which he/she lives. Culture, social norms, and rules of interaction place the schizophrenic in social settings from the family to the outside world where expectations of behavior and interactional response are the medium of life. Not meeting such expectations has multiple, complex ramifications for intra- and inter-psychic experience, which when viewed as behavior becomes part of the process of schizophrenia itself.

The literature on stigma addresses the social and political prejudice against people with mental illness, who are often considered to be deviant or dangerous; there is also literature that examines the impact of Western medical culture on the mentally ill through devaluation, dehumanization, and disempowerment of those diagnosed with schizophrenia (Goffman, 1963; Henry, 1973; Kleinman, 1980, 1988; Laing, 1967; Lally, 1989; Sullivan, 1953,1962).

Recognition of the problem of stigma attached to mental illness is not new (Arieti, 1974; Fromm-Reichmann, 1959; Henry, 1973; Laing, 1961, 1967, 1969; Perry, 1972; Spotnitz, 1999; Sullivan, 1953, 1962). Erving Goffman, who has studied behavior in public places (1964) and has focused on the hidden rules of social interaction, specifically analyzes of the experience of stigma, of being perceived as different, or alien, and shunned by society. In the case of persons who are mentally ill, the shame to the family can greatly increase the sense of shame of the person so affected. Further, as the family shares the stigma of mental illness, it may seek to hide the person's illness from others (p. 54). Goffman addresses how quickly and easily stigma can become a part of the person's identity.

The theme of stigma is relevant in the work of psychiatrist Thomas Szasz (1970), an advocate against the involuntary hospitalization of people said to be mentally ill. Szasz posed that "mental illness" itself is a myth. He asserts that people are labeled as "mentally ill" when their problems of living lead to personal conduct "which violates certain ethical, political, and social norms" (p. 23). Thus he could be said to see the label of "mental illness" as a stigma in itself.

Szasz (1970) points out that people diagnosed with mental illness are feared as dangerous to society and locked away so that the public will be "safe" from these bizarre and unpredictable people. It is indeed a popular conception of mentally ill persons that they are "insane" criminals and "deviants," and thus, he says, it is no wonder that, once the label "schizophrenic" has been applied, all the associations to that label stigmatize and alienate that person from general acceptance in our "civilized" society (pp. 56-57).

Kleinman's (1988) approach to the problem of schizophrenic behavior and the social stigma attached is to describe this bizarre behavior as breaking with "cultural conventions about what is acceptable appearance and behavior, while invoking other cultural categories of what is ugly, feared, alien, or inhuman" (p. 159). This is how Kleinman describes a person stigmatized by the social response to him:

> ...shunned, derided, disconfirmed, and degraded by those around him, though not usually by the immediate family. Eventually, the stigmatized person comes to expect such reactions, to anticipate them before they occur or even when they don't occur. By that stage, he has thoroughly internalized the stigma in a deep sense of shame and a spoiled identity. (p. 160)

Strauss, Boker and Brenner (1987) in *Psychosocial Treatment of Schizophrenia* (1987) summarize current thinking about the cultural and social environment of the schizophrenic person, and thus the effects of stigma:

> Although the theory of adverse secondary reactions was first worked out using institutionalism as an example, this is an extreme and probably limiting case of a much more general rule. Attitudes to discharge from day centers, hostels, and group homes tend to follow the same pattern. People with schizophrenic impairments tend to become defeated. Their low motivation may then be regarded as a manifestation of a purely 'primary' deficit even when it has been amplified, and could be partially overcome, by environmental influences. (pp. 19-20)

Those who work with schizophrenic persons tend to have low expectations of them and their families. Many caregivers believe that schizophrenic people cannot recover, or regain a useful place in society. Strauss (1987) points out that this benign but negative attitude on the part of others can contribute to the stigma, low self-esteem, and sense of uselessness so often encountered in treatment settings (pp. 23-25). Stephen Lally (1989), whose study of the schizophrenic's subjective experience of becoming identified with the illness (reviewed below) adds that stigma can become a part of the mentally ill person's identity.

Fabrega (1989), mentioned previously, gives a general description of schizophrenia within a universal or cross-cultural framework in an article in the aforementioned *Schizophrenia Bulletin*, in which he reviews many cross-cultural studies of schizophrenia. Fabrega observes that notions of the self in contemporary Western thinking are based on biomedical psychiatry and psychoanalytic conceptions of subjectivity. He describes what he perceives as a taken-for-granted cultural model of the self in much Western psychiatry as "entirely centered in the psychical person who is viewed as responsible, autonomous, and agentive" (p. 281).

Fabrega (1989) points out that current cross-cultural research in medical anthropology indicates that conceptions of the self and relationship with others vary considerably from this view. Explanations for disturbances of the self do not take for granted, or even include, some of our Western assumptions about the self. These alternative conceptions of the self offer an opportunity to understand and comprehend both mental health and schizophrenia, using a different standard, broadening our conceptualization of the phenomenology of schizophrenia and, thereby, of possible alternative, possibly more effective treatment. He cites several examples of cross-cultural studies that describe psychotic phenomena as a loss of the life force that allows a person to be part of a society. In some cultures, schizophrenic phenomena are shaped and normalized within the role of shaman. In each of these conceptualizations, the person is not regarded as the agent of the illness, but is regarded as being either burdened by or gifted with the illness. In this way, stigma and shame attached to the schizophrenic and to the family are reduced or non-existent. The person with schizophrenia is thus not rejected by the culture (pp. 281-286). I find this to be a valuable and useful counter-notion to the contemporary western notion of schizophrenia as a chronic illness, with all its concomitant losses in social status.

Fabrega (1989) argues that notions of the self are best understood from a symbolic interactionist orientation, which he asserts offers a broader and more complete understanding of the self by including the influence of the environment and the culture. Within this framework, Fabrega suggests that schizophrenia interferes with the person's ability for self-reflection by "drawing on cultural norms and age-specific performance standards, and being able to judge oneself in relation to culturally constituted phenomena, such as gender norms and social expectations" (p. 278). Thus the condition affects the person's ability to connect with others in the environment. The concept of the self, then, is a "cultural entity" defined by:

> The way an idealized person is represented (in any society) as being, thinking, feeling, and behaving in the ideologies, myths, ideals, and institutions of a group of people, and provides a guide to what is normal behavior within a particular culture. (p.280)

Thus, he argues, the value of studying mental illness across cultures to understand what is universal about schizophrenia is the opportunity for mental health professionals and researchers to better understand what are the fundamental features of mental health – what it means to be a competent member of a society.

Paul Lieberman (1989), a psychiatrist, objects to the medical culture's emphasis on using quantitative, objective, methods to research the qualitative, subjective phenomena of schizophrenia. Though the "scientific method" has led to wonderful breakthroughs in medical treatment for mental illness, the fact that "brain" is not "mind" has been overlooked. Schizophrenia as an illness of the mind, of the self, cannot be treated without involving the person. The mind is the "instrument of meaning," and an illness of the self has to include the meaning of the illness to that self. This point of view is echoed frequently in the current literature on schizophrenia (see Estroff, 1989; Fabrega, 1989; Lally, 1989; Romme and Escher, 1989; Strauss, 1989).

In a similar vein, Christopher Dowrick (2000), a medical educator in England, questions the validity of the concept of "mental health." He challenges the medical and psychiatric community's adherence to objective, observable, scientific categorizations of mental illness. Like so many of the theorists, researchers, and anthropologists already cited, who favor a more subjective, individualized, and experience-near approach to illness, Dowrick poses thoughtful questions about an alternate concept of mental illness, asking whether the absence of mental health should be automatically considered as mental illness, or can it be considered as an adaptive strategy? As an example, he notes that from the point of view of grief, depression can be understood as an adaptive strategy to loss.

If that is true, Dowrick (2000) questions how long a person can be depressed before he/she is diagnosed with the label of major depression, or are there a discrete number of short-term experiences of grief and loss that should determine the presence of a mental illness? He also asks whether or not mental illnesses should really be divided into discrete categories, or should they overlap as "manifestations of similar underlying psychopathological processes" (p. 546)? When symptoms of one disorder can be observed or reported in another disorder, how can we be sure that the patient has been put into the right category? I know, from my own experience, that once labeled with schizophrenia, it is difficult to change the diagnosis, even though that diagnosis is no longer accurate. I have had to argue more than once for a change of diagnosis for a client, even though many treatment providers agree that a diagnosis is only a guideline for treatment.

Questioning how diagnoses are made, Dowrick (2000) asks if they are based on observable behaviors or on subjective experience? The treatment provider may not see any observable behaviors of an illness and can rely only on what the person reports. Can a diagnosis be made on self-report alone, or do there need to be observable behaviors to corroborate these reports? What if the person who comes for help sees the world through the lens of his/her symptoms, unable to understand that this is not the “reality” observed by the treatment provider? How then can we help that person to see the usefulness of treatment?

He suggests that mental health providers become more aware of their own cultural and personal biases to be able to listen more closely to their patients. By becoming more open to the patients’ experience and understanding of their problems, the medical community can reduce the impact of its rigid models of understanding mental illness and perhaps offer more effective ways of working with people with problems in living. Szasz, Knoff, and Hollender (1958), in an article on the doctor-patient relationship, make a similar point. Tracing the historical and cultural context of the patient-doctor relationship, they argue for a more open, shared partnership between patient and doctor to achieve a more comprehensive and effective treatment for mental illness. I think this is an important idea but one that still meets with some resistance among mental health providers.

In a similar vein, Spotnitz (1999) observes that the diagnosis of schizophrenia has changed over time, often mirroring cultural and social changes in our society. The symptoms, levels of severity, and course of the illness vary so considerably, he wonders if schizophrenia is one disease or many, and how much of the illness is a socio-medical construct. I had never thought about schizophrenia in this way, but if this is true, it offers many new possibilities for thinking about and treating schizophrenia.

Experience of Schizophrenia as an Ongoing Condition

The literature to be reviewed in this section addresses the importance of understanding the illness experience from the point of view of the person who suffers from schizophrenia. A reconceptualization of treatment evolves from recognition that the person living with schizophrenia is an active agent in the illness experience and could be so in its treatment. What actually is the subjective experience of the person with schizophrenia in terms of symptoms and being in the world has been the subject of some research, clinical observation and interpretation. In this literature schizophrenia is treated as a process rather than a static condition. I hope that my research has contributed to this idea.

The Subjective Experience of Schizophrenia

I begin with William Pollack (1989), who observes that earlier work on understanding the experience of schizophrenia was from the perspective of the treatment provider. It was assumed that people with schizophrenia would not be able to clearly articulate their experience. He states:

> Theorists have only variably, however, addressed the true subjective inner *experience* of the schizophrenic patient, tending at times to focus more upon the experience-distant and esoteric “inner world” of defenses or inner structures; or, alternatively, abandoning the patient altogether in search of pristine theoretical debates over etiology. What has been all too often ignored, then, are the subjective, actual feelings, thoughts, and experiences of the affected individuals. (p. 311)

When I first began working with people with schizophrenia, my colleagues would often talk about our clients, in their presence, as though they were not there! We often assumed that they could not contribute to our understanding of their illness!

More in line with my current thinking about schizophrenia, Estroff (1989) asserts that if schizophrenia is to be understood as an illness in Kleinman's sense, the subjective experience narrative of the person becomes crucial. She reflects the views of other researchers (Strauss, 1989; Cutting & Dunne, 1989; Greenfield, Strauss, Bowers, & Mandelkern, 1989; and Lieberman, 1989) that in recent years, psychiatry has focused almost exclusively on schizophrenia as a disease for which medicine can find a cure. Strauss (1994) asserts that what is overlooked is that the person's subjective experience has a substantial effect on the severity, treatment, and outcome of the disease.

The Impact of Subjective Experience of Schizophrenia on the Sense of Self

The role of subjective experience permeates attempts to understand the disease of schizophrenia as an illness. It has been found that the reporting of symptoms is not unitary or consistent but depends upon social and personal factors. Likewise, the impact of these experiences is affected by both intra-personal and inter-personal factors.

For example, Manuel Peralta and Victor Cuesta (1994), Spanish psychiatric researchers, compared nine recent quantitative studies on the reporting of subjective experiences of symptoms in schizophrenia in order to better understand the nature of these experiences. They found that different symptoms were reported at different stages in the illness. In the acute stage of the illness, positive symptoms (hallucinations, delusions, formal thought disorders) were reported, whereas during the chronic stage, reports were of negative symptoms (affective blunting, asociality, loss of drive, alogia) (p.203). The subjective experience of symptoms appear to wax and wane over the course of time as the illness is exacerbated or remitted. Ordinary life stress can trigger a relapse, as people with schizophrenia remain vulnerable to becoming acutely psychotic again.

Relapse triggers may be related to psychosocial stress, discontinuation of medication, drug abuse, or internal psychological processes. Persons who are psychologically fragile may be more vulnerable to relapse. In addition, Peralta and Cuesta (1994) found that a higher level of education and the presence of insight were associated with more frequent reports of subjective experience. In general, women report more subjective experiences of symptoms than do men. This report raises two issues: first, some people may not be quite so willing to report on their symptoms in such settings provided in the studies Peralta and Cuesta reviewed. Second, symptoms may vary with various other personal and social experiences.

In another quantitative study, G. Gross (1987), a German psychiatric researcher, used the Bonn Scale for the Assessment of Basic Symptoms (BSABS) to describe some of the subjective experiences of people with mental illness. From a sample of 450 people hospitalized at least one time with the diagnosis of schizophrenia, he and his colleague found that the most commonly reported subjective symptoms were lack of energy and resilience, inability to tolerate emotionally intense events, crowds or loud environments that over stimulate and frighten the person or tend to be confusing, inability to work under time pressures, inability to tolerate emotionally intense television programs or movies, distractibility, poor concentration, memory loss, inability to grasp the meanings of words, blurred vision, hypersensitivity to light or visual stimuli in general, hypersensitivity to noise, insomnia, depression (pp. 126-133).

The report of subjective suffering of people with schizophrenia is corroborated by the findings of Kim, Sakamoto, Sakamura, Kamo (1997), researchers for the National Institute of Mental Health in Japan. Using a three-dimensional scale, dealing with awareness of the need for treatment, of the illness, and of psychotic experiences, they measured the insight of 63 inpatients and outpatients with schizophrenia. They found that experiences of thought disorder were associated with a distorted, generally negative, sense of self, creating a sense of misery and oppression (pp. 49-55).

Strauss (1989), remarks that reported symptoms of schizophrenia all contribute to a diminished sense of self and "incredible discouragement" (p. 183). Lally (1989) interprets what some of the reported symptoms might mean to the person, suggesting that auditory or visual hallucinations cause "a splitting of the person's world and identity into real and unreal, me and not me" (p. 260). He asserts that these hallucinations also have a cultural meaning "and present a strong threat to the person's sense of self" (p. 260), because the person knows that these experiences are not normal and separates them from the experiences of others.

Charmaine Williams and April Collins (1999), psychiatric social workers in Toronto, studied the impact of schizophrenia on the sense of self. Their qualitative study of life-history interviews with persons diagnosed with schizophrenia indicates that the experience of psychosis represents a sense of having lost control of one's life.

Williams and Collins (1999) suggest that the experience of schizophrenia is similar to subjective descriptions of trauma in the psychiatric literature. Their respondents described "a sense of threat, feelings of fear and helplessness, and aftermaths in the form of distressing recollections and fear of recurrence" (p. 73). Their respondents also described an intense loneliness and sense of isolation that has been commonly described as part of the experience of schizophrenia, as well as a loss of the "ideal self." They mourned the loss of self they might have been had they not become ill. All these feelings of loss, grief, and fear contribute to the suffering experienced by persons with schizophrenia. This closely mirrors Charmez's (1983) description of the loss of self and suffering of people who experience chronic illness.

The terror of such schizophrenic experiences is addressed by Naudin, Gros-Azorin, Mishara, Wiggins, Schwartz, Azorin (1999), faculty of the Neuropsychological and Neurophysiological Laboratory in Marseille, using a Husserlian phenomenological reduction method for describing the foundations of psychiatric experience. They concluded that the person with schizophrenia loses the usual “taken-for-grantedness” of the body, the other, and internal time, and that this loss of the usual is a source of terror.

John Cutting and Francis Dunne (1989), two medical researchers in England, studied accounts of the subjective experience of a first psychotic break, using structured interviews with 20 remitted schizophrenic patients. Two different interviewers were used in order to test interrater reliability. A second interview six months later tested reliability over time. Participants described, in vivid recollection, their first psychotic experience as a qualitative change in perception in several areas of mental functioning. They remembered that things were not changed out of all recognition, but just became strange to them; often a sense of distance was experienced, between the perceiver and the perceived. Some described two simultaneous perceptual worlds, and described a “dramatic change in the way they perceive the world and experience the working of their own mind at the onset of the disorder” (pp. 229- 230).

Schizophrenia as a Process

The subjective experience of living with schizophrenia has several dimensions. In the first place there is the person’s experience of his/her illness itself. The schizophrenic suffers from a multitude of experiences that constitute the symptoms. Those symptoms can be not only debilitating but also frightening. Some of these symptoms as well as interpretations of their ontological nature have been described in the literature reviewed above. The resultant social role/identity arises not only from the experience of symptoms as an assault on one’s personal sense of the usual, but stems also from social labeling, stigma, hospitalization, loss of social roles and gradual social isolation. All of which have further impact on one's sense of self as well as on one's continual being in the world. This is the process of living with schizophrenia as a chronic illness.

One such process was researched by Lally (1989) who studied the process of "engulfment" into the role of "patient" by schizophrenic persons. He defines "engulfment" as the increasing organization of the person's self-concept and behavior around the role of psychiatric patient, "the deviant role becomes a master status to which others are subservient" (p. 255). In this article for the afore-mentioned *Schizophrenia Bulletin*, he reflects on the information he had gathered in an earlier 1984 study for which he collected psychiatric patients' labels and theories about their illness. He asserts that hospitalization is "a threat to the patients' view of themselves as competent" (p. 258). Further, adoption of the "sick role" is related to the number of alternative, competent, roles that a schizophrenic person has available to him/her. Psychiatric hospitalizations tend to "strip away a person's former identity and replace it with a patient identity" (p. 256), thereby limiting, or eliminating altogether, alternative roles. He argues that the chronicity of mental illness includes more than "just the persistent and recurrent nature of the illness; it also includes the relatively permanent shifting of expectations and definitions of self" (p. 254). It is for this reason that it is so important to listen to patients in order to understand their subjective experience of the illness.

Lally (1989) outlines how this loss of a previous, non-sick self can become total, as the identity of the person becomes "engulfed" as a mental patient. The outcome of this process is determined by several factors in the person's life: the strength or fragility of his/her general psychological development; number and competency of the alternative roles available; number of hospitalizations; educational background and positive or negative life experiences; relationships with caregivers – family and treatment providers. The more negative the life experiences the person has had, the lower the educational level, life success, and positive roles available, the less self-esteem, self-confidence, and self-trust the person has. These persons will then have little capacity to experience their illness as only one aspect of an otherwise satisfactory life and to continue to feel competent. At the beginning, the person will be in conflict between the negative beliefs and prejudices about schizophrenia, and finding oneself in that category. Many people will either deny or minimize their own experiences in order to distance themselves from the inclusion in the category of "crazy," "mental patient." Some patients, however, will begin to self-label and self-stigmatize themselves. Each rehospitalization seems to reinforce the label as a mental patient.

Lally (1989) gives an account of one of his research participant's conflict with his own prejudice:

> Like I had always looked down on mental institutions, like when I was in high school there was a guy who was 3 years ahead of me and he wound up in a hospital. And I would always look down on him, for just being in here, in a place like this. Then when I got here, it was like my life had ended. (p.259)

Lally (1989) describes the “middle phase” of engulfment: the person gradually comes to identify himself/herself more closely with other mentally ill persons and with the treatment providers, feeling less “alien” and better understood by them than by “normal” people. This results in a gradual withdrawal from the outside world.

During the “late stage” of engulfment, patients begin to experience their illness as a permanent disability. They no longer see themselves as useful or productive members of society, but as parasites, hopelessly impaired, unnecessary “hangers-on” in society. From this place, they mourn a lost self, a hoped-for self that now can never be. They reach a place of resignation, giving up, and are engulfed in their identity as an ill person. They have become “a schizophrenic” (Lally, 1989, pp. 259-263).

In my work with people with schizophrenia, I too have met people who have become engulfed in the schizophrenic identity. Yet, I have known some of these people to find, even after many years, a way out of this engulfment. In other words, I believe that this process of engulfment is not necessarily permanent or irreversible. I hope that my research may be able to shed some light on how this process can be reversed.

Coping Strategies

Coping strategies of persons with schizophrenia closely resemble those coping mechanisms used by people with chronic illness. Because of the difficulties encountered in understanding the subjective experience of the person with schizophrenia, this has been, until recently, an area much neglected by investigators. Strauss (1989) was asked, early in his research, by one of his subjects: "Why don't you ever ask what I do to help myself" (p. 182)? Recent research focuses directly on this method for understanding how a person copes with this chronic illness. Coping strategies will be discussed within the subheadings: the person as an active agent in the illness; symptoms as coping strategies; finding an enduring sense of self; identity reconstruction; control; and healing narratives. Some of the researchers and thinkers I have reviewed previously will be revisited as I review their conclusions about this aspect of the experience of schizophrenia as an ongoing condition.

The Person as an Active Agent in the Illness

Lieberman (1989) reminds us that biological models of schizophrenia, so much a part of modern psychiatry, treat schizophrenia as a disease in which the patient is the passive recipient of the medical treatment offered. The patient is assumed to be dependent, unable to care for himself in a competent way. On the other hand, older theories of schizophrenia depicted schizophrenia as an illness, in Kleinman's terms, in which the person continues to struggle actively to regain a sense of mastery and control in his/her life (Fromm-Reichmann, 1959; Laing, 1967; Lidz, 1973; Perry, 1972; Rosen, 1953; Sullivan, 1953).

Lieberman (1989) asserts that the contributions of sociology and anthropology, particularly medical anthropology, offer a more complete and useful understanding of schizophrenia than do those of modern psychiatry, particularly as it pertains to the understanding of the mind and of the subjective experience of the illness.

Strauss (1989) echoes this point of view. From the sociological literature, the symbolic interactionist perspective lends to the study of schizophrenia the concept of:

> ...the person as a goal-directed being; the person's feelings, interpretations, and actions as helping to drive the phases of disorder and improvement; and the existence of psychological regulatory mechanisms that have major determining influences in that evolution. (p.179)

Strauss (1989) further asserts that by learning to listen more carefully to mentally ill persons, we move from a narrow focus on symptom reduction or symptom management to a broader focus on the whole person, including "learning about and understanding patients' competence, skills, and other features of psychological health" (p. 180).

From this position, the meaning-making, goal-directed person influences the experience of the illness and improvement. Strauss (1989) suggests that both positive and negative symptoms have a regulatory function in the schizophrenic. For example, hearing voices (a positive symptom) may be interpreted by the person as serving the function of companionship or advice. Negative symptoms (withdrawal, apathy, muteness) may serve the function of self-protection from the stigma, shame, and loss of role-function as a result of the illness. The person adjusts "perceptions, interpretations, and actions to maintain a certain level of self-esteem, structure and involvement with the world" (p.184).

Strauss (1989) emphasizes that the person and the illness are not the same, that they can be separated, and that the person can "objectify" the illness, much as a person with a chronic physical illness can objectify the body. This allows the person an avenue to cope with the illness by distancing himself/herself from "it" and allowing the person to find a way to have a life in spite of, or along with, the illness.

Lally (1989) cites several ways in which people with schizophrenia struggle to define a "competent internal self-concept": (a) choosing a less stigmatized label for an illness, such as "depression," or "nerve trouble"; (b) reducing the stigma of the label by citing important persons such as Lincoln, Christ, or the Apostle Paul as having been given a similar label; (c) de-emphasizing incompetent aspects of the self by declaring that their symptoms are not as bad as the really "crazy" people; (d) emphasizing competent aspects of the self; (e) and separating themselves from the illness (objectifying the illness) (p. 254).

Estroff (1989) suggests that for some people with schizophrenia, the illness may become, in Kohut's terms, an object, separate from the self. For others, it may become more of a self-object, a part of the self; for others it may become inseparable from the self – engulfing the whole identity of the person.

Nonetheless, whatever enduring aspects of the core self remain, the person remains and continues to struggle to recreate a coherent sense of self.

In my work with clients who live with schizophrenia, I have often wondered why some of them manage to maintain a sense of self that is separate from the illness and others are engulfed by it. What is clear to me is that each person determines how he/she copes with schizophrenia. I hope my research may help shed further light on the factors that contribute to this phenomenon.

Symptoms as Coping Strategies

Dawson (1994), cited previously, agrees that symptoms themselves can be means of coping. He maintains that delusions are a reparative measure, an attempt to make sense of a psychotic world. They can be understood as a coping strategy to "maintain a coherent mental life in the face of apparently overwhelming disturbance at the deepest (ontological) levels of mental functioning" (p. 595).

Marius Romme and Alexandre Escher (1989), two Dutch psychiatrists investigated how people cope with hearing voices. They sent questionnaires to several hundred people who had responded to a television show about hearing voices, and from those respondents, chose 20 people to speak in a face-to-face meeting. Their speakers defined three general phases in the process of learning to cope with auditory hallucinations. Most people described their first experience with voices as "startling and anxiety-provoking." Some people described their voices as positive, enhancing self-esteem or giving good advice, or offering companionship. Others experienced their voices as negative, self-denigrating, or frightening.

Those who experienced their voices as negative used the strategies of escape (using drugs or alcohol to drown them out), arguing with the voices, or ignoring the voices. None of these strategies seemed to work very successfully, and often led to spending so much energy trying to deal with or stop the voices that other, meaningful, activities were curtailed. They experienced these voices as creating chaos in their minds, “demanding so much attention that the people could hardly communicate with the outside world anymore” (Romme & Escher, 1989, p. 210).

The most fruitful strategies for dealing with the voices were found to be selecting and talking only to positive voices, dissociating one’s self from negative voices, and beginning to accept the voices as a part of the self – a process of growth toward taking responsibility for one’s own decisions. These strategies for coping led to a sense of gaining control and mastery over these experiences, and letting go of the panic and helplessness they had first experienced.

Participants used various frames of reference. Some believed the voices were impulses from the collective unconscious, flashbacks from previous traumatic experiences, mystical experiences, a special gift much like that of a medium, demon possession, or simply as a part of the self. Those who believed the current psychiatric definition of voices as being due to a biochemical imbalance in the brain seemed to experience the voices as outside of their grasp, and therefore uncontrollable except by medication. The development of a frame of reference used to understand the phenomenon was an important strategy for learning to cope with the voices. It did not seem to matter so much which strategy was chosen. What mattered most was that the person developed a frame of reference from which to understand and give meaning to the experience and thus gain some sense of control and mastery over it.

One of Romme and Escher's (1989) participants described this coping strategy as follows:

> Next, I send away the messenger, and I say aloud or in my mind, 'you just go to your friends, don't bother me with this.' That is the first step. The second step is choosing with my own will to make contact – to associate with the light in me, the most beautiful thing there is. I have a source of heat and a healthy core, consisting of pure healthy energy. I know such a thing is present in each human being and that we can choose whether to make contact or not. (p.212)

Lorna Benjamin (1989), a psychologist who studied the relationship that develops between a person and his/her voices, offers a cautionary note about "adaptation" to auditory hallucinations. Her research, in which she used the Structural Analysis of Social Behavior questionnaire to rate 30 hospitalized patients, indicates that people do develop a social relationship with their auditory hallucinations, in which it appears "that all the richness of social interaction can also be found in the internal world represented by the voice" (p. 308). If the voices serve the adaptive function of helping the person cope with the isolation imposed by the illness by increasing the withdrawal from others, then the voices may increase the intractability and chronicity of the illness. She cautions that in these cases, encouraging the person to find social outlets may help reverse this trend.

Finding an Enduring Sense of Self

Sandra McNally (1996) completed a qualitative dissertation on the self-talk used by her schizophrenic participants in their recovery process. Using open-ended interviews with 10 participants, she found that the "I," an "enduring psychical observing agency," was found to be continuous throughout the course of the illness but manifested itself differently depending upon which phase of consciousness the person was in. In the beginning phase, a sense of "boundarylessness" pervaded the participants' consciousness. It was experienced as a sense of alienation, loneliness, fear, and despair. They gradually moved from this phase into a "moment of doubt" in which they begin to question their psychotic self-statements. Confusion and struggle, fighting with the voices or trying to ignore them, dividing the self into categories of "sick" and "well," and finally beginning to negotiate with the self characterized this phase. The third phase, "reflexive self talk," helped them to utilize the non-sick aspects of the self to use reason and logic, reality checks with others, and self-affirmations to gain a sense of mastery and perspective about the illness. This use of reflexive self-talk helped her participants begin to rebuild a coherent self, in which the schizophrenic aspects of the self were incorporated into a new, competent sense of self.

David Roe (1997), in his dissertation on the relationship between self-esteem and course of the illness, found that self-esteem is an important factor in learning to manage schizophrenia. His quantitative study of 43 people hospitalized for severe mental illness consisted of several interviews over the course of two to four years that were rated using several different scales. He found that engulfment by the illness is more likely in persons who have a more fragile or negative prepsychotic self-concept, and this fragile self-esteem is more easily influenced by the negative or fearful responses of others in the environment. The fewer positive enduring aspects of the self available to the person before the illness, the more difficult it may be to rebuild a cohesive, competent self within the context of a schizophrenic illness.

Larry Davidson (1993), studying aspects of recovery in schizophrenia, in a study that was conducted over three years of interviews with 74 adults hospitalized for severe psychiatric disorders, found that the discovery of an enduring sense of the self as an agent of action, separate from the illness, appeared to provide an important aspect of improvement for people with schizophrenia.

Davidson and Strauss (1992), in a series of intensive, semi-structured interviews over a two-to-three year period with 66 people, found that the reconstruction of “an enduring sense of the self as an active and responsible agent provides an important aspect of improvement” (p. 131). They found that the process of becoming more aware of a functional sense of self, and “building upon it in the midst of persisting psychotic symptoms and dysfunction,” provides schizophrenic persons with an enhanced sense of self, with a “refuge from their illness and a foundation upon which they may then take up the work of recovery in a more active and determined fashion” (p. 131).

Davidson and Strauss (1992) described four aspects of the reconstruction of a functional sense of self: discovering the possibility of a more active sense of self; taking stock of the strengths and weaknesses of this self, and assessing possibilities for change; putting into action those aspects of the self that reflect one’s actual capabilities; and “using an enhanced sense of self to provide some degree of refuge from one’s illness and the detrimental elements of one’s social milieu (i.e. stigma) and to provide a resource with which to battle them” (p.134). They suggest that these four aspects may be related, overlapping, and interactive.

Davidson and Strauss (1992) describe the rediscovery of self made by one of their participants:

> It is being active, and I take pride and I’m independent to a certain extent…like in my jazz music, like *I’ll* turn on my jazz radio, and *I’ll* love it… it’s *my* interest. *I* turn the radio on myself, no one had it going to nourish *themselves*, to entertain *themselves*, like parents would at a house. *I* turn it on, *I’m* responsible, *I* enjoy the music, *I* make notes and draw while I’m hearing it. (p.138)

These findings were corroborated by Teri Phripp (1995), who conducted six in-depth interviews each with three participants asking each of them to write about their experiences. Her findings indicated that by redeveloping manageable involvements in activities, roles, and relationships, the people in her study were actively engaged in reconstructing their identities and their lives.

Control as a Coping Mechanism

The research of Williams and Collins (1999), reviewed above, shows that psychosis represents a tremendous loss of control of the mind, one's identity, and finally one's life when a person is hospitalized against his/her will. As a result, the struggle for control remains a central feature in learning to cope with schizophrenia. This includes not only the struggle for symptom control, but also the struggle to regain a positive self-image, social competence, and the ability to meet social expectations of others.

Gross (1987), reviewed above, delineated several ways in which people with schizophrenia control their environment to reduce the risk of relapse due to stress or overwhelming experiences which may shatter their vulnerable psyches:

1. They avoided negative emotional situations, over-stimulating visual or aural contacts with others, and avoided physical or mental strain. Some schizophrenic persons also avoided talking about their psychotic experiences with a therapist, since such conversations could re-activate these experiences.
2. Compensatory mechanisms were employed, such as reducing work speed, structuring tasks so that only one thing is done at a time, taking frequent breaks, limiting the amount of information they are required to handle at any given time, and shielding themselves from other stimuli when working.
3. Adaptation to and acceptance of the limitations imposed by the illness were used to reduce the suffering.

4. They compensated for the illness by working harder to maintain their self-esteem.
5. They practiced "certain functions or performances they experienced as weakened or impaired" in order to become more capable in their tasks (pp. 127-128).

Carr (1988) found similar coping mechanisms in his study of 200 non-hospitalized schizophrenic patients to assess how they coped with the symptoms of their illness. His participants described: (a) distraction of attention away from the symptoms such as listening to music, physical exercise, or leaving the situation; (b) physical changes, such as just withdrawing and becoming quiet, or walking just for the movement to help reduce the symptoms experienced; (c) indulgence, such as eating, smoking, drinking or using drugs, going to a movie; (d) socialization with friends or writing letters; (e) cognitive controls, such as suppression of unwanted ideas or thoughts, shifting attention away from these thoughts, or problem-solving; (f) medical care, although only a few persons sought this first as a way of coping; and (g) symptomatic behaviors, such as locking oneself in a room with a knife to deal with paranoid delusions (pp. 346-350). Carr reports that, in most cases, this latter increased the intensity of the symptom.

Marten deVries and Philippe Delespaul (1989) found that schizophrenic persons felt best in a small group environment of one to three persons, and larger groups or being alone for a long time increased their symptoms. From data collected from nine schizophrenic subjects and seven non-psychiatric controls using the Experience Sampling Method, their results suggested that persons with schizophrenia may do less well in large clinical settings or isolated from others.

Healing Narratives

As with physical illness, narratives have been found to serve the function of helping the person make some sort of order out of the chaos of mental illness. The reconstruction of a self is more difficult for those who suffer from a mental illness than it is for sufferers from a chronic physical impairment. Elicitation of a narrative in mental health practice offers the person and his or her treatment provider a way to construct a story about the illness that can help give coherence to a self, shattered by psychosis (see Estroff, 1989; Greenfield, Strauss, Bowers, & Mandelkern, 1989; Lieberman, 1989; Pollack, 1989).

Psychiatrist John Launer (1999), drawing on examples from his practice suggests that the narrative approach in psychotherapy is based on a change in the understanding of what the “talking cure” actually involves. It has changed from “the search for a normative explanation of someone’s problems toward the search for an appropriate new story for each patient” (p. 117). This change includes a construction or reconstruction of a “new” definition self, so important for a person with an ongoing condition.

Lars-Christer Hyden (1995), a Swedish psychiatric researcher, analyzed the life narrative of a psychiatric patient. He found that assigning the illness a place in his life narrative allowed him to assign it meaning and moral sense and became a basis from which the reconstructive work on his new identity could begin. It became a way to make sense and order out of these chaotic events.

Davidson (1993) did a phenomenological analysis of schizophrenic delusions. He found that delusions could be viewed as narratives or stories that can be analyzed. These narratives can provide insight into the structures of lived experience and can disclose the subjective life of people struggling with schizophrenia. His findings suggest that delusions may play a role in "the course of the disorder as regulatory mechanisms that help people modulate the amount of change to which they will have to adapt in the context of significant life events" (p. 200).

Ingrid Mittmannsgruber's (1997), research analyzes the life narratives of several people with schizophrenia who attended alternative groups for the mentally ill. She explored their strategies of identity reconstruction, finding that the narratives schizophrenics use to reconstruct their identities sometimes reject the biomedical explanation, preferring instead supernatural or "autobiographical" explanations. Identities thus constructed were often unusual or abnormal but constituted significant steps in the personal growth and well being of these persons.

First Person Accounts

The *Schizophrenia Bulletin* began, about 1980, to include first person accounts in each of its issues. As advocacy organizations, such as the National Alliance for the Mentally Ill and Recovery, Inc., gave a voice to mentally ill persons, they began to insist that persons with schizophrenia tell their own stories. This is a source of vivid narratives of people living with schizophrenia, describing their journeys. I have chosen a few of these narratives to illustrate how people describe their subjective experience of the illness, the meanings they give to the experience, and how they cope.

Mary McGrath (1984), in her autobiographical account of living with paranoid schizophrenia, describes her loss of self:

> The reflection in the store window – it's me, isn't it? I know it is, but it's hard to tell. Glassy shadows, polished pastels, a jigsaw puzzle of my body, face, and clothes, with pieces disappearing whenever I move. And, if I want to reach out to touch me, I feel nothing but a slippery coldness. Yet I sense that it's me. I just know. (p. 638)

She goes on to describe her rediscovery of a sense of self:

> But I know I'm still me in the experience. And I'm creative, sensitive. I believe in mysteries, magic, rainbows, and full moons. I wonder why it's expected that I be quieted, medicated whenever it seems I'm stepping out of the boundaries of 'reality.' Should I let anyone know that there are moments, just moments, in the schizophrenia that are 'special'?... Where there's an awareness, a

> different sort of vision allowed me? Moments which I can't make myself believe are just symptoms of craziness and nothing more? (p. 639)

Janice Jordan (1995), in another issue of the *Schizophrenia Bulletin*, begins her narrative this way:

> The schizophrenic experience can be a terrifying journey through a world of madness no one can understand, particularly the person traveling through it. It is a journey through a world that is deranged, empty, and devoid of anchors to reality. You feel very much alone. You find it easier to withdraw than cope with a reality that is incongruent with your fantasy world. You feel tormented by distorted perceptions. You cannot distinguish what is real from what is unreal. Schizophrenia affects all aspects of your life. Your thoughts race and you feel fragmented and so very alone with your 'craziness.' (p. 501)

Esso Leete (1989) writing about managing his illness, outlines the strategies he uses to stay in control of his life:

> To maintain my mental health, I found I had to change my priorities and take better care of myself. I modified my attitudes, becoming more accepting and nonjudgmental of others. In addition, I altered my behavior and response to symptoms. I have also had to plan for the use of my time. When one has a chaotic inner existence,

> the structure of a predictable daily schedule makes life easier. (p. 197)

Pat Deegan is a psychologist and a person living with schizophrenia. She has written extensively about her experience. In her article on "Recovering Our Sense of Value After Being Labeled" (1993), she advises others with schizophrenia to let their anger become their guide to recovery:

> Let your anger, especially your angry indignation, be your guide. See how your anger flares up into angry indignation each time you get referred to as an illness. You are not an illness, and that angry indignation is like a fiery shield that blazes up to protect you and your dignity. Some people will try to tell you that your anger is a symptom of mental illness. Don't believe them. (p.9)

Deegan also talks about acceptance of her illness, and living within the limits imposed by it:

> I've decided that I have a disability. To me it's important to say that I have a disability but that I am not a disabled person...one of the biggest lessons I have had to accept is that recovery is not the same thing as being cured...recovery is a process not an endpoint or a destination...being in recovery means I know I have certain limitations and things I can't do...to me recovery means I try to stay in the driver's seat of my life. I don't let my illness run me. (1993, p. 10)

Deegan (1993) goes on to say that it is important to learn to live with the illness, incorporating it into one's identity. She has learned to live as a whole person within her illness:

> They may tell you that your goal should be to become normal and to achieve valued roles. But a role is empty and valueless unless you fill it with your meaning and your purpose. Don't become normal. Our task is not to become normal. You have the wondrously terrifying task of becoming who you are called to be. And you are not called to be an inhuman thing. You are not called to be a mental illness....You were born into this world to grow and it is possible to grow into a whole, healthy person who also has a psychiatric disability. Your life and your dreams may have been shattered – but from such ruins you can build a new life full of value and purpose. (p.11)

Conclusion

The conceptualization of schizophrenia as a disorder of the mind, which affects the sense of self and personal identity in the world, seems to me to be the most accurate way to describe schizophrenia, and fits the most closely with my experience in working with people with this serious mental illness. The literature that I have reviewed is an effort on my part to draw together what is known about chronic physical illness and its impact on the person living with an ongoing condition, and literature that approaches schizophrenia as a prolonged illness with periods of quiescence and periods of psychosis, particularly in response to stress. It seems as though this would be an obvious way to conceive of schizophrenia, but the literature makes clear that much of the current research on etiology and treatment views schizophrenia as a chronic brain disease to be treated primarily with medication.

The researchers and clinicians I have reviewed disagree with this point of view. They perceive schizophrenia as an illness of the mind, find the most effective treatments for schizophrenia to take into account the person's subjective experience of the illness, and see the person as remaining an active agent giving meaning to the illness, ultimately directing the course of its impact on his/her life. Meaning is seen as determined by the subjective experience of the illness, responses of others, and cultural assumptions about the illness. Thus, I reviewed the theoretical framework of symbolic interactionism, stigma, and the impact of culture on the meaning of illness.

The literature which I reviewed also makes clear how important it is for someone who works with people who are ill to listen to their personal experiences, their life narratives, in order to understand fully what the illness means to the person. The subjective accounts of illness reveal how the person understands his/her illness and how that person copes with the symptoms that come and go. It is through dialogue with ill persons that health care providers can most effectively help those who suffer from ongoing illnesses.

The literature on schizophrenia indicates that although earlier theorists and clinicians sought to understand schizophrenia by exploring their patients' subjective experiences from a primarily psychoanalytic point of view, with the advent of more effective medical interventions in the treatment of schizophrenia, the thrust of the research and treatment of schizophrenia has been centered on treatment of the brain. Only recently have researchers and clinicians begun to try once again to understand schizophrenia from the sufferer's point of view and to understand some of the symptoms of schizophrenia as the way in which people seek to make meaning of their illness and to cope with its impact on their lives. They recognize that in order to treat schizophrenia, the health practitioner must treat the "whole person." My experience with this group of people has been that they experience their illnesses in unique ways, and that each person defines the illness in his/her individual way. This influences how they live with their symptoms, and how they make meaning of their lives.

The difference between schizophrenia and chronic illnesses is that the person affected by the illness so often does not know or recognize that he/she has an illness. With physical illnesses, the person is aware of the illness, and has ongoing physical symptoms with which to cope. It is easier for a person with an illness of this sort to see the illness as separate from the self. Since schizophrenia is an illness of the mind, and affects thinking itself, it is difficult for the ill person to gain the perspective needed to talk about the illness, or the experience of it. Surprisingly, the literature indicates that they do try to communicate their experience to others, and to try to make meaning of this experience that will allow them to stay connected to the world around them.

Drawing all these ideas together from research and theory, my research explored, through dialogue with people with schizophrenia, their narratives as persons living with an illness of the mind and how it affects their sense of self, their identity, and how they make meaning of this illness.

CHAPTER THREE: METHODS OF INVESTIGATION

This study addressed the question: How do people diagnosed with schizophrenia come to terms with this illness? In this exploratory study, I examined how people who have been diagnosed with schizophrenia experience and live with their illness. This is a study of subjective experience in which narratives were obtained through in-depth interviews. The opportunity to tell his/her own story offers a person living with schizophrenia the opportunity to share with another how he/she has come to an understanding of this experience. The social context of their experience was also explored.

Methodological Approach and Research Design

This is a theory-generating study using the "constant comparative method" of qualitative data analysis (Glaser & Strauss 1967). Other researchers (McNally, 1996; Phripp, 1995; Powell, 1998; Williams & Collins, 1999; Thorne, 1999) have noted that qualitative methods of research are best suited to the investigation of the illness experience. Strauss and Corbin (1990) state that qualitative research is appropriate for uncovering and understanding what lies behind a phenomenon such as illness, and can give a fresh slant on something, such as schizophrenia, about which much is already known. Since the method does not begin with hypotheses or preset categories, it allows the investigator to derive findings from data gathered in interviews on the nature of the schizophrenic experience in the unique context of an individual life. It was hoped that the data generated in these interviews would be as varied and rich as each individual's life story. For my own part, I believe that I, informally, do this type of research every day in my work. Each day, I listen to the narratives of my clients' lives, clarifying with them what they mean so that I can better understand. I then compare these stories with the stories of other clients, interpreting and analyzing this material, so that I build on my knowledge and understanding of the problems with which they live. In this way, I am constantly building hypotheses in my mind about their experience in order to use this knowledge to help them cope more effectively with their mental illness. From this point of view, qualitative research methods offer a structured approach that is congruent with my clinical research concerns.

The data for this study was gathered in open-ended, semi-structured interviews in which the discourse between the interviewer and the respondent can result in the joint construction of meaning as described by Mishler (1986). Mishler stresses that when the language, values, and experiences of the interviewer differ from those of the respondent, and when a respondent may be fearful of talking with a stranger, a standardized questionnaire is not appropriate. It is my experience that people with schizophrenia have a great deal of trouble talking about their experience. Although over the years I have found that persons diagnosed with schizophrenia do have difficulty expressing their thoughts in a coherent way, as described in much of the literature, many more of my clients can talk about their experience but are afraid to do so. They have been told that their experience is "not real," or that their experience is proof of their illness, or they have made others uncomfortable, even frightened, when they have tried to tell their stories. An open-ended, interactive approach allowed my participants to describe their experiences in their own way and allowed for my exploration of the subjective meanings they attach to these experiences.

Analysis and interpretation of data followed the “constant comparative” method (Glaser & Strauss, 1967). Each participant’s responses were individually analyzed and interpreted for its contextual meaning and then compared with the responses of the other participants. Stressing the contextual nature of meaning, Mishler (1986) suggests that a “one-shot” interview between strangers who are unfamiliar with each other’s social contexts or life experiences might not provide the necessary “contextual basis for adequate interpretation” of the data (p. 24).

Charmez (1999), in her address to the Qualitative Health Research Conference, asserts that one interview with a participant may not elicit complete or adequate information about the subjective experiences and meanings that people attach to their illness experience. She states that it takes time for the two people to build a climate of trust and safety so that the participant will be able to share openly this personal history of living with illness. The people with schizophrenia, with whom I have worked, are reluctant to talk about their experience with someone they do not know; this can be complicated by paranoia, which is often part of the symptom picture of schizophrenia. Phripp (1995) notes that she interviewed her participants three times each in order to gain a perspective that was as close as possible to the subjective everyday experience of her participants as they live with their schizophrenia.

Mishler adds that in traditional interviewing, the participants are not given the opportunity to comment on the interpretation of their words and intentions.

He criticizes an “asymmetry of power” in that approach, which strips the participant of the power to maintain the social and personal context of their responses. Offering participants the opportunity to comment on the interpretation of their responses, or to refine their responses, encourages them to speak more clearly and deeply in their own “voices.” Further, empowering respondents to find and speak in their own voices also empowers them to produce narratives that allow them to apply the understanding they gain from this story. Gaining some perspective on their lives may offer a new avenue for acting in accord with better understanding their own interests and motives.

I proposed, therefore, to interview my participants more than one time, in order to offer them some time to get to know me, to understand more clearly what I was asking, and the chance to comment on my interpretations of what they had said. I hoped that this might increase their ability to tell their stories in a way that enabled them to feel heard and understood. As it was, I interviewed five of the participants twice and two participants one time only, as they felt comfortable and able to complete a long interview at one time.

Validity and Reliability

Mishler (1986) observes that in traditional interviewing, the assumption is made that asking identical questions of each respondent will generate more “valid” data, because they are exposed to the same “stimuli,” and therefore the responses will be more comparable. He argues and cites evidence that even the most experienced interviewer will subtly alter questions through rewording or additional comments as needed when the respondent is not clear about the meaning of the question. Further, he demonstrates that each interview is necessarily unique in that it is contextually grounded in the life experiences of each participant. Unless the responses are to be “yes” and “no,” the interview is a dialogue in which both parties seek to build a joint understanding between them of the subject being discussed. It is in this dialogue that the most valid responses to an interviewer’s questions are to be constructed. He observes that “validity” as a concept assumes that there is a “true” interpretation of data and that the application of standardized technical procedures can produce a more accurate result. In Mishler’s view, the validity of a study resides in the rigor with which the research is conducted, from the care given to the observing and interviewing, documentation, the specification of the rules of the analysis, the “explication of a theoretical framework and of the ways that inferences and interpretations of analyses are grounded in and related to it,” and “the judgments of various interested audiences, including the subjects of a study, as to the plausibility and meaningfulness of interpretations” (p.113).

Participants

Nature of the Sample

This study focused on the narratives of people living with schizophrenia. The *DSM-IV-TR* (2000) defines schizophrenia as “a disorder that lasts for at least 6 months and includes at least 1 month of active-phase symptoms (i.e., two [or more] of the following: delusions, hallucinations, disorganized speech, grossly disorganized or catatonic behavior, negative symptoms)” (p. 298). Since a majority of the clients with whom I work are diagnosed with the subtype of paranoid schizophrenia, I wanted to include in my study as many participants as possible who have been given the diagnosis of paranoid schizophrenia by a psychiatrist, the essential feature of which is defined in the *DSM-IV-TR* (2000) as "the presence of prominent delusions or auditory hallucinations in the context of a relative preservation of cognitive functioning and affect" (p. 313). Because the purpose of the study was to generate rather than to prove or disprove hypotheses, I interviewed people of varied backgrounds and experience to offer as wide and rich variety as possible.

Strauss and Corbin (1990) advocate that the sampling strategy be aimed at maximizing the variation in the phenomena being studied. Williams and Collins (1999) note in their methodological considerations that outcomes in coming to terms with living with schizophrenia vary widely from person to person. This matches my experience as well. People understand and interpret their experience differently and their life histories reflect this variation. The inclusion of people who have had different outcomes in living with their illness may offer different perspectives about the way they interpret their experience.

Glaser and Strauss (1967) advocate smaller samples from 5 to 10 participants. They qualify that suggestion with the admonition that sampling should continue until the central themes of experience across the variations among the persons being interviewed are saturated, and no new themes or patterns of experience emerge. They state that without this saturation, the theoretical interpretation and analysis of the data will be incomplete. I interviewed 7 people altogether, 5 of them twice in order to enter into their worlds as much as possible, and to understand as fully as possible their experience and their meanings. I shared with my participants my perceptions and interpretations so that they could comment on the accuracy of my observations and analysis.

Criteria for Selection

The primary criterion for selection was the diagnosis of schizophrenia, as defined by the *DSM-IV-TR* (2000). It has been my experience that some diagnoses are changed over time, according to the shifting of symptoms or treatment providers. Over time, the symptoms become clearer as the person is better able to communicate them, and a stable diagnosis emerges. I proposed, therefore, to interview both men and women who have lived with this illness long enough for them to have a stable diagnosis, and who have experienced more than one psychotic episode, thus having had to confront the issue of living with an ongoing condition. The majority of initial psychotic breaks occur for men in their early to mid-twenties and for women in their late twenties (Arieti, 1974; *DSM-IV-TR*, 2000; Begley, 2002). For this reason, I proposed to interview participants who are over the age of 30. In addition, all my participants were people who are not conserved and could sign their own consent forms. Conservatorship of person is the term used in California for persons unable to provide their own food shelter, clothing, etc., who have been judged incompetent and have been assigned a guardian.

Recruitment

Participants were recruited through letters to both colleagues who work with me and professionals from other agencies, explaining to them the nature of the study and the criteria for the participants (see Appendix A). In my letter, I asked them to select clients who fit the criteria and who might be willing to talk with me about their subjective experience. I asked them to approach these clients and discuss with them the nature of the study. If a client was willing and interested in participating in the study, I included consent forms (see Appendix B) for the prospective participant to sign, giving me permission to contact them and to set up a time to meet with me for an initial screening interview (see Telephone Contact Format, Appendix C). The contact consent form is necessary because colleagues from other agencies may not release any information about their clients without their written consent, and this form gives me permission to contact them.

At that screening interview, we reviewed the nature and purpose of the study, the length of the interviews, number of interviews, the assurance of anonymity and confidentiality, and permission to audiotape the interviews in a quiet place that they would choose, either in my office, their home, or their treatment provider's office (see Screening Interview Format, Appendix D). If they were willing to participate in the study, I asked them to sign an "Informed Consent" (see Appendix E) indicating their understanding of the study procedures and their willingness to participate. I read this consent form to them to insure that they understood what they were signing. At that point, a first interview time was scheduled which was agreeable to both this researcher and the prospective participant.

Data Collection

Data for this study was gathered through the use of semi-structured interviews using the approach described by Mischler (1986) as related above. Five of the participants were interviewed twice for approximately 30 to 40 minutes each time. The interviews with the two participants, who were interviewed only once, were approximately 90 minutes each. An Interview Guide (see Appendix F) was prepared to assure that the same basic topics would be covered by each interview. New unanticipated topics that emerged during the course of the interview were incorporated into the interview guide to further inform the research. Probe questions were structured to help the interviewer rather than to structure the answers of the participants. It was not necessary for the questions or topics to follow in any specific linear order or for all the probe questions to be asked. Some of the probe questions were influenced by a training in cultural competency that I attended recently with my coworkers and are drawn from a book by Anne Sadiman (1997), *The Spirit Catches You and You Fall Down*. I liked these questions because they seem sensitive and nonjudgmental. This flexible approach seemed to encourage the participants to elaborate on their stories and allow for further understandings and meanings to emerge and evolve.

When using the "constant comparative" method (Glaser and Strauss, 1967), analysis of the data begins with the first interview. The second interviews were used to give the participants an opportunity to elaborate on the previous interview, to respond to my interpretations of what they have said, or to explore any additional topic areas that may have emerged out of the previous interview.

Interview Guide

The first interview began with a general statement about the purpose of the research and about how I intended to proceed (see Introduction to Interview Guide, Appendix F). I was aware that what I would be asking them to talk about might be difficult, so beginning by asking about their lives, background, and history was designed to make it easier. The interview then proceeded to the history of their illness.

The following topics aided and guided this researcher and provided a framework for discussion and elaboration. The topics have been suggested by the literature, by my experience, informal conversations with coworkers and other colleagues, and by *The Spirit Catches You and You Fall Down.*

Background and History

Addressing this topic offered the participant a way to begin talking about his/her life. I was interested to know the demographic profile of the participant – about the person's life before the diagnosis of schizophrenia. This provided valuable information about that person's sense of self prior to the diagnosis and about experiences that may have contributed to how the person now copes with schizophrenia.

Experience of the Diagnosis

This topic explored the participant's understanding of the diagnosis of schizophrenia. I have found that many people I have worked with have never had the diagnosis explained to them and have developed definitions of their own, which sometimes reflect their experience of the diagnosis. In light of how they understand their illness, the participants were encouraged to share with the researcher their initial responses and experiences of being given this diagnosis. Probes included the context in which the diagnosis was given, the people involved in the diagnosis, and how they felt about being told that they had a mental illness. Did they believe what they were being told? It was important to ask the participants about their symptoms as they understand them and what they experience when they have symptoms. The literature suggests, and it is my experience, that some people do not understand their symptoms as symptoms but have other explanations for these experiences. This researcher was sensitive to this aspect of their experience and explored with them their symptoms as they understand them.

Relationships with Other People

It is important to find out how the person sees himself/herself in relationship to people who do not have a mental illness, whether other people in the family also have mental illness, how the person's family has responded to the diagnosis, how the person has experienced his/her family relationships both before and after the diagnosis, relationships with other people in the community and with treatment providers. I was alert to experiences they may have had of being evaluated or judged by people with whom they have come in contact, and I encouraged them to talk about how they have coped with these social responses to them.

Coping with the Illness

This topic addressed the active measures the person has taken to cope with the ongoing experience of the illness, such as the waxing and waning of symptoms, experience of medications, and any experience of self-medication in the form of drugs and alcohol to deal with symptoms.

Meaning of the Experience

It is important to learn how the person diagnosed with a mental illness makes meaning of this experience, how he/she interprets and understands this experience, and what it means to have schizophrenia. Many of the people I have worked with explain their illness in terms of their delusions. As Dawson (1994) suggests, delusions can be seen as a reparative measure, an attempt to make sense of a psychotic experience. Many of the people I have worked with have been told that their delusions are not real, but it has been my experience that "delusions" are often the most important aspects of the person's thinking about their experience, the meaning it has for them, and how they understand what has happened to them. Delusions can be understood as the way they structure their world.

Sense of Self

The literature (Davidson, 1994; Estroff, 1989; Lieberman, 1989; Strauss, 1989) asserts that the person with schizophrenia remains an "active agent," a meaning-making, goal directed person who influences the experience and course of the illness, who continues to struggle for mastery and control in his/her life. The participants were encouraged to talk about themselves as separate from the

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illness, as persons with strengths and abilities that have not been compromised by living with an ongoing illness. Some of the stages of living with the illness emerged during the interviews and were influenced by the severity of symptoms at the time of the interview (McNally, 1996), and whether or not the person has been "engulfed" by the illness (Roe, 1997).

Conclusions about the Interview

An important aspect of this study was the collection of data about the interview experience of the participants. The interviewer was sensitive to any issues that may have come up in the course of the interview, and elicited from the person their response to being asked such personal questions. The researcher offered to talk further with the participant about these issues, or be available to talk further before the second meeting, should the participant indicate that the first interview was stressful.

Depending on how many of the topics were covered during the first interview, or how much the person was able to say about each topic, the first interview concluded with specific suggestions for further discussion at the second interview, and exploration with the person of other topics that he/she may wish to discuss, including the spiritual aspects of the illness experience.

The Second Interview

As stated previously, discourse is a joint construction of meaning (Mischler, 1986). The second interview offered the participant an opportunity to expand upon or to complete topics discussed in the previous interview, to give feedback and corrections to the interviewer's interpretation of the participant's responses, and to explore further topics that may have emerged during the previous interview, until both people were satisfied that the interviewer understood and responded satisfactorily to the participant's history and meaning. At conclusion, the researcher then asked for further thoughts and feelings about the interview and the interview process. It was hoped that the telling of one's story may elucidate for the participant aspects of his/her life that were previously unnoticed or unresolved and offer the person a new perspective on his/her sense of self, previously unrecognized strengths and abilities, the "non-sick" aspects of the self, and potential avenues for change.

Data Analysis

The "Constant Comparative" method of qualitative analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1990) was used to analyze the interviews. This approach offers a systematic procedure for generating hypotheses from the themes and patterns that emerge from participants' narratives. Analysis began with the first interview and proceeded in a comparative manner, with each participant's interviews being closely analyzed while at the same time comparisons were made across individuals. Mishler (1986) notes that the construction of narratives is the natural way that people order and make meaning of their experiences.

In qualitative research, the researcher's "theoretical sensitivity" is an important feature of the analytic process. Awareness of subtleties of meaning in the data is based on the researcher's experience and a growing awareness of concepts, relationships, and meanings as the researcher moves back and forth between the data protocols and the emerging analysis (Strauss & Corbin, 1990).

Following each interview, the researcher made notes about thoughts and reactions to the interview, and any further questions that arose. Listening to the audiotape strengthened this process. The audiotape of the interview was then transcribed with attention to Mishler's (1986) assertion that systematic transcription of interviews is essential for capturing as accurately and completely as possible the discourse between the two people and is essential for valid data analysis. He recommends that the transcription include all the "linguistic and paralinguistic features" that occur routinely in naturally occurring speech (p. 47). He also recommends that the transcriber return repeatedly to the tape-recording to insure that the transcription has been heard correctly in order to further insure that the analysis is accurate.

Initial analysis of the transcribed material then proceeded with "open coding" procedures as defined by Corbin and Strauss (1990). This consisted of breaking down the text into units of meaning, comparing these units to one another first within and then between each interview, and categorizing each unit. This conceptualizing process included the application of theoretical sensitivity, in which units of meaning were analyzed for all the possible meanings, so that none was overlooked. This process also helped to highlight the interviewer's biases and assumptions about the material and opened up the material to new meanings.

Corbin and Strauss (1990) define a second coding process, "axial coding," as the "set of procedures whereby data are put back together in new ways after open coding, by making connections between categories" (p. 97). They offer a paradigm to guide this coding procedure, which stresses action/interaction process and conceptualizes the developed categories as conditions, context, action/interaction strategies and consequences. Though their paradigm may be used to guide this process, the researcher may devise his/her own paradigm.

The process of coding and development of conceptual categories by collapsing, expanding, or deleting continues as interview protocols are compared, returning back to the data to check conceptualizations. Revision and refinement continues until no more core categories emerge from the data.

The final steps in the data analysis include the development of a description about the central phenomenon of the study, the conceptualization of the story, or "the story line." This is aided by "selective coding," which is the process of selecting the core category (the "phenomenon"), relating it to other categories by means of the paradigm, validating those relationships, and filling in categories that need further refinement and development. Statement of the hypothesis or theory grounded in the analyzed data completes the process.

The next step was interpretation of the data, based on the nature of the core category and the relationships that emerged amongst the thematic categories and their dimensions and organized into a formal model of experience that addressed the study question.

Presentation of Findings

In the presentation of the findings, the participants are described in such a way as to protect their anonymity, and data that are unique enough to threaten this anonymity were disguised. The findings address common features and variations as well as dissimilarities, and the categories and sub-categories are described with examples from the data.

In the final chapter, the patterns and themes discovered in the analysis of data are interpreted and discussed in terms of the study question. Any thematic variations or deviant cases are discussed in terms of their relationship to the overall emergent pattern. Findings are discussed in relationship to the literature. Limitations of the study and issues of validity and reliability are addressed. Finally, the hypotheses generated by the data are discussed in terms of suggestions for further clinical research and implications for people living with schizophrenia.

CHAPTER FOUR: FINDINGS

This study explored the subjective experience of living with schizophrenia. Specifically, it focused on coping with the ongoing nature of this condition and the consequences of being diagnosed and identified as being schizophrenic. This study was designed to explore the common features of the experience of living with schizophrenia, while at the same time offering my participants a chance to tell their own unique stories. The findings reflect the participants' descriptions of the subjective experience of psychosis, their understanding of this experience, the ways of coping they have developed for dealing with ongoing symptoms of psychosis, and the meanings that they have ascribed to this experience.

The Context of the Interviews

I have had the opportunity to work with people with serious mental illness for a long time as a clinical social worker. As I noted in Chapter 3, it is in this capacity that I have learned how seldom they are consulted about their understanding and experience of the diagnosis of schizophrenia. As this study is ethnographic, I put aside my clinical role. Using the semi-structured interview method, as described by Mishler (1986), the discourse between us put the participants in the position of consultants to me, empowering them to speak more freely about themselves than they might have done in a clinical setting. However, I was able to use my experience of working with people with schizophrenia to guide my responses to them and to set the context of the interviews in a safe and non-judgmental frame. I believe that this frame encouraged the participants to draw on the healthiest aspects of themselves as they talked with me. Because they did not feel as though they were being evaluated, they were able to speak openly about their ongoing struggles with symptoms as well as to share with me their delusions, ideas of reference, and their hallucinations.

All of the interviews took place in a setting that was chosen by the participant and at a time that was convenient to them. I interviewed two in their treatment settings, two in the offices where they work, and three of them in their homes. I interviewed five of the participants twice and two of the participants only once. These last two participants, "F" and "G", have had the opportunity to talk about their schizophrenia both professionally and in the context of their work. As a result, they are both comfortable talking about their condition, and very articulate; we were able to complete the interview at the first meeting.

Descriptions of the Participants

The participants are described according to letters of the alphabet for the purpose of protecting their anonymity. Seven participants, two women and five men, all diagnosed with schizophrenia, were interviewed. Six of the participants have been diagnosed with Paranoid Schizophrenia, and one participant, "G," has been diagnosed with Undifferentiated Schizophrenia.

Although I had originally designed the study to include only people who had been diagnosed with Paranoid Schizophrenia, participant "G" was included because I felt that she filled a gap in the maximum variation sample and because she was able to articulate her experience so clearly. I wondered how her experience would compare to the rest of the sample. According to the *DSM- IV-TR* (2000), the major difference in symptomology between Paranoid Schizophrenia and Undifferentiated Schizophrenia is the absence of paranoid ideation and the delusions of grandeur associated with the paranoid type. In general, "G's" experience of living with schizophrenia was similar to the other participants, although her delusions and hallucinations lack the threats of harm, the pervasive sense of fear, and the grandiosity that accompany the hallucinations and delusions of those participants who have been diagnosed with Paranoid Schizophrenia.

The participants were chosen to reflect as broad a population as possible, and they varied in age, ethnicity, cultural background, education, and socio-economic status. They ranged in age from 32, participant "F," to 57, participant "A." Two participants "A" and "B," are African-American, participant "C" is Chinese-American, participant "D" is Filipino, "E" is of Puerto Rican descent, and "F" and "G" are Caucasian of European descent. All of the participants but one has been on SSI, and all have been hospitalized more than one time. The participants ranged in socio-economic status from being unemployed and on SSI to working full time. Their educational levels ranged from having finished high school to having achieved a Ph.D. Participants "C," "E," "F," and "G" have had some psychotherapy. All of the participants are currently on psychotropic medication and see a psychiatrist regularly.

The participants also varied in their understanding and acceptance of their diagnosis. Participant "A" continues to believe that he does not have schizophrenia, even though he has been hospitalized many times since he was 21 years old and is on medication. His thinking is often illogical, and it was difficult to follow his thought or at times to understand what he was trying to say. Participant "B" knows that she has schizophrenia and can talk about this, although her speech pattern is affected by her thought disorder. Participant "D" vacillated throughout the interviews between speaking of his schizophrenia as an illness or as a messianic "curse." Participants "C," "E," "F," and "G" experience their condition as an illness that can be treated and their symptoms as symptoms.

Although the participants in this study are somewhat better educated and more articulate than many of the people I see in my clinical work, I believe their conceptualizations of their experience of living with schizophrenia are representative. These participants were referred to me because they could talk about their experience in a way that others are not able to do, but I believe they do speak for the larger community of persons living with this condition.

The subject of the dual diagnosis of mental illness and substance abuse is threaded throughout this research. The community treatment program in which I work as a clinician is a dual diagnosis program. It has been my experience that many people diagnosed with schizophrenia have used drugs and alcohol as a means of self-medication and emphasize this aspect to avoid the stigma attached to the diagnosis of schizophrenia. For them, it is socially more acceptable to be diagnosed with a drug/alcohol problem than it is to be diagnosed with a serious mental illness. Many of the people I see as a clinician have told me that they go to the hospital because they have problems with drugs or alcohol, not because they have schizophrenia.

In my sample, three of the seven participants, "B," "C," and "D," talked about their problems with drugs and alcohol. They described how the drugs/alcohol they used to cope with the symptoms of their mental illness made the symptoms worse. They talked about how they used drugs and alcohol to deny their mental illness and the problems this created for them in their lives. These three participants no longer use drugs or alcohol and participate or have participated in self-help recovery groups, such as Narcotics Anonymous, Alcoholics Anonymous, or in Dual Recovery Anonymous. In this respect, although their experiences are representative of many who cope with a dual diagnosis, their understanding and acceptance of this phenomenon permits them to talk about it in a way that others may not be able to do.

Four, "A," "B," "C," and "E," of the participants have been homeless in the past. They described many difficult transitions in their ongoing process of learning to live with schizophrenia. All participants are currently living independently, although three, "A," "B," and "D," continue to have the support of a case manager. Their case managers assist them with finances, oversee their psychiatric and medical needs, and help them to structure their time.

All of the participants have reflected, to various degrees, about spiritual concerns and shared their speculations about why they have schizophrenia. Each has come to his/her own understanding of this question. Each has pondered the question of control – of their symptoms, of their illness, of their lives; all have some recognition that they are not always in control of their lives.

I had been prepared for the participants to be fearful of being audiotaped, reluctant to speak to me about their illnesses, or to find my questions painful to answer. To my surprise, all were happy to share their experiences with me, and all told me that what I am doing is important to them. In their experience, each has felt unheard or devalued, so being asked to tell their side of the schizophrenia story felt "relieving," "important." As one participant told me, it made him feel like "I am somebody." They talked freely with me about their lives, although three, "A," "B," and "D," have some difficulty with communication because of their symptoms. As a result, it was sometimes difficult for me to understand what they were trying to tell me, and I had to clarify with them whether I was correctly interpreting their meaning, if not their words. All of the participants continue to struggle with symptoms of ideas of reference, delusions, hallucinations, difficulty concentrating, racing thoughts, etc., some of which were present as we spoke, as will be seen in the data quotes below. In spite of this, they were able to be articulate about these experiences and, in some cases, consciously identified them as symptoms.

It is not surprising that the participants' language is culturally based. All have learned from the treatment providers who have worked with them to use current psychiatric terms to describe their experience. They express the same cultural biases about mental illness that is grounded in our social conceptualizations of schizophrenia. In addition, five of the participants, "B," "C," "D," "E," and "F," have been exposed to the 12-step model and use this language from time to time in their interviews. "C" and "D," who both have extensive drug histories, are currently active in a 12-step program. "F" is a peer counselor and is active in a program known as the Wellness Recovery Action Plan (WRAP) and uses this language from time to time in his interview. "G" is active in Schizophrenics Anonymous, a 12-step program that utilizes some of the language and concepts of Alcoholics Anonymous as a way to help people cope with and manage the ongoing symptoms of schizophrenia. She referred to this from time to time in the interview.

At the end of each interview, I asked the participants if they had a statement that they would like to make about their experience that would be helpful to those of us who work with people with mental illness. Each of them was more than happy to do so and offered suggestions that, based in their own experience, might help others to better understand how to help someone who lives with schizophrenia.

Overview

This study focused on the experience of living with schizophrenia as an ongoing condition. Living with a condition that is often misunderstood, feared, and described as a hopeless illness, for which there is no cure, has been a significant obstacle in their lives. Participants' narratives of their experiences can be described as a difficult journey of self-discovery, containing different levels of understanding and awareness along the way. Participants "A" and "D" seem to be struggling with understanding the nature of their symptoms, and have difficulty in understanding or accepting them as part of an illness. This makes the ability to regain stability in their lives more difficult. Both continue to partially deny that they have an illness. They remain engaged with their voices, believing them to be real, and they remain actively delusional much of the time, unable as yet to regain as much control over their lives as have the other participants. They have not been medication compliant, which appears to have affected their effectiveness at managing symptoms.

The other participants have all come to some acceptance of their ongoing condition of schizophrenia. They take their medications regularly and understand, to varying degrees, that their symptoms are treatable. This has allowed them to become more stable as they have found strategies to cope with their symptoms.

All of the participants are aware of the perception of people with schizophrenia as crazy, incompetent, bizarre, and frightening. Each of them has experienced some or all of these perceptions and has had to find ways to cope with this lack of understanding and acceptance. Thus, stigma has been an important element in their experience of coping with schizophrenia. Participant "G," although her diagnosis is different from the rest of the participants, has also experienced stigma in her life.

I asked each of the participants if they believed that schizophrenia is a condition that will be ongoing for them. Two, "A" and "D," expressed the belief that "cure" is possible. It is interesting that these are the same two participants who do not fully accept that they have an illness. They also seem, among the participants, to be currently suffering the most with their illness. Two participants, "C" and "F," believe that remission of symptoms is possible as long as they continue to take their medications as prescribed, and the other three participants, including "G," believe that they will have ongoing symptoms that they must continue to manage with medication and support. "G," the participant whose diagnosis of "undifferentiated schizophrenia" differs from the others, experiences ongoing psychiatric symptoms in spite of the fact that she is on three anti-psychotic medications. Even with this, she continues to work in the mental health field.

I have conceptualized their experience as a journey of self discovery, which I will describe within five overarching themes: "The Initial Psychotic Experience"; "Experiencing and Conceptualizing Ongoing Symptoms"; "Rebuilding a Life and Finding Hope"; "Attributing Meaning to the Experience of Schizophrenia"; "Suggestions for Better Understanding and Treatment of Schizophrenia."

In the presentation of data that follows, each category and its properties or sub-categories will be described and illustrated with verbatim excerpts from the interviews. Before describing the data, I will present a summary narrative of my participants' stories.

The journey began with the first psychotic episode, hospitalization, and an initial resistance to treatment. All of the participants described an initial confusion about what had happened to them, a striving to understand this experience, and some denial about their psychosis. All lived with their symptoms for some time before they began to confront the ongoing nature of these symptoms.

They felt confusion and fear as they began to realize that the symptoms that they were experiencing were defined as an illness and that these experiences were different from those of other people. All tried various ways to understand and interpret what was happening to them, or to escape into drugs, alcohol, or delusions, only to be hospitalized again and confronted with the ongoing nature of their symptoms. They experienced a sense of loss of who they had been in the world, as these ongoing symptoms affected their lives in dramatic ways. They became aware of the loss of status that comes with being labeled, "crazy," which affected their self-esteem. One participant said that it made him feel like a "nobody." Each of them experienced a sense of fear about his/her future as the ongoing nature of this condition became apparent to them.

Yet each has found within himself/herself a determination to understand this experience, and in that determination all have found the will to go on, the will to reclaim their lives, and to find meaning in their experience. Although they have reached varied levels of stability, varied levels of understanding, and varied levels of acceptance of the illness, all have improved their quality of life significantly, and each continues to cope with the ongoing struggle of living with schizophrenia.

Various aspects of the process of learning to manage the ongoing symptoms of schizophrenia were described, including being able to take back responsibility for one's life, the acceptance of medications as necessary, and acceptance of help and support from others. This implies recognition of the symptoms as a part of a condition that can be treated – that can be helped. The realization that one does not have to continue to suffer alone and that others could help has been a source of hope. Most of the participants have realized that, though most people who have never experienced psychosis cannot understand the schizophrenic experience, there are people who are willing to support them and help them to see themselves as “persons” rather than as an “illness,” thus giving them a measure of self-respect and dignity. Participant, “G,” has a sign over her office door: “Know me by my name, and not by my illness.”

The participants in my study were all diagnosed with schizophrenia between the ages of 11 and 23. However, the length of the diagnosis is not correlated to their level of understanding of their condition or their psychiatric stability. It seems more closely correlated to the type of treatment and the amount of support that they have had in the course of their illness. Those participants who have been given better understanding, support, and treatment for their condition seem to have been able to stabilize sooner and to find ways to live with the ongoing nature of their symptoms more effectively than those who had less opportunity to receive that kind of support. These participants also conceive of their condition as an illness, which permits them to understand their symptoms as symptoms rather than as phenomena outside of their control.

Each participant has thought deeply about the meaning of his/her experience. One, “D,” described it as a “gift and a curse.” He believes that God has asked him to suffer so that he can contribute in some way to relieving the suffering of others in the world. His description of the meaning of his experience is larger in scope than that which other participants attributed to the experience. However, it reflects a general feeling among them that, whatever the cause of the illness or its ultimate course, they would like to use this experience as a way to help others – to give to others the understanding and coping strategies that they have been able to achieve. For some, their experience has taken on a spiritual significance, becoming a source of meaning in their lives. Five of the participants described their experience as a trial or a test given to them to overcome. Participants "A" and "D" described it as a burden, but all believe that their condition offers an opportunity to help others. They described a desire to "give back" to others who suffer from schizophrenia, or from any mental illness, as a way of making their own painful experience have value for themselves and others.

From their experience, each of the participants was willing to share some advice or suggestions for people who work with or are related to someone with schizophrenia. The general theme was that of compassion and respect. Reflecting on their own experience of stigma, they asked others to understand and respect what they have to say, even if that seems to be illogical, impossible, or bizarre. All the participants talked about the importance of support and understanding from others as a key element in one's ability to cope with and overcome the challenges of living with schizophrenia.

The Initial Psychotic Experience

All of the interviews began with an invitation to reflect on the participant's early experiences and how those experiences might have influenced the course of the illness. All of the participants shared either traumatic, unusual, or difficult experiences in their childhoods that they believe either brought on their first psychotic episode or contributed to it.

Regarding the time of the first psychotic episode, all the participants described some stressors in their lives that they believe contributed to the precipitation of the first psychotic break with reality. Two of the participants, "C" and "E," were in college and one, "F," had recently finished college. Two of the participants, "A" and "B," had lost their parents, one, "G," was in an abusive family, and participant "D" had just lost a relationship with his girlfriend. Two of the participants, "C" and "D," feel that drugs and alcohol played a part in their first psychotic experience.

Their descriptions of that initial experience with psychosis are portrayed as confusing and frightening. They described, in various details, a sense of losing a grasp on reality – not knowing what was real and what was not. These experiences were intense and disorienting. Some of their initial experiences were accompanied by hearing voices, and some were not. The first psychotic symptoms were often experienced as a gradual withdrawal from normal occupations and from other people, to a gradual confusion about what was real and what was not. This confusion was disorienting and frightening to them, and was construed as bizarre or frightening to the people around them.

This, in most cases, led to the initial hospitalization, a confusing and frightening experience in and of itself. For instance, participant "E" was told that he would have to take medication for the rest of his life, but the treatment providers at the hospital did not tell him what he had been diagnosed with, since they thought he could not tolerate hearing the truth about his condition.

The participants shared their interpretations of what had happened to them following their first hospitalization. They talked about their confusion, fear, and embarrassment or shame. Several of the participants talk about the delusions they developed as a way to explain this experience to themselves.

Early Experiences

These early experiences included painful and difficult events in their early lives, early symptoms, and feeling different from others. Participants talked about the impact of the cultural or social environment in which they grew up, the support they received or did not receive from their families, and the influence of other interests and opportunities on their abilities to cope with their symptoms. They also made attributions of connection between early events and their subsequent symptoms or their ability to deal with such symptoms.

Difficult Childhood Experiences

Five of the seven participants experienced various painful and/or traumatic experiences in childhood, from physical and sexual abuse, the loss of parents or parental involvement, to participating in a murder as a member of a gang when only 15 years old. This participant, "D," believes that his schizophrenia is a punishment for this murder and for other crimes he has committed. His guilt and remorse, however, have taken on delusional proportions, making him responsible for fixing the problems of the world:

> ...um...I believe that it [schizophrenia] serves this function, but (he clears his throat) I don't believe that it is necessary that...um..., for the most part, schizophrenics are homicidal...(he clears his throat) I believe that I was chosen to have schizophrenia because...uh... I was told that my purpose was to fix all the dysfunctionality in America...

Although the other participants do not exactly point to their early painful experiences as a cause of their schizophrenia, they do believe that such events may have contributed to their difficulties of dealing with a mental illness, and there is some implication that early events lead to their confusion.

Participant "B" described to me how the experience of the loss of her mother contributed to her first hospitalization:

> At the age of 10 or 11, after she died, I left home, and I went to the state hospital, and that was the end of my life with my family and with my mom and my brothers and sisters and my father. I turned around and ... I even tried suicide. I put my foot through a window...I busted two of the tendons in my foot....

Participant "A" states:

> My dad died when I was 6 years old, 6 years old, and my mother died when I was 10 years old...My mom died from...uh... cancer and my father died from old age. I hated to lose my mother, and

> I...I lost direction when my mother died because I was only 10 years old.

He believes that the losses he has suffered in his life have caused his schizophrenia.

Participant "G," who described her childhood with a violent and abusive father, explained to me that having a mental illness and having to deal with her father's demands and abuse caused many problems for her both academically and socially. Yet another participant, "E," explained to me that he was a very lonely child and that his parents were not really involved with his life. It is this feeling of loneliness that has made living with his schizophrenia so difficult.

> I was alone in my family; I was alone at school (he sighs). I was not a...um... popular guy, and the girls did not like me...So I...uh... started to lead a fantasy life. I started to live life in my own world, since my interaction with the world was not satisfying, and I left the world (he sighs). That is part of what I would define schizophrenia...All my life, I have been meandering through college, through board and care homes, through mental institutions, and I am alone (he sighs again).

Early Symptoms

Six of the participants felt certain early experiences as initial psychotic symptoms ranging from sensitivity to noise, to anxiety, to hearing voices. Participant, "F," told his mother that he was experiencing sensitivity to noise, and she took him to see a mental health professional. However, it was not assessed as a possible prodromal symptom of psychosis, and the matter was dropped.

> I....um... had my first break when I was 23, but when I was 12, I had an interesting experience.... I don't know...I'm not sure, how this relates at all, but when my mom was drinking coffee, I...uh... would hear her sipping her coffee, and I would just like totally freak out, you know. I couldn't stand it. I couldn't be in the room with her while she was drinking her coffee (he laughs ruefully). It was like, you know, fingernails on a chalkboard. That and other reasons, being twelve and whatever, she took me to see a counselor one time, and that was it. But that was pretty unusual I always thought. Perhaps the brain was going through changes already, and I don't know if it was beginning then, but...uh... I had my actual first break when I was 23.... I was having symptoms a few years before that.

It is not clear how many of the other participants told their families that they were having symptoms, but two of the participants were hospitalized early – participant "B" at 11, and participant "G" at 13.

Participant "E" talked about the anxiety he experienced shortly before his first break.

> I...um... forget how long before I went to the hospital, but I think I was a junior in high school. I was at a Jehovah's Witness meeting, and I felt this fear come over me, this anxiety (he clears his throat). It is called signal fear, signal anxiety, and it is one of the signals

> that schizophrenia is coming, and I remember that it was worse than the fear of death (he sighs). It was...um... a fear of losing yourself, fear of losing your personality and character.

It is interesting to note that he refers to his experience as "signal anxiety," a psychiatric term that he has learned from all the books that he has read on mental illness. In order to explain his experience, he has tried to frame it in clinical, thus less judgmental, terms.

Participant "A" described his first psychotic experience as follows: "When I was young in a car, I heard a voice saying, 'Henry Ford'...I heard a voice coming from above my head, saying, 'Henry Ford", and so I started drawing and painting a lot of cars." Participant "B" told me that she had started hearing voices when she was 3 years old. Participant "D" told me that, "when I was a little kid, I heard a voice. I didn't know if it was God, but it told me that I was a great leader from the east." Participant "G" told me about a "protector" that she has had since she was a child: "Eventually, I have had both auditory and visual hallucinations of him. He is two feet tall, and he shrinks to six inches when he is angry."

Feeling Different from Others

Four of the participants described their sense of being different from those around them. They either felt different in their families or different from other children. Participant "B" talked about feeling different in her family: "I was born different out of the whole family. I mean that my mother and father had the disorder of alcoholism, and when you are carrying a baby, it is not good to smoke or drink." She implies that her schizophrenia might be the result of her parents' alcoholism. This is an example of the kind of attribution of cause that these participants tend to make.

Participant "E," who described his loneliness in his family always felt as though he were different from all of those around him. Participant "C" described himself as a "sort of an outcast in high school. I was a bad boy, hanging around the parks and smoking cigarettes. They called us 'Parkies' because we would hang around the park and smoke cigarettes and pot or whatever." Participant "G" shared with me that she "really never had friends or peers around much as an adolescent, "because my parents never allowed me to have people around much, and they would not let me go anywhere."

Early Influences

Each of the participants shared with me various influences that have been important to shaping the values, choices, and coping mechanisms used to deal with his/her illness. For example, four of the participants were raised in religious families, or exposed to religious influences early in life. These experiences seemed to have shaped the way that they interpreted initial experiences with psychosis, such as being possessed by the Devil. There is a sense that what is operative here is the age-old struggle between good and evil, which some of these people seem to be caught up with, and which is a strong cultural theme.

Participant "E" put it most clearly: "I am a child of God, and I am not God or the Devil, or anything like that. It is clearer now than it was at the time, and I think that at the time, I felt hopeless in life." Participant "D," whose belief that he must somehow save the world, spoke of being possessed by "Beelzebub" and then described his experience as follows:

> ...my face changed (he coughs). It was like a combination of anger and laughter. I...um... turned to my side, and my father saw me, and he said, 'You are a powerful son' (he coughs). I know it was wrong, but it seemed right at the time.

He talked in these grandiose terms throughout the interviews, as he struggled to come to terms with his confusion between being a powerful leader who must save the world and being a person who is just trying to get his life back on track. Participant "B" told me that she had "fearful ways about thinking that I was the devil or that I was doing devil things." She shared that her voices still tell her that she is "bad," but she has learned to ignore them, and to concentrate on staying positive about herself. Participant "A," who denies that he has schizophrenia even as he talked about it, told me that he had studied Scientology for a while and was told by a woman at that church that he was a "smoking demon" because he smoked. He believes to this day that this was one of the causes of his schizophrenia. If he could give up smoking cigarettes, he would be cured of schizophrenia. He has been religiously preoccupied and has preached on the street. This has led to his hospitalization more than once. It is interesting to note that one of the common symptoms of schizophrenia is "concrete thinking." Someone called him a "smoking demon," so he literally believes that he is a demon because he smokes.

As mentioned above, several of the participants felt that the lack of family support has made their schizophrenia more difficult for them to cope with. Either the loss of the parents, the breakup and divorce of the parents, or the lack of parental or family support added stress to their already fragile psyches. But two of the participants, "F" and "C," felt that they have had much support from their families, and both believe that this has also greatly contributed to their current stability. Participant "C" spoke of his mother in this way:

> My mom, like, has given me everything that I wanted...um...She will not enable me in drinking my life away. But other than that, I mean, she has given me everything that I want, and supported me in my music, and things like that...I look forward to being with my family, since...uh... I understand how much they have done for me now. They have supported me and they continue to support me.

Participant "F" spoke about his mother throughout the interview as a person who was always there for him when he needed her and who got him to the doctor when he needed to go, got him into a treatment program, and allowed him to live with her as he struggled with his first years of dealing with his schizophrenia. He says later in the interview that the support that he received from his mother and from the other people in his life really helped him to turn his life around.

Participant "G" spoke of the support of a therapist whom she has had since she was 12 years old. She believes that this person and the psychiatrist that she has now had for 29 years have been the most important sources of support and recovery in her life.

At least four of the participants talked about the influence of music, art, and reading in their lives. They described these as activities they had discovered before they were diagnosed with schizophrenia and that remain important sources of relaxation, stress relief, and enjoyment for them to the present time. Participant "C" put it this way:

> When I turned 18 and went to college, I, like, got introduced to classical music. I am really...um... gung ho for the arts in school. It really changed my life. Going to school and learning about symphonies and the instruments and the time periods, the history of jazz. It has enriched my life a lot. I am, like, really glad that the arts are there. I really support the arts, because...um... it has really had a lot of impact in my life.

The First Psychotic Episode

The ages of the participants at the first psychotic episode varied markedly. The youngest break occurred at age 11 for participant "B" and the oldest at age 23 for participant "F." Interestingly, the reasons that the participants gave for the break occurring at that time were all similar. Each of them referred to a stressful time in their lives when they seemed to break under the strain, either from family stressors, school stressors, or from a breakup with a girlfriend. Two of the participants, "C" and "D," cited drugs as part of the reason that their breaks occurred when they did.

The first psychotic episode was characterized by some sense of an alteration of reality, or a loss of a sense of reality, a loss of a sense of control, fear and confusion. Each of the participants responded to these frightening experiences by beginning to act in bizarre or frightening ways that brought attention to him/her. This behavior, in most cases, resulted in the first hospitalizations. Participants describe a period of confusion, fear, and denial about being diagnosed with a psychosis, and most refused to take the medications or treatment offered. Others were forced to do so. All have had negative hospital experiences. Their desire to stay out of the hospital appears to have been one of the most important elements in choosing to become psychiatrically stable.

The confusion and fear that surrounded the first psychotic break appears to have led to the development of delusions about this experience, either as a way to explain these events, or as a way to find meaning or protection in them.

Precipitating Stressors and the First Psychotic Episode

Each of the participants described stressors occurring in their lives at the time of the first break. Participant "B," as mentioned above, had her first psychotic break when she was 11, at the time of her parents' breakup. Participant "G" was experiencing abuse from her father at the time of her first break and hospitalization. Participant "A," had lost his parents and had just moved to live with another aunt at the time of his first break. Participants "C" and "E" were in college, and "F" had recently finished college. Participant "C" described it this way:

> Things were like really bad. My dad was...uh... hounding me to graduate. And...uh... I was not going to graduate on time. It was the last semester that he was going to pay for school. I,...uh... I flunked my harmony class, and I couldn't get any dates.

Participant "F," also describing his first psychotic episode, talked about the symptoms that he began experiencing in college. He went to see a psychologist, but quit because he did not think it was helping him. He said he gradually began to detach from reality over a period of months and then soon after had his first break: "Well, at that age, people are going through a lot of things, and it is hard to tell what is normal and abnormal, but I was getting into spirituality and meditation...when it finally happened."

Participant "E," who was on scholarship at university, had his first break while he was a student. As a result, he was unable to finish his degree, a source of sadness for him to this time:

> I was accepted [to the university], and I stayed on campus (he sighs). I was...um... walking down the street, and the next thing I knew, I was in the hospital...I...uh...I was disqualified [from graduating] two or three times. I went to college, and I was just going to classes and doing the work. I was just there to occupy my life...(he sighs).

Later he talks about the anger he feels about this: "Why can't I just be like them? Why can't I do that? Why can't I finish college?"

Participant "D," who had been in a gang and was heavily into drugs, both selling and using, described his first psychotic break this way:

> ...there...um... was an incident that happened to me when I was on my way back from Sacramento. It was...um... in October. I got paranoid. All these trucks and all these cars had their headlights on. I didn't know if they were the Hell's Angels or the Mafia or the Ku Klux Klan...(he coughs). I thought they were trying to run me off the road. At my exit, they...um... started to speed up, so I started to speed up. I was doing 80 when I hit a guardrail on the off-ramp...That is...um... when I first started hearing voices (he coughs).

Descriptions of the First Psychotic Episode

Some of the participants' descriptions of their first break were quite vivid and conveyed the sense of confusion and fear that they felt. Participants "C," "D," and "F" were able to describe them in detail. "A," "B," and "E" were only able to describe it briefly. The communication difficulties that "A" and "B" experience make it difficult for them to describe their experiences. "E" shared that he remembered very little about it. Participant "G" gave only a brief description. All of them described it as a negative experience, ending in hospitalization. Participants "C" and "F" described the first break as similar to Jim Carry's experience in the movie, *The Truman Show* (Pleshette & Weir, 1999). Participant "F" described his experience of thought broadcasting and ideas of reference as follows:

...um...The best movie I have ever seen that shows what the experience is like is the "Truman Show." Jim Carrey with cameras everywhere and everybody is watching him, and that is what it is like. All the...um... paranoia that he was having is justified. In schizophrenia, you think that people can read your mind, or,...uh... something happens and people know what is happening in your mind, but they are not letting on. That is what the experience of paranoia is in paranoid schizophrenia. The wind blows and whatever happens is a sign. You...um... imagine that you are in a fish bowl and everybody knows everything about you.

He goes on to describe his first break in a similarly vivid way:

...I was at this community, and I just.... started to have the symptom of having special meaning in signs. I...um... don't know what you call it, but I would see a bird, and I would...um... think it had a special meaning for me, and everything was like giving me a sign, you know, and I was making all these connections between things. I was getting more and more out of control, and finally, I just, you know, kind of blew out, and they...um... had to remove me from the community. I had this confrontation with this guy, and my energy was just...um... really intense with things going on. I remember the bus ride home, and my brain felt, you know, like it had been to the moon, and I felt like I was in a decompression chamber, and my whole energy felt very strange. I was...um...

> doing things like running through the property up there. I was freaking out and I was really scared.

Participant "C" described his first break similarly in reference to *The Truman Show* (Pleshette & Weir, 1999):

> It was like the "Truman Show." Have you seen that? Jim Carrey is a genius. He totally got the whole idea down. I...uh... thought everyone was like plotting against me, they could read my mind and they knew how much hair I had on my head, that's how smart people were.

Other descriptions were equally scary, such as the following description of his auditory hallucinations and his delusions of grandeur by Participant "D":

> I...um... thought it was the voice of God, and the voices were so overwhelming sometimes that I had to follow, because I became afraid sometimes and I feared for my life...I was...um... lonely at the time. I was having delusions of grandeur, and I thought I was a CIA operative, and I was going on missions. I...uh... went to a powerhouse. It was all mixed up. It took a while,... but I was using all my credit to...um... finance my travel, and I was also buying clothing because that is what the voices were telling me to do. I was really, I mean, I was gung ho because I was accepted into the CIA and I thought that was a really noble position...I...uh... would hear voices in the Bible that would tell me to do what was right, and I did everything that was right (he coughs).

The First Hospitalization

It is interesting to note that participants "D" and "F" were not hospitalized following the first psychotic episode, and continued to struggle without medications or treatment for some time following this experience. The other participants, who did not really remember much about their first break, remember their first hospitalization much more clearly. They all describe an experience of being suddenly picked up out of nowhere and put into a hospital. Participant "A" described his experience this way:

> I wanted to preach the gospel, and I was preaching at a hotel, and the next thing I knew, they had me in seclusion...I started preaching the gospel in this place, and they took my Bible away from me and threw me in a room with just a (he mumbles), I said a mattress on the floor, and I don't remember...uh... too much after that.

Participant "E" described it similarly:

> I...um.... don't remember how I got to the hospital, but... Anyway, they told me at the hospital that I would have to take medication for the rest of my life. I...uh... think it was Mellaril. I decided that I didn't like that idea (he sighs), so when they let me out on pass, I decided to just walk home.

Participant "G" spoke only briefly about her hospitalizations in terms of not wanting to spend her life in hospitals as the chief reason for her recovery. Participant "B," as cited above, simply states that after her mother died, she was sent to the state hospital, and that is how she lost her family.

Those who remembered the first break well spoke of the hospital experience. For participant "F," it was both a relief and very frightening:

> So...um... they took me in, and in this hospital you couldn't be outside, and I was indoors for 24 hours, and I stayed there for about a week, and I felt very cared for.... But one thing that happened was that when they tried to get me to take a shower, I...um... refused to take a shower because I believed that the room where the shower was, I would be like locked up. That is how bad the delusions were. So they started chasing me, and I was busily running away from them. They finally caught me, and...um... gave me a shot and put me in five–point restraints. I think I was, you know, out of it for a while.

The Development of Delusions

All of the participants shared with me their delusions, many of which occurred during or after the first psychotic break. I was able to ask some of them about these delusions and the function they serve in their lives. They all described their delusions as serving as a way to explain their experience, as a protection against loss of self-esteem and as a protection against their fears. Four of the participants described delusions of grandeur. Participant "B" believed, and continues to believe, that she is the daughter of a famous singer. Participant "E" believed that he was a top mathematician and shared with me that he sometimes still struggles with that delusion. Participant "F" believed that he was also a top mathematician and, at one point, that he was St. Francis.

Participant "D" continues to struggle with the delusion that he is a messiah figure, sent to save the world. Participant "G" shared with me that she believes from time to time that she can fly. She told me that it is to help her escape from all of the emotional and psychological pain she has had to face in her life. Participant "A" believes that he is a great preacher, and Participant "C" believes that everyone he knows can still read his mind, but instead of plotting against him, they are now plotting for him. It is noteworthy that the quality of the delusion of participant "G" is different from those of the others; she is the participant who is diagnosed with undifferentiated schizophrenia. Her delusion is an avenue of escape from pain. The others have delusions of grandeur that offer an escape from the fear and sense of helplessness that they experience. Her description of the purpose of delusions is also different. She conceives of her delusional system as a protection:

> I think they protect you. I have had a protector since I was a child. Eventually, I have had both auditory and visual hallucinations of him. He is...uh... two feet tall, and he shrinks to six inches when he is angry. He is in the Navy, and he is a lawyer, and...uh... a doctor, and he can fly. He goes all over the world and helps children. He comes and tells me stories. When I...uh... was 8, I wrote a poem about him. It goes: "I have a little brain tucked safely in my head and another little brain that is in the air instead. This one plays with me and talks with me in bed, the other one confuses me, the one that is in my head." He is just...um... my protector.

> But...um... I get into trouble, because when I am decompensated, I think I can fly, and I have gotten hurt a few times very badly. When I am decompensated, my voices become very derogatory, and it is very difficult for me. But everybody has one delusion, that we are not going to die, and if, and if we did not have that delusion, we would not be able to function. So you see that some delusions are helpful to us.

Participant "E" was also able to talk about the function of delusions, and his delusional system is more typical of people who struggle with Paranoid Schizophrenia:

> I think delusions are...um... the result of helpless aggression. I have often felt helpless in my life: what can I do about this world; what...um... can I do about finishing college, which I never did; what can I do about being a great chess player, which I never did...I feel that I am helpless. I think the delusions that I am a great this or that, I think temporarily alleviates some of the helplessness and most of the fear (he sighs). I think that is the function of the delusions.

The function of the delusions, as my participants described it, is either to protect them from emotional and psychological pain, or to protect their self-esteem, or to explain their experience, as participant "D" has tried to do, struggling to explain his experience as real events.

Experiencing and Conceptualizing Ongoing Symptoms

The participants all described to me, in various ways, a period of time after their first psychotic experience, after their first hospitalization and even to the present time, in which they continue to deny that their experiences were an indication to those around them that they are "ill." Participant "A" described to me an experience shortly after his first hospitalization in which a police officer took him to the hospital. He recalls that the officer told him that he was "normal" and that he did not need medications. It was clear to me as I listened to him that, although his logic is not clear, his desire to avoid and deny the severity of his mental illness is. He continues to the present time, 36 years later, to struggle with this issue. He goes on to tell me in the next sentence that he goes to the doctor and gets medications, but throughout the interview, he says he does not have schizophrenia, even as he talks about it. The same is true for participant "D," who talks at one time about being in the hospital and taking medications and later talks about his delusions that he is a messiah figure, denying that he has schizophrenia. Participant "E" recognizes his delusions as delusions, as quoted above, but he also told me that he sometimes still believes his delusions. At those times, he denies that he has schizophrenia. All participants described the various ways they still experience symptoms and the strategies, including delusions and drug/alcohol use that they have used to cope with these experiences.

Most of the participants shared with me that they refused to take medications at some points since their symptoms began and were hospitalized again, sometimes many times. Participants "B", "C," and "F" told me that they did not take their medications regularly for a long time, because they did not want to believe that they had a mental illness. "E" did not take his medications, because the doctors he saw did not initially tell him why he had to take medications. "G" indicated that she went on and off medications when she was younger. The ongoing symptoms that they experienced led to loss of jobs, of schooling, of living arrangements, of friends, of family support – a spiral into isolation, loss of self-esteem, and finally loss of hope.

For participants "B," "C," "E," and "F," such an accumulation of loss became a turning point at which they made a choice to learn about their condition, accept medication, use the support of those around them, and begin to rebuild their lives. They began to understand their experience as indicating an "illness" (accepting the definition provided to them). "G," who has had the close support of a therapist and a psychiatrist since she was a teenager, never lost quite as much as the others. She has certainly struggled to overcome the limitations placed on her by her condition, including the loss of her marriage, the loss of jobs, and the lack of respect from other professionals. These limitations appear to be due more to her lack of acceptance by others than to her own lack of acceptance of her condition.

Two participants continue to struggle with medication compliance. Participant "A" told me that he does not always take his medications because he does not believe that he has schizophrenia. This is true also for participant "D."

What I learned from them, and this fits with my clinical experience of people living with schizophrenia, is that medication compliance is closely related to the understanding and acceptance of schizophrenia as an illness. This awareness and acceptance of the experience of psychosis as a physical illness provides the understanding of why medication compliance may be necessary. In my sample, "A" and "D" do not fully understand that their symptoms are evidence of an ongoing condition which must be treated daily. As a result, they do not always take their medications regularly. "B," "E," and "G" continue to experience symptoms, even though they do take their medications regularly. They told me, however, that the medications help reduce the symptoms they experience, especially auditory hallucinations.

Denial: Running Away from the Problem

All of the participants have been through a period of trying to deal with their symptoms by denying that their experience was evidence of an illness. As indicated above, "A" and "D" continue to do so to some extent. Both continue to think of their symptoms in a positive way (special powers), while at the same time they struggle with the idea that the events of their experience are untrue, false, signs of an illness, and remain confused in their thinking about this issue. When they do talk about their schizophrenia, "A" and "D" both describe it as a punishment for earlier sins.

The other participants shared that they too did not want to believe that they were ill, nor did they want to be labeled as persons who could never get well. They resisted the rejection and loss of respect implied by a diagnosis that is accompanied by imputations of being "crazy" and incompetent.

"B," "C," and "D" talked at length about using drugs and alcohol to avoid dealing with problems they were encountering as a result of their symptoms, and as a way to deny the existence of an ongoing condition. "A" and "E" have abused alcohol in the past to escape from their problems.

Special Powers

Participant "F" shared that although his mother had taken him to a psychiatrist after his second psychotic episode:

> I...uh... refused to admit that I had a mental illness. The psychiatrist recommended that I take medication, but I refused. I was into this vegetarian thing, and I...um... did not want to put any substances in my body, but the truth is that...um... I did not want to admit that I had a mental illness, so I was like in really big denial.

In fact, it was not until after his third psychotic episode that he was finally hospitalized and his denial confronted by such experiences as being asked to leave a second community where he had been living and losing his job. During this time, he was hearing voices and acting in very bizarre ways. He described it as similar to being on a "non-stop LSD trip," which he perceived in terms of special powers, as he here describes:

> There were....uh... voices right before my hospitalization. I was hearing voices of people that I knew, so I, I...uh... thought that I was in telepathic communication with all these people, and I would

> hear their voices, and I would think, "Yes, that's what I am going to do." It was...um... like a big adventure, and I was being guided by these people; sort of like a scavenger hunt going from point A to point B (he laughs softly).

Participant "D," who believed that he worked for the CIA, shared that he now knows that this is not true, but he still struggles with the belief that the voices he hears are from God and that he has special powers to help the world:

> I...um... also believe that certain people are chosen to have gifts, and suffer a curse... I...um... believe that all the factors that are involved in my life, the way my family is, the people I have met on my jobs, and my friends, I was given a secret to be honored. I believe that I am the first of my country to bring the Philippines and the United States, the first to say that we must return to the land of our mothers and fathers to feed the poor.

Participant "E" relates ongoing struggles with his delusion of having special powers:

> Every once in a while, I...uh... have to struggle with the delusion that I am a great karate person. I'm not, but every once in a while, I...uh... I have to struggle with that idea... Another struggle I have is the delusion that I am a great mathematician, which I am not.

Participant "A," who loves to preach, told me that he describes himself as a "theologian and a scientist, and I like politics." He says that he talks to God a lot about the power of the Holy Ghost, and sometimes he prophesies in church.

Escape into Drugs and Alcohol

The three participants who abused drugs and alcohol talked about their use of these substances as a way to either escape or explain away their symptoms. Participant "B" describes using drugs and alcohol to escape from her schizophrenia:

> Before I found out that I had schizophrenia, my relationships were negative-positive, but then [after she found out about her illness] it went down to drugs and alcohol, and it went straight down to negative. I turned around and collapsed with drugs and alcohol, and then, when it got to my mind and thoughts that schizophrenia was affecting me, I felt positive about going to the doctors...

Although her use of language is awkward, her meaning is clear. She began to use drugs and alcohol after her diagnosis to deal with the shame and failure that she experienced. It was not until she could begin to see that her schizophrenia was the condition affecting her mind, and the source of some of her difficulties, that she could begin to accept treatment.

Participant "C" spoke about struggling to be "open and honest" about his mental illness. He used speed as a way to cover his symptoms and to explain his bizarre behavior:

> When...um... I was using, I couldn't be honest. "Oh, yeah, I used speed the other night, and I am on speed now." You can't be honest; you have to like lie and make excuses, then you have to tell more lies, and then...uh... you can't tell what is true yourself.

Participant "D," who still struggles with his belief that he is a messiah figure, used drugs to both enhance his perceived supernormal powers and to escape from the realization that he was ill. He spoke vividly of this struggle over a period of years:

> I made a lot of...um... assumptions, and I believed that I was getting divine inspiration by reading the Bible, but I (cough) realized that the Devil was making these things up, and I felt like I had to battle him on his ground, and that is why I...um... took methamphetamines.

Being Punished

The three participants, "A," "B," and "D," who still struggle the most with their delusions, told me that they believe that they have been given the burden of schizophrenia because they have been "bad" and are therefore suffering schizophrenia as a punishment.

"A," whose wife and child left him many years ago after he "slapped her," regrets this action. He spoke about it several times. In his concrete thinking, he told me that he believes that this action is the precipitating factor, along with his smoking, that caused his schizophrenia. He believes that God (through his auditory hallucinations) has told him to quit smoking cigarettes, and because he does not, he continues to suffer with schizophrenia. He believes that had he not hit his wife, he would be walking "on a straight path," not having to struggle with his illness. He believes that the cure for his illness is giving up cigarettes and making amends to his wife (referring to his sense of being cursed as a "smoking demon"). I asked him what caused his schizophrenia, and he replied: "My wife. Getting a divorce and losing an eight-month old girl." Later, after he again tells me that he does not have Paranoid Schizophrenia, he tells me, "If I could just get rid of smoking, I think everything would be all right" (implying that he would no longer have schizophrenia).

Participant "B" believes that she has schizophrenia because she is "homosexual," although she described this more as sexual-identity confusion. She continues to wonder whether or not she would have schizophrenia if she had not been given this burden. She explained to me that she has always struggled with confusion about whether she is a male or a female and the stress of this confusion was partially the cause of her mental illness. She labels this sexual-identity confusion as a "disability":

> My growing up, knowing that I had a disability... I went into mental collapse [schizophrenia]... My disability was homosexual. I know it was [the cause of her schizophrenia]... But I would say that if I am a man or if I am a female, put it on paper, and show me who I was – don't walk around without the truth of your life.

Participant "D," who continues to struggle with his belief that his schizophrenia is a "curse," vacillates between understanding that he has an illness and believing that it is the will of God that he carry the burden of schizophrenia to make up for his past and to help save the United States in some way, as quoted previously.

Ongoing Struggles and Loss

As their symptoms continued over a period of years, along with consequent hospitalizations, each of the participants experienced ongoing losses in their lives: they lost time; they lost their place in the world, friends, family, living arrangements, the respect of others, their own self-respect, and finally hope. An accumulation of losses seemed to affect the determination to make changes and to improve the quality of their lives.

Ongoing Symptoms: Experiencing the Voices

Each of the participants shared with me the content of their auditory hallucinations, most, although not all, of which, are derogatory and frightening, some commanding a response. All have struggled with how to deal with these voices. "A" and "D" are still very much engaged with and continue to respond to their voices. "B," "E," and "G" continue to hear voices but respond only to those voices that are positive, that help them to stay stable. "C" and "F" only hear voices intermittently and try to ignore them. At the beginning, however, the participants did not know how to cope with this phenomenon, and it affected their lives in negative ways.

Participant "A," who remains very engaged with his voices, told me that he preached on the streets because he hears voices, but that people have given him a "hard time" about it, and the police have come by and taken him to the hospital, and one time to jail, for this activity: "The cops picked me up and arrested me. I also got picked up for preaching the gospel. They took me to jail." He continues to struggle with his voices:

> I feel like people are threatening my life from my voices. I talk back to my voices. A lot of people say things to you and you can't see them and you are scared. That is being paranoid...I answer their questions...They are always (mumbles) aggressive. I can't have no peace with them. That's why I smoke. [It helps with the voices.]

Participant "D" described struggling with his voices over a several year period:

> I heard voices...um... telling me to go to church, because that was the only thing that would save me. I was thinking before that these people might try to hurt my family.... I was just thinking about myself... So I...um... did what they told me, and I turned my life around. I thought it was the voice of God, and the voices were so overwhelming sometimes that I had to follow, because I become afraid sometimes, and I...um... fear for my life.

He continues to struggle with whether or not to respond to them:

> I am trying to maintain balance now. Before it used to be one or the other, God or the Devil, and now I understand that I am living in a gray area...I am working on myself and I have friends.

In my next interview with him, he tells me that he still hears the voices telling him that he "was put in this nation to suffer a coma and to suffer a death." Though he continues to vacillate between seeing himself as a person who has been directed to save others and a person who has to stay in a "gray area," he reiterates that he has begun to believe that he can "gain more power over the voices and they will cease to afflict me. I feel that I have a choice."

"C," who hears voices only intermittently now, described a period of time, early in his illness when they overwhelmed him, and he tried to meet their demands:

> Oh, they used to like call me stupid, and call me all these racial names. They told me...um... to clean this and clean that, crawl on the floor and lick things, eat out of garbage cans, jump into Lake Merritt, put my head in the toilet and flush it, telling me to drink urine, lick things off the floor... I thought if I didn't do those things, I...um... would be raped by these black men.

"F's" voices were once frightening to him. He now knows that these are his own thoughts, but at one time, he believed what he was hearing and thinking:

> What finally happened that time is that, is that I finally disrobed in public. I was...um... having thoughts that I was going to cause this massive destruction. I was like having really violent thoughts.
>
> That happened again two years later, and I was...um... having, you know, thoughts that I had this sword, and that I was just killing and killing.

"B," "E," and "G" did not describe their voices in detail, except to say that the voices tell them that they are bad or that they are failures, and "B" still hears command hallucinations telling her to go back to doing self-destructive behaviors, such as non-compliance with medications or using drugs and alcohol again or engaging in self-destructive relationships. She shared that it was years of struggle with these controlling voices before she could begin to comply with her medications enough for her to begin to ignore them.

"F" explained why reality testing is so difficult: "The thing that you are using to evaluate your experience is the thing that is affected by the illness, so your judgment is really compromised." Thus, he acknowledges that schizophrenia affects a person's ability to distinguish what is real from what is not.

Hospitalizations

All of the seven participants have been hospitalized more than one time, several of them numerous times. Their hospital experiences have not all been negative, but all say that they do not want to go back to the hospital again if they can avoid it. "F," the most articulate about his experience, explained that his hospital experience, although he felt "very cared for," was still frightening. It was this experience, however, that convinced him that he had a mental illness:

> So they...um... took me in, and in this hospital you couldn't be outside, and I was indoors for 24 hours, and I stayed there for about a week, and I felt very cared for...and that is when I thought, "Okay, I have a mental illness," and the denial didn't last after that...I know a lot of people even after they get hospitalized still...um... are in denial, but I think I knew that I had something wrong.

Admitting that something was "wrong" with them was difficult for all the participants. They know the labels, they know the stereotypes, they know what this implies about them and their lives, and they were afraid to face it for a long time. "F" said that, when a psychiatrist told him he would have to take medications:

> I, I thought of the stigma. I think if, I mean, I think if mental illness was considered like any other illness, I think that I would not have felt so bad about it, and it would have...um... been easier to accept treatment... A few days before I got hospitalized, I drove by a hospital, and I thought, "maybe I should go in there," but then I...um... thought, "No," so I guess that I began to recognize that something was wrong.

When he was placed in treatment, he did not want to be with other people with mental illness or be identified with them:

> I did not want to go, and I was...um... not used to the population, and I was, you know, really put off by that, and it was really intense, but I agreed to try it, and that was...uh... when I really began to get things back together again.

"E," at one point, described hospitalizations as benign:

> I was in several state hospitals. I wouldn't say that I got bad treatment, but I would say that most of the time I got no treatment. I just...uh... watched television and ate, and they had dances at night that I went to, and I really feel that I received non-treatment.

> We got medication, and we were...um... allowed to be in the hospital until they felt we were ready to go back into society. But I would not say that I received bad treatment... Some of the things that people told me in the hospital were, were just ludicrous, but...um... people are just people, and they were just doing their jobs.

He also described, however, one hospitalization during which he received electro-convulsive therapy (ECT) treatments. These treatments, once common for schizophrenia, now no longer used, were both frightening and dangerous. I can only imagine the sense of powerlessness, helplessness, fear, and intrusion that he must have felt:

> Well, it is very different now, but in those days, they put a tongue depressor in your mouth so you wouldn't swallow or bite your tongue. It was very difficult. They sent the electricity through you, and you started shivering and shaking, and then...um... you lost consciousness. It is much less painful now. But they electrocuted me 20 times.

"A," who has been in and out of hospitals for the last 36 years, described his experience as "short stays" in hospitals, but added, "I spent what felt like a lifetime in hospitals, maybe a total of two years." He said that he did not like going to hospitals. "A" made comments throughout the interviews about wanting to stay out of the hospital so that he can be "normal." Thus he seems to associate the hospital itself as a source of his condition.

"C," who recently went to the hospital voluntarily to have his medications adjusted, says, in the first interview, that he liked some of his hospitalizations. However, in the second interview, he told me the reason that he takes his medications faithfully each day now is that every time he was involuntarily hospitalized in the past, he had either been asked to leave school, lost his apartment, used drugs, or all of the above. He does not want that to happen to him again.

"B" talked about her experiences in the hospital as varied. She was in a state hospital as a child, and due to her chaotic living situation before and after hospitalization, she saw this experience as providing safety, security, and structure. Her later experiences in the hospital were not so positive. Now, she takes her medications every day, and stays away from drugs and alcohol so that she can stay out of the hospital. For her, too, hospitalization is associated with losing all that she has gained.

"D" spoke only briefly about his hospitalizations: "Every time I feel like I am going to die, my father is stoic, like he knows that nothing will happen to me, even though I am scared out of my wits. So I go to the hospital." He implies that he cannot at that moment distinguish reality from paranoia, but he trusts his father to help him deal with his fear, and to support him in going to the hospital.

"G," on the other hand, began very early to avoid going into hospital. "When I was a teenager, and I was in and out of hospitals, I decided that this is really what I did not want to do with my life. I decided to do something different with my life..." She proceeded to work with her illness instead of fighting it. This attitude spurred her into completing her education and dedicating her life to working with people with mental illness.

Stigma

All of the participants have encountered stigma at one time or another and described it in various ways. I have included the experience of feeling isolated within this category when it is spoken of as being "shunned" or "cast out," or when this is implied.

"F" seemed to speak the most clearly about this subject. He has felt stigma most strongly at work. He works as a "peer counselor," and explained to me that he hopes that they will change his title to "peer advocate" because, "when I go to see a professional person on behalf of our clients, they don't trust me when I say that I am a 'peer counselor'." Later, he explained to me that when he goes out with co-workers, he does not tell them that he does not drink because "the stigma (even with people in the mental health field) is a daily experience." He believes that if he revealed that he did not drink, that might cue his co-workers to the fact that he has a mental illness, and he fears that they would lose respect for him if they knew he was a consumer. He continues:

> They are trying to open up a new mental health center not far from where I work, and I...uh... went to a city council meeting, and, and although the people are careful about what they say, you...uh... get the idea that they don't want these people in their neighborhood. The other problem is the internalized stigma, which is also one of the hardest things to deal with. It is dealing with the self-esteem

> issues. When you think about schizophrenia, you, you get this very strong message that you are...um... not a full person, that you are compromised, that you are, you know, defective in some way, there is something wrong with you. Part of overcoming that is the internal work of knowing that a lot of people have to deal with self-esteem issues, and that this is just another part of it, but it is... um... very difficult.

Because of stigma, many people who have mental illness, such as "F," are afraid to "come out" about it for fear that their community will no longer respect them. "G," who describes the difficulties that she has encountered in school and in the work place, talked passionately about her belief that people with schizophrenia want what everyone else wants but that those around them do not believe that people like her can manage these responsibilities:

> They want all the things that any normal person wants – a job, a house, a relationship, and a car. People don't see that, or hear it, or the people who work with them don't believe that they can do it. There are people out there who have...um... major mental illnesses, and they won't come out and say that they are making it, and who could be inspirational to others.

"G" went on to tell me about her own decision to "go public" with her mental illness and to begin to tell her story publicly:

> I had some hard times with jobs, because I lost jobs due to my mental illness, and symptoms, but anyway, I looked at it as a

> learning experience, and I...uh... learned to keep my thoughts and keep my voices in the background, like a radio, and I just ignore them... So I got an internship, but when the director [of her program] found out I had a mental illness, she...uh... did everything she could do to make me quit. She was awful; awful to me... I decided about 10 years ago to come out publicly with my illness... but anyway I guess I did not want to hide what I am. This is not to say that I am a schizophrenic person. I am a person with schizophrenia, and I am a person first.

She also talked about the stigma she encountered when she tried to get pregnant:

> What was stigmatizing about that was that, when I went to see a doctor to find out why I could not get pregnant, I told him that I was on Thorazine. He said, "Well, I don't want you to have a child, and I am not going to help you because you are schizophrenic, and you are not capable of raising a child."

When she tried to finish her Ph.D., she encountered more stigma:

> When I decided that I wanted to get a Ph.D. in psychology, that was very hard, because...uh... there are a lot of professors who were dead set against consumers treating other consumers, even though they all recognized that AA was a good program. So I had a lot of professionals who were very...uh... stigmatizing, even worse than the general public.

The other participants talked less articulately about stigma, but it was often implied in what they said. “A” implies stigma when he talks about wanting to be “normal.” After he told me about the police officer who had taken him to the hospital and told him that he was “normal” and that there was nothing “wrong” with him, he goes on, later in the interview, to tell me that he does not want to be at his treatment program because he is not doing “normal” things that other people can do, like paying his own bills, which are paid for him by his case manager. He told me that he “should be doing that.” He says that he does not have schizophrenia; he has “depression” – a label less stigmatizing. He talked about his wanting to be “like” other people and feeling angry that he doesn’t have what other people have: “When I walk on the street, minding my own business, I’ll be looking at people, and when they call you schizophrenic, that’s bad.”

“D” also implies stigma, but very indirectly. He did talk about ”separation” from his family and friends, having resentments about having schizophrenia, seeing it as a punishment, and that he has been angry with God at times for giving him the burden of schizophrenia:

> I believed that when I...um... was in high school, that my friends and I would support each other to be better citizens...I feel [now] they are a threat to me... I have resentments... about having schizophrenia... I believe that it...um... serves this function [punishment]... I have been mad at Him sometimes.

However, each time I asked him about subjects related to his feelings of being different or isolated, he would become very grandiose, talking about being "chosen" by God to "fix" the world, or having a "secret to be honored" as a person whose mission is to "feed the poor." He used his delusions of grandeur as a protection against talking about his real situation in a residential treatment program, where he is trying to stabilize and learn about his dual diagnosis. His life has been chaotic and unstable, in and out of hospitals for the last nine years. It appears that either he has not encountered as much stigma as the others have, or else he has not yet begun to deal with it.

"B" was also indirect about stigma, but it was implied in much that she said regarding feeling different and shut out. Since she started hearing voices when she was three years old, she always felt "different" from everyone else in her family. She knows that other people "don't understand" what she "goes through every day," and she also continues to feel alienated from her family: "I asked my father, after he had a couple of drinks, 'why do you call me angel, and you still won't give me your telephone number, and you make me feel like I have to get out of the family?'" "E" also has felt stigmatized within his family:

> They relate to me much better, now that...um... my life is sort of in check... I have the idea that when...um... I was in the throes of mental illness, they really didn't want any contact with me. Nowadays, I think they...uh... want more contact with me. I don't hold that against them, and I...uh... I am not saying anything derogatory, but when I was living in that paranoid world, they did not want contact with me so much.

The following reveals stigma that “E” has felt at work. Although he was hired as a mental health consumer to work with other mental health consumers, he is senses some prejudice or judgment about him on the part of his coworkers:

> So, maybe even though I am...uh... a consumer, something about me that makes some of the people here wish that I would just crawl off somewhere and go away (he looks down).

“C’s” family seems to have supported him in his efforts to cope with his mental illness, but he has encountered stigma elsewhere. He talked about the girlfriend whom he was with when he had his first hospitalization:

> Well, the girl I had [at the time]... even though [she said] it was about the drugs, it was the schizophrenia. She couldn’t handle it. She did not know like how to handle it... A lot of people think that like people with schizophrenia are less intelligent... One of my friends told me that my disabled bus pass is a “retard card” (he laughs).

Loss

Each of the participants spoke with me about the losses in their lives. As they told about these experiences, there often was a note of sadness and/or anger at having to have experienced these losses. Many of them described an experience of reaching a low point, where they had nothing left, including hope, but it was here that they found the determination to change their lives and to try to find a way to cope with this difficult illness.

Again, it is "F" who describes his lowest point the most vividly. He had, as mentioned earlier, lost his job, and was staying alone in his apartment, just existing:

> It was really intense. I was...uh... going with it, but it was a pretty demanding experience to go through. I was like being on 24 hours a day. It was like being on stage all the time... It is like being in a fog. My mother's boyfriend talked about my recovery as going from the dead to the living. I think that is pretty accurate. It is like being the walking dead, existing without really existing... I...uh... remember at the beginning that I was in an enforced silence, and I, I didn't have my voice. I was having all these intense feelings, but I couldn't express them.

"E" also described his losses vividly as he struggled with his illness. He continues to struggle with loneliness, and feels very sad that he has never had an enduring relationship with a woman. Before he became psychiatrically stable, he had lost his scholarship to university, his family did not want contact with him, he had been homeless, starving, and without a job for many years. He had been in and out of hospitals and board and care homes. His life was filled with a sense of failure, of lost dreams, of hopelessness:

> All the bad things that have happened in my life, starvation, living on the streets, and I starved for 30 days once, but then I picked a fight with the police, and they took me to jail and gave me some meals, and it saved my life, because it gave me the strength to go

> on for another 15 days [until he got his next SSI check]... I just didn't have enough money. Back then, the social security was very small, and it was very hard to live on. I ended up lots of times without an address, and I had to have an address for my social security and I had to pay the money for a hotel room.... That is why...uh... I have trouble with my weight now...

The other participants also reflected on the losses they have had over the years. "A" has lost most of his family, who have died. His wife divorced him 30 years ago. His life has been in and out of hospitals, and although he worked for a while, he has not had a job in many years, and he would like very much to be employed again. He described his current life as lonely and somewhat boring, but he seems to have only a vague understanding about what has happened to him: "I don't know what happened to me. I don't know how to get over it. I don't know how to recover from it. I want to recover from it."

"D" talked mostly about losing relationships in his life. He has lost his girlfriend, he seems to be estranged from his family, he has lost his old friends who are still using, and he lost his job and talked in a very sad way about his life. He is, as previously mentioned, in a residential dual diagnosis treatment program. He is working on trying to rebuild his life: "I am trying to maintain balance now."

"B," who has been in and out of hospitals since she was 11 years old, talked about her current stability and the losses she has endured, including the loss of her child, who was removed from her care when he was a year old:

> I have worked hard for this.... I was in state hospitals since 1972. I have been in independent living, I have been in transitional housing, and I have been in shelters. I have been in rescue missions. I have been treated for my disease of schizophrenia and diabetes. I have had a change of attitude from going to AA to take medications for my schizophrenia and for my diabetes.

"C" talked about his losses before he was able to face his illness. He had been unable to finish college, and had left three college programs. He had lost friends, his family did not want much contact with him because of his drug use, and he had lost his apartment. He was living at a transient hotel and finally reached a low point, when he felt as if his life could not get much worse:

> I got really crazy. I was like, "Screw my family, screw everybody! I am going to live in the streets." And I took myself to the streets, and I broke into this one house, and I opened the refrigerator looking for food, and there wasn't any, so I left. Then it...uh... started raining, and I had wet clothes, so I took them off, and I, and I crawled into a dumpster, and like, ten minutes later, this...uh... guy opened the dumpster and called 911. And they 5150'd me. I had all sorts of things when I went to the hospital. I started eating out of the garbage and licking things off the floor (he laughs). I don't know why. I think I did it just for punishment. [Because he was afraid of what the voices told him would happen if he did not do these things.]

"G," too, talked about the losses she has suffered, although not in such graphic detail. She talked about the loss of her marriage, and the loss of jobs she has suffered because of her illness:

> When my children were 4 years and 2 years old, my ex-husband left. I was working full time, and trying to finish school. I started sleeping every other night, because I could not write when they were up, so I stayed up every other night to write while they were sleeping.

Rebuilding a Life and Finding Hope

I asked each of the participants what they thought enabled them to begin rebuilding their lives. Although "A" and "D" could not really talk about this in the same way as the others, they had clear ideas about what they thought they need to do in order to stay out of the hospital, or out of jail. "A" described it as staying "on the right path." For him, this is listening to his doctor and his case manager, taking his medications, at least most of the time, and coming to his treatment program every day. "D" knows that he needs to take his medications every day, stay in his program, and stay away from drugs, so that he can begin to rebuild his life. Although they remain ambivalent about whether or not to comply with these treatment strategies in order to stay stable, they know from experience that following this regimen will help them stay "balanced," as "D" put it, and out of the hospital. But they also seem to have less faith and hope in their ability to regain control of their lives than the others. It is my experience as a clinician that this is a common experience for many people living with schizophrenia.

The other participants seem to be at a different level of awareness and acceptance of their condition, describing it as an illness that can be treated in part by help from others (treatment) and in part by managing their symptoms. Though their symptoms continue, they appear to have an awareness of these experiences as such and thus become less overwhelmed and overpower by them. The process of coming to acceptance is going on to some degree for all participants and appears to begin with some sense of finding hope by becoming responsible for their lives.

This theme of rebuilding a life and finding hope will be described within three categories: Taking Back Control; Elements of Regaining Control; and Cure or Ongoing Symptom Management.

Taking Back Control

Because the participants in this study have at times felt helpless and dependent, with their lives in the hands of others, taking back control seems an appropriate phrase. This section describes what it appears to take in order to begin the process of recognizing their condition and rebuilding their lives.

At the least, all participants are aware that, in order to stay out of the hospital and out of jail, they have to take some responsibility for their behavior. This remains confusing for “A” and “D,” who feel they have so little control over what happens to them, though, on some level, they both recognize the relationship between their experience of symptoms, their response to it, and the consequences that ensue if they act on those experiences. They have come to recognize and accept, if only intermittently, the need for medications and the need to listen to those persons they feel they can trust to help them. This is the most basic level of acceptance of responsibility for their illness. From my clinical experience, I know that the acceptance of medications alone is not enough. Schizophrenia is a condition that affects the person's sense of self. Medication may be able to ameliorate some of the symptoms, but this condition affects people's lives in ways that are beyond what medication alone can fix. Rebuilding a life after the loss of status, loss of the ability to be a productive person in the community, the loss of self-esteem, of self-respect, of control over one's life involves much more than medication compliance. It involves education, support, and therapeutic intervention for a person to really make strides in taking back control of his/her life.

As participants "B," "C," "E," "F," and "G" described their struggles to regain control of their lives, they described the necessity to face their fears about their symptoms, about their diagnosis, and about their futures. Beyond that they have had to learn that in order to regain control of their lives, they would have to accept help and support from others while also accepting their own limitations.

Facing Fear

Facing fear is related to dealing with the often-frightening symptoms. "A," as yet unable to manage his symptoms, continues to engage with his voices and to placate them. He smokes to control them. I have heard this in my clinical work; those who hear voices have told me that cigarettes help diminish or quiet the voices. That, apparently, is why so many people with schizophrenia smoke. Of my seven participants, only two do not smoke. "A," who suffers so much from his voices, described them as aggressive and threatening his life, gets "no peace" from them, although he tries to answer all their questions. He has not yet found a way to begin to manage the voices and face his fear of them. He does not perceive the voices as symptoms of an illness.

"D" seems more willing to face his fear, although he vacillates between describing his experience as a cosmic struggle between good and evil, in which he must play an important role, and letting go of this great burden in order to take care of himself – "be balanced." Although he talks more about his drug recovery than about his mental illness, it is a hopeful sign that he has willingly placed himself in a residential dual diagnosis treatment program. Here he may be able to come to a better understanding of the nature of his condition and learn strategies for facing his fear and controlling his symptoms. He says:

> Before...um... it used to be one or the other, God or the Devil, and now I understand that I am...um... living in a gray area. I am doing the program now, and I...um... probably won't be in a relationship during my first year of recovery. I am working on myself, and I have friends.

Others have more consciousness of their condition and the fear it engenders. "B" described how she has dealt with her fear:

> I don't fear it [the schizophrenia]. I used to fear it, and I used to run and hide, but now I don't fear it anymore. I have control of myself.... I think about the things I have accomplished and my volunteer work and my jobs, and I do think that schizophrenia is

> one step at a time. And I pray that one day, if I...um... live a long enough time, I will meet with my son.

"C" still struggles with fear engendered by his voices, which tell him that he will become a "sex slave for older men who are disabled." But he has found ways to face this fear and to cope with it:

> It freaks me out, but I am used to it...Let's put it this way. I am no longer scared that people are like plotting against me, but that they are...um... plotting for me. My delusions are just as strong as they ever were, and...um... in some ways they are stronger, and they are still there, but I am not...um... scared about it any more.

"E" explained it is his delusions which help him deal with the fear he experiences and his sense of failure:

> I have often felt helpless in my life: what can I do about this world; what can I do about finishing college, which I never did; what can I do about being a great chess player, which I never did (he clears his throat)? The highest I ever got was expert. I feel that I am helpless (he sighs). I think the delusions that I am a great this or that, I think...uh... temporarily alleviate some of the helplessness and most of the fear. When...uh... a person is afraid, they feel very weak, and if they get angry, they feel as strong as a fireball.

"F" described discovering that if he talked about his fear with someone he trusted, it really helped:

> ...It was just getting worse and worse, and scarier and scarier. Another time, I had a real live panic attack. We were walking through Golden Gate Park, and we...um... came upon a large homeless encampment, and suddenly I...uh... was triggered into this fear thing, and I felt as though I was going down a well, falling down a well, going deeper and deeper. I...uh... I was with friends who didn't know that I was having symptoms, and it was...um... just terror, abject terror, and I don't think...um... I have ever been so scared in my life. The way I got out of it was by talking about my mental illness and talking about my symptoms, about my father. It was like...uh... the courage to be able to voice the fear that I was having about discussing with a friend what I was going through. That was awesome (he laughs).

This was the first step in overcoming his fear and facing his symptoms. He goes on to talk about how he also dealt with his delusions. Like two of the other participants who have had delusions that they have extraordinary gifts or powers, he has had to learn that he is just a person with a problem that he is learning how to live with and overcome:

> I had delusional thinking. I thought I was like a top mathematician. I thought that I was all these people. I thought I was like all these spiritual figures. I don't know if I...uh... thought I was reincarnated, or just them. I don't remember all the people that I thought I was, but I remember I thought I was St. Francis. I think, you know, I

> thought at one time that I was Jesus, but I was...um... gradually able to break down the delusions by thinking that I am not Jesus, but I am St. Francis, and gradually, I was able to break them down by thinking that I am this one, but I am not that one, and gradually, I was able...uh... to realize that I am not any of them.

He goes on to talk about his first experiences in treatment:

> When I finally got on the right medications, and I was beginning to feel a little bit better, I have, you know, this memory of being with these people who were 60 years or older, and I was amazed that you could...uh... even live that long, because it was really torture when I was feeling that way. I don't know, I mean, I don't know if I thought that everybody was feeling the way that I was feeling, but I added up how bad I felt in one day, and multiplied that by 60 years, and I was amazed that anybody could live like that. I....uh... was very impressed that people could live that way. I guess because life was so painful for me to live that I...uh... thought it was the same for the other people.

"G," who has struggled with schizophrenia since she was 13, and continues to struggle to this day, describes how she has learned to face her symptoms. She continues to work hard to overcome the voices and continue to be productive in her life:

> I learned to monitor my thoughts and not blurt out inappropriate things, concentrate better. It takes a lot of work and energy, and it

> is tiresome. When I get home, I am very tired. I have developed techniques to handle stress and medications side effects, depression, and my voices.

Accepting Help

For people who have felt so powerless and stigmatized, this was a difficult part of the journey back to an effective sense of self. All of the participants have struggled with the willingness to accept help, in the form of medications, support from others, therapy, or all of the above. They talked about how hard this was for them to do, both because their thinking was so badly disturbed that they could not see they needed help, or because the help they were offered seemed punitive, shameful, or unhelpful.

"A" has a good relationship with his psychiatrist, whom he seems to trust. Even though he does not want to take medications, because he does not feel that he needs them, he does so, he says, because he can't stop smoking, which he believes is one of the causes of his schizophrenia:

> He [the doctor] brings out the best in me. He is a good doctor. I told him that I was not going to take any more medications and that I was going to stop taking them (he mumbles something). I said, "I can do without the medications if I stop smoking." The only thing that happens is that I can't get to sleep unless I'm smoking during the night (mumbles)... [so] I took the medication today.

"D" talked a great deal about learning to listen to the teachings of Alcoholics Anonymous and Narcotics Anonymous as the most important part of his regaining control of his life. Like many of the people in my dual diagnosis treatment program, he would rather describe himself in terms of his addiction than in the more stigmatized terms of a mental illness. Many people with mental illness perceive that it is more socially acceptable to be an addict or an alcoholic than to be schizophrenic. He did not talk much about his medications or his experiences with the hospital, but he seems to understand that he needs to take medication and to participate in treatment in order to reclaim his life:

> When it [the schizophrenia] is managed by medication, it is...um... controllable. At times when I am afflicted, there is nothing I can do about it (he looks away).

"B," who has suffered from schizophrenia since she was 11 years old, struggled for at least 20 years before she could begin to take responsibility for her illness by accepting help. Because her thought disorder affects her speech patterns, she is a little awkward in the way she tells it, but her meaning is clear:

> I lost a lot of money, and I lost a lot of things, and what was holding me back was that I wanted to know the truth. I turned around and I went to church and I prayed and I wanted to know if my schizophrenia was a blessing, and I wanted to know... if my schizophrenia is true... I learned to listen to other people, and being with other people, talking about their problems, and I had to settle down and understand that if I wanted to go back into the family, I needed to go to a group and live in a community, and I turned around and I did that for 8 years [in board and care homes].

"C," who always saw himself as an "outcast" or as a "bad boy," described his lowest point just before he began to take back responsibility for his life. He too did not want to accept that he had a mental illness. He thought of himself as a drug addict, a more acceptable identity for him. But it was at this point that he began eating out of garbage cans and was finally sent to the hospital and then to a residential treatment program, where he began to learn about and accept responsibility for his mental illness.

> Yeah, and I am not as scared as before [he accepted that he had schizophrenia]. Before, it would creep me out. It was like really creepy. I wouldn't know how to act. I didn't have any coping skills or any social tools... I would...um... sleep for long periods of time. [Now] I can be functioning even though I believe it [his delusions].

"E" talked about the lowest point he reached in his mental illness, when he began to recognize that his delusions of grandeur were false. It was at this point that he was able to begin to accept help:

> I got tired of it, because the more that I...um... tried to make things happen in this world with my mind, with my thoughts, nothing happened. Another thing was that I realized that this is an illness, and that it was driving me crazy. I was trying to gain control by doing these things that were making me lose control of my life. Just like Rosa Parks. When she was asked why she...um... did what she did, she said that she was sick and tired of being sick and tired.

"F" explained earlier that that he just couldn't deny his illness to himself any longer, but he initially refused to take responsibility for it until he got into treatment. He illustrates clearly why medications alone were not enough for him to begin to rebuild his life. It was not until he got into a treatment program that he was able to begin to find a way back to himself:

> So I realized that I had an illness, but I...uh... abdicated all responsibility. We went to see some sort of a crisis psychiatrist where I could just get meds refilled. My mom was basically just, you know, taking care of me. I should not have let go of all decision making, because even in that state, I still had the power to make some decisions... I was being deceitful and lying, and I had never done that in my life, but that was the state that I was in. It was in that period that she took me to treatment...

Finally, "G" told me that her recovery began when she decided that she did not want to live her life in and out of hospitals. This desire to remain out of the hospital appears to be the motivation for all the participants to begin reclaiming control over their lives. In my clinical experience, it is the involuntary hospitalization in a psychiatric setting that most exemplifies to people that they have problems that are different from the people around them, and that they are in need of help from others. This is a source of shame, indignity, and stigma to them. Being able to stay out of the hospital means that they are not "sick." This seems to be why it is so hard to begin to accept help, because so often it has come in the form of punitive control or, at least, in a form that they could not understand as "help" (see above regarding hospitalization and first diagnoses).

Accepting Limits

Each of the participants seems to have come to some acceptance of limits imposed upon them by the condition of schizophrenia, giving up some activities in order to manage the stress of their symptoms. For "A," it has meant accepting that he needs the help of his case manager to manage his affairs, and a treatment program to structure his time. For "B," it has meant that she can only do part-time volunteer work at this time, in order to stay stable. "C" has not yet been able to finish college, is not yet ready to handle the stress involved in doing so. "D" has had to accept that he needed to be in a residential treatment program in order to begin to find stability in his life. "E" has had to accept that he needs a lot of alone time in order to manage his symptoms. "F" has learned that he needs to take time so that he does not have to hurry, as this kind of stress causes him to experience symptoms. "G" sometimes has to slow down her workload so that she can manage her symptoms and stay stable. Recognizing the limits imposed by their illness has been painful for all participants, as this points to the ongoing nature of the symptoms, which need to be continually monitored and controlled. They have recognized that they are not in control of whether or not they have schizophrenia, but they have learned that they can find ways to handle it, so that they do not lose the control over their lives that they have acquired with such effort.

"B," whose comments I found particularly important on this subject put it this way:

> I always have to make room and time to go to church, to take my medications, to eat healthy, and if you are going through a predicament, talk to friends or go to see a psychiatrist, or go to a program, or do some recreation, or do whatever I have to do to stay well... I know that people still have custody of my money, I just turn around and I get stressed. It is just something that I have to deal with, and I need to change my attitude to remember that I am blessed. It is not good to make a sin of something that is not true, and I need to understand that people are trying to help me... I know I can't stop it [the schizophrenia]. It will just have to be God and the spirit. I hope that I can do it (she laughs).

"C" explained how he copes using the language he has learned through the 12-step program:

> I like taking my meds every day. I take them as prescribed every day because they like help me a lot. I religiously take my meds. I have not had any cravings for alcohol...I...uh... ask my higher power humbly to remove my shortcomings, staying in the present, seeing reality, no anxiety. My defects of character can be removed.

"D," who is trying to "live in the gray area," talked about this as a coping mechanism for dealing with his symptoms:

> I would say that right now I am trying to gain balance (he clears his throat), and that...um... at one time I believed that there is no gray area. As I have gotten older, I...um... have realized that you have to live in the gray area. Most of us (clears his throat) are not...um... able to live outside of that.

"E," who is often solitary, as a way of coping with his symptoms, describes it like this:

> So with me, it is the loneliness and the anger. I have gotten used to being lonely and being angry, so now I...uh... need to be alone and I need to be angry. That is why I live alone in my apartment. I go home to my apartment and I read a lot, and I watch television (he sighs). Even though sometimes it is nice to be in contact with other people, I have come to need a lot of alone time.

"F," who is active in a recovery movement for people with mental illness, uses stress management as a way to stay stable. He is using here the language of his recovery program to talk about it at length:

> One of the biggest issues in recovery for me is...uh... the stress factor. I feel that in my recovery, my threshold for stress is lower.... That is one of the main ways I, I maintain my recovery is by stress management. That is the main thing that will trigger symptoms, and so I have to slow down... Time issues [are a stressor]... when I was growing up, I was always a, you know, "5 to 10 minutes late" person, but now I am an early person. Now I....um... manage by

> always leaving early, and by leaving myself plenty of time, and if I had not had a mental illness, I probably...um... would always have been a late person, but because of the stress issues that I have to live with, I have to be careful with that, and I have to leave big cushions of time everywhere, and I have to stay on top of things... Things that have to get done stress me out. Things that stress everybody out, but things like [that] really affect me differently. They [other people who do not have schizophrenia] have some kind of resilience to be able to handle it, but it...uh... becomes very overwhelming for me, and I can become very overstressed, and it is something that I work with all the time... Things like setting boundaries can really help. You can put in place the way you respond to situations so that you do not let yourself get stressed... I am learning on my job how to not get overextended, and I am, you know, very, very focused on taking care of myself. There is...uh... nobody that can do it for me.

"G" shared with me the strategies she has learned to deal with her symptoms. She told me that she stays very organized and takes time off work when she needs to do so. She keeps a rocking chair in her office, because this also helps her when she is feeling stressed. She discovered this strategy when her daughter was first born, and has used it ever since. "G" told me that when she was a child, she used to rock back and forth, but as she became older, she recognized that others would think of this as a bizarre behavior:

> After the baby was born, I...uh... wanted to make a lot of changes, because I did not want her to see some of the odd behaviors that I had had. One of them was...uh... rocking on the couch, which I had done since I was a little kid, to music, and it was very soothing to me. So I got a rocking chair, and at first it wasn't as good, but then I got into the swing of it, and I could nurse her while I was rocking in the rocking chair, and it would not look odd.

These participants all found ways of dealing with the stress of their condition which give them some sense of control over their lives – accepting help, facing fear and accepting limits are all means of acting on their lives rather than remaining victims. One could see these as coping strategies but also as ways that they draw upon the healthy parts of themselves.

Elements of Regaining Control

The stories that my participants told, about their journey to regain control of their lives with schizophrenia contained many elements. Those described above focus on their developing awareness or consciousness of their condition and of ways of alleviating symptoms and stress. What is left to illustrate is how they are rebuilding their lives. I asked each of them to tell me about what was most important to them in this process. I will describe this data within four categories: Reclaiming a sense of self-respect; Finding and maintaining values and goals; Reconnecting with others; and Rejoining the world. All of the participants have discovered at least a few of these elements necessary to improving the quality of their lives.

Reclaiming a Sense of Self-Respect

All of the participants shared a desire for self-respect, which they experienced as having lost (see above, "loss" and "stigma"). As people who live in the same culture with us, their ideas about the ingredients of self-respect are the same as our own. They each desire to be able to maintain a sense of dignity that comes with being able to be as independent as possible in their daily lives, including living in their own apartments, and they want make their own choices. They all would like to work in some capacity and to have a useful niche in the world. They all want to "fit" into the world and to have as normal a life as possible. They have all found value in themselves, and they are all determined to continue to plan for the future. In order to do that, they have had to go through the difficult process of finding a way to reclaim some of what they have lost, or to gain what they never had.

"A" does have a small job at his treatment program that gives him a measure of self-respect. He inputs data onto a computer, and is quite proud of his work. He talked quite often about work during our interviews, and at one point told me how important work is for him and how he tries to help others at his program:

> I want a business job now. But I (mumbles) don't have too many skills. If I had some, (mumbles) I said skills, I would get me a job where it would last you a lifetime, so I could work until I was 90 or 80 some years old. I...uh... don't want to retire at 65. I want to work for a long time.... when I get a job, I am going to quit [his

> treatment program]... I would like to be married and have a good job... [right now] I help people [at his treatment program] a lot... I talk about their problems and...um... try to help them solve their problems for them.

"B" has just recently gotten her own apartment. She is very proud of this accomplishment and talked about her newly found self-respect. She would like to work, but currently she is busy with volunteer work, AA, Bible study, and church. She feels she needs to stay busy in order to stay well, and spoke often of her self-respect, explaining to me that she has worked hard for everything that she has gained and believes that her life is worthy of respect:

> My life has had a lot of big change. You can stand up in city hall and tell them how you feel. It doesn't make any difference if you are not working. I have respect for what is going on with my life.

"D" described to me how he has found self-respect in his illness. He talks about schizophrenia here in the third person, as though he himself does not have schizophrenia. His choice of language is somewhat bizarre, and he is religiously preoccupied, but he believes that people with schizophrenia are intelligent, even brilliant, and that they can be good people, giving him a measure of self-respect as a person who also lives with schizophrenia:

> I believe that I...uh... have schizophrenia, but schizophrenia is a strange diagnosis, because I...uh... believe that it is the only one that separates different individuals (he swallows). You can...uh... be poor or rich, of high intelligence, or low intelligence (he clears

> his throat). Some schizophrenics are creators. I think about Einstein, Beethoven, John Nash. I think of...uh... people that have read the Bible. Some don't know the difference between God and the Devil (clears his throat). Some believe that the Devil is God. Some choose God, the Creator of everything.

"C," who talked about his friend referring to his disabled bus pass as a "retard card," was able to laugh when he told it. I asked him about this, and he said that, "I just let it all out. I don't hide it from anybody. I tell them I take medications." In a later interview, he told me that he is trying to learn from others, and:

> ...I am trying to find the highest good for myself... How can I be useful? What is the most useful thing I can do? How can I be of service? I still have some rebelliousness in me (he laughs). Service this, what a bunch of BS. But now I understand it, and it...uh... like helps my self-esteem, and it is just the right thing to do... [I] kick back and relax and take off my mask and be myself.

"E," after having spoken of his failures to get through college and to be a chess master, told me that his self-respect comes from not giving up on himself, and he also points to work as a means of self-respect:

> I think that is true for a lot of us schizophrenics. Sometimes we just give up on life. The food is there, and you can get what you need, but you don't think it is going to work, so you...uh... don't press the button. For some reason in life, I don't give up...I gave up [on

> chess]... That is in the past, and I am putting the past behind me and this is my life now... I am good at my job, and I got a promotion last year, and I will get another one this year, and I feel pretty good (he pauses)... I am reading books, and I work on my computer, and I...uh... think I can do some things, and I feel confident... I...uh... think having this job has been part of my self-esteem.

"F," who is working full time, still faces some self-esteem problems, though he has found great respect for himself in the accomplishments that he has made so far and has reclaimed some self-respect:

> The hardest thing is...uh... to realize that I am not a bad person. I look at it from a karma perspective, and say that this is supposed to happen, and this process that was supposed to happen to me, I look at it as an opportunity for growth (he pauses)... To be able to go through schizophrenia and gotten my life together, and I...um... have survived, so what else can happen? I know that I have been through some very hard times, but right now I feel so strong. It really opened me up spiritually. People can pray, "Oh, God, come into my life." But when you are totally broken open, and you have nothing left, and you are like some Jell-O on the floor, that allows something greater than yourself to come in and reach you because you don't have the defenses and the walls... You are not like a businessman with the money and all the defenses. From that perspective it was, you know, very wonderful for my spiritual life.

> But also just.... in terms of dealing with life, that it...uh... is a major thing to overcome, and I feel very strongly about it. I feel very powerful just in terms of what I have been able to accomplish, and...um... nobody can take that away from me!

"G," though she has been diagnosed with schizophrenia since she was a teenager, has found self-respect in her clearly great accomplishments. She completed a Ph.D. and works in an important position within an agency. In addition, she speaks publicly about her illness, and has had published articles about her experience. She is active in several organizations that deal with mental illness and corresponds with several people around the world who struggle with schizophrenia. She has been a source of support and hope to them. "G" told me that about 10 years ago, she decided to go public with her story, as a way of reclaiming her self-respect.

From my clinical experience and from what this participant told me about herself, I do not believe that the fact that her diagnosis of undifferentiated schizophrenia differs from that of the other participants is a factor in her ability to accomplish so much. She attributes it to the solid support and encouragement she has received throughout her life from her treatment providers, colleagues, and her children. "F" is considering applying for graduate school either in psychology or social work, so that he can become a clinician in the field. He too believes that it is the support and encouragement that he has received from his family and his treatment providers and colleagues that have given him the strength he has needed to come as far as he has.

Finding and Maintaining Values and Goals

Connected with regaining self-respect, all participants described values, including what they most value about themselves. Some of these values involve specific goals. For instance, most of the participants express the goal to work, to be independent. For some, this is about regaining losses by gaining self-respect and respect for others. All of their goals refer to ways of making their lives more whole. Sometimes it is very personal in regards to regaining a specific loss. Their values appear to coincide with these goals. Without exception, each one of them expresses a goal to help others in some way.

"A," in the following example, reflects upon his desire to find an intimate connection with another wife and the desire to have a good job as a way to make his life whole. He too uses the third person here, perhaps putting some distance between himself and his illness. He continues by connecting this idea to a concern with not allowing others (in this case, even a psychiatrist with whom he would cooperate) to take over his life:

> I think that if a person has a good (mumbles) job that relates to him, a wife, and I would like to adopt some kids, later on, as soon as my wife comes back to me. I think that...uh... while a person is under a psychiatrist, they should (mumbles) cooperate with him, but they should not allow him to take over their lives.

This quote as a whole shows a yearning for an independent, yet connected life.

"B" expresses her most important value as the ability to be independent and, at the same time, to be reconnected to her family (make her life whole) by making them proud of her independence. But she also has other ways of gaining this reconnection – by maintaining a spiritual belief and maintaining forms of abstinence.

> I have to remember that I have to pay my bills, and I have to be responsible for myself, but I have to believe in God and keep the spirit so my family will be proud of me... I have learned to stay away from drugs and alcohol, to stay away from sexual sin, and to also believe that there is a God...[and] courage. Keeping up my courage, telling myself that I have to be independent, that I have to struggle through all the things I want to do.

Regaining self-respect once lost appears to be the goal that is expressed through the value "C" describes. He had spent much of his youth using drugs and using people. He now puts a high value on honesty:

> ...Lying, cheating, stealing. My concept of that was that if I didn't get caught, and nobody saw it, it didn't happen. But God sees it, and now that I am totally honest, I have to be...um... accountable... I have to be rigorously honest.... I don't even like white lies (he laughs).

He tells me in the next interview how hard it was for him to be honest about his mental illness, but now he just "lets it all out." He takes off his mask, and just is himself.

"E," who defines schizophrenia as "helpless aggression," values most his "unconquerable soul"; he too seems to be struggling for a sense of wholeness in himself:

> There is a poem that says, "I thank whatever gods there may be for my unconquerable soul. In the foul circumstances, I have the wits to cry aloud." I thank the gods for my unconquerable soul.

Later, he tells me that having schizophrenia has made him stronger and that he perceives himself as a fighter: "I am willing to do what I have to do to survive. If someone thinks I am not worth anything, then that is their opinion and they are welcome to it."

While the above examples show participants values and goals in terms of their own selves – gaining wholeness and, for some, reconnection with what was lost – most would like to contribute something and to be in some way productive. For some this involves having productive "work." All say, in some way, that they want to help others. Some of the participants talked about it in terms of "giving back" to others all the support and help they have received.

"D," who perceives his schizophrenia as retribution for his crime, values most doing something for other young people:

> I have...uh... a few things planned out like a non-profit for at risk youth. When I...um... was young, I idolized drug dealers and murderers (he clears his throat). Now I don't want...um... to see that happen, I don't want to see...um... that happen to my niece and nephew, or for any of the youth, you know.

In the next interview, he told me that the thing he liked best about himself is that he is "meek." He goes on to repeat that he would like to build a "charity, a foundation. All the donations would go to worthy causes, preferably for programs for children."

"F" values his ability to find his self-worth and dignity in the face of his illness; he connects this to being able to help others find dignity:

> I have a career now, and it is a neat thing (he chuckles). I don't...uh... know what I will be able to do personally, but the...um... idea of fighting for people's rights and fighting for the dignity to come to a group of people who are really undervalued, and who are an underclass, and who are not only undervalued, but discriminated against right and left. A lot of it...um... has to do with finding your own self-worth and finding your own self-dignity, and doing the internal battle against feeling that you are worthless and that you are not a dignified human being. I...um... think that if I can do that, I think it will, you know, give me a lot. It will feel very self-nurturing, and...uh... compassionate for myself to help other people and give them some dignity.

"G," who has struggled against the discrimination she has faced as a professional and as a mother, values her courage to speak publicly about her illness and her activism. This reveals her self-respect as well as her wish to, and actual work with, helping others:

> So, I guess I came out of the closet...I...uh... decided about 10 years ago to come out publicly with my illness, and I have written two articles about my life. One of them was published in...uh... an international magazine, and now I correspond with three people in Japan. Two of them have schizophrenia, and one, one has a sister with schizophrenia. I correspond with a man in Brazil who...um... has schizophrenia, and a 15-year-old girl who has schizophrenia. I also correspond with a woman in Israel, and a...uh... woman in the Middle East. I have been very worried about her, with all the terrorism going on. I also correspond with a nurse in Appalachia who has bipolar disorder, and...um... she said that I inspired her to go to the mountains and do something about domestic violence there, since is it rampant there.

Reconnecting with Others

All of the participants spoke of the isolation from others that they have felt during their struggles. The theme of being able to have relationships with other people appears to be an important part of their reclaiming their lives and finding hope. It can be seen in the above section on values and goals. Here I will focus on it.

"A" spoke about his isolation several times during our interviews. He began his story by telling me about the death of his parents when he was a young child. He went on to say that the people who raised him, especially his grandfather, to whom he was especially attached, are now all dead. One of the most important memories he had of his childhood was a memory of saving a dog from drowning. He was so happy that the dog did not die. Later, he told me of his divorce from his wife. When I remarked to him that he seemed to have a lot of happy memories from his childhood, he told me that he doesn't have any friends now. He brings it up again when I asked him how serious he thought his schizophrenia was: "Very serious! I find it hard talking to people and making friends." When I asked him what he thought paranoid schizophrenia is, he told me that he conceives of schizophrenia as "a problem talking to people." When I asked him if he had learned anything from talking with me, he told me that:

> I learned that I am (mumbles) social, and that I can relate to people. I would like to relate to people more often, but you can't...uh... relate to people if they are on the bus, or out in a car, or walking around because they've got something to do.

What he is saying is that the connection with me had made him feel that he could connect with people, which is such an important value for him. But he is also referring to the fact that if he tries to talk to strangers on the street or out in public, that he will be perceived as intrusive or bizarre. I am sure that he has had that experience in the past, and has learned that it is not appropriate for him to do so.

"B," whose values revolve around being accepted once again by her family, brought this up several times during our conversations. When I asked her who the most important people in her life are, she told me that it was her family and her case manager. She told me that the most important positive change in her life, since she has gotten more stable, has been her relationship with her family:

> Yes, especially with my father and my brothers and sisters. I feel like it is a big change that happened. It's big to understand my schizophrenia. I didn't think I could turn around and get out of behind the shell of being treated for schizophrenia, taking my medication, and getting treated for another disease of diabetes. I didn't think that I...uh... would open up my life and let me be strong to share my reality with the truth of it.

"C" says that being able to reconnect with his family, have a girlfriend, and have a few solid friends has been the best part of reclaiming his life:

> But now it has totally changed. I...um... want to tell you about one instance. They have these like family meetings [at his dual diagnosis treatment program], and me and my mom...um... have been going, and we started talking, talking about the meeting after the meeting, and things are much more healthy now. I mean, I look forward to being with my family, since I...uh... understand how much they have done for me now. They have like supported me and they continue to support me... I have never had a girlfriend before, except for the girlfriend I...uh... had for three months at the university, and now I have a girlfriend, and we have been going out for two years... Most of my friends are in recovery. I have been

> going to NA and AA for 3 years. I know a lot of people there. I also have a wonderful support group at [his treatment program].

"D" is just learning how to have relationships with other people in his residential treatment program. He spoke little of his family, from whom he is somewhat estranged, and spoke of the loss he still feels about his former friends and girlfriends. He goes on to say that he has begun to make friends at his program, but he remains very isolated, according to his case manager at his program. He justified his isolation by using some of the concepts he has been learning in his 12-step meetings:

> I...um... am doing the program now, and I probably won't be in a relationship during my first year of recovery. I...um... am working on myself, and I have friends.

"E," whose lack of relationships has been his most difficult burden, spoke often about this problem. When I asked him what brought on his schizophrenia, he said that his loneliness as a child was:

> ...part of it. I don't know what else to say about it. I did not have a normal childhood like everyone else, and I...uh... think that I had a time bomb ticking inside me. Eventually, if someone did not defuse it, it was going to go off.

When I asked him about the most difficult aspect of living with schizophrenia, he told me:

> I would say the loneliness. And part of it is the idea that I am separated from everybody else, and I have to live this life alone (he

> sighs). Other people do not understand. The loneliness has brought me to tears many times.

Both "F" and "G" clearly stated that the most important part of their ability to reclaim their lives, and the source of their hope, was the right medications and support of other people. When I asked "F" what the key to his recovery was, put it the most articulately:

> I think it was having supportive people around me. I remember that when I was in the partial hospitalization program that my treatment coordinator spent a lot of time with me, and it was a safe haven... But the...uh... in thing that clicked for me was being put on Zyprexa. It was like an overnight experience. I think of all the time that my treatment coordinator spent with me, and it...um... was very supportive but nothing was happening until I got on Zyprexa, and then it was "boom," and three days later, it was like night and day. So for me, you know, that was the major thing – that and being in the recovery movement, the client centered movement. I know...um... that it is not all PC to be on medication, but that is what gave me the ability to begin to put things back together. At that point, I could be in a relationship after the Zyprexa... It was all these things too, and one of the hardest things about having a mental illness was...uh... not being able to be in a relationship. I just couldn't. It was not really possible. I mean, I wasn't in any shape to be in a relationship. It wasn't just...um... that I didn't have

> the desire, but I just couldn't do it. There were a couple of girls I met at the hospital, but they were not really relationships. I just couldn't do it... the fact that I was so much in survival mode that just trying to survive the day, just trying to exist, and get through the day was so great that I couldn't take care of myself, so how was I supposed to be available to another person? How could I do all the things I needed to do to have a nice relationship and all the energy that is needed to put into a good relationship to make it work?

He goes on to tell me about his current relationship with his girlfriend, someone he has been with for over a year. They are thinking about moving in together.

"G" told me that her greatest goal in her life was to have children, and she considers her relationship with her children to be the most precious part of her life, and her greatest achievement. When I asked her what she liked the best about herself, she told me simply: "My relationship with my children. I like being a mom and having them in my life."

Rejoining the World

This speaks to the need we all have to belong. All spoke of this need in one way or another as an important piece of their journey to reclaim their lives. This was a recurring theme throughout many of the interviews, particularly with those participants who are the most solid in their recovery. Wanting to be a part of the world in which they live, instead of separated from it as a theme.

"A" told me that he would like to have a job where he "would create jobs, help people get jobs." He told me that the experience of talking to me about his schizophrenia made him feel "like I am a somebody."

"B" feels her accomplishments are monumental. She has done all the things that she has been asked to do to rejoin the world:

> I turned around and did it from the acceptance of my heart, and I tried to...uh... change my attitude, and I am going to the doctor, I am going to AA, I am seeing my sponsor, and I have been getting back with my family, and I turned around and have accepted my problems with drugs and alcohol, and I have been going to the medical doctor.

She told me that she hoped that our interviews would be able to help someone else with schizophrenia.

"C" now wants to become a drug/alcohol counselor. He hopes to become a peer counselor one day, as a way of using his experience to rejoin the world:

> I just want to say that I am very thankful for the support systems I have now. That's why I want to give back for all the help I have gotten from the system. I...um... have gotten so much help from the system. I have gotten so much help

"D" talked about rejoining the world directly. He told me that he believes that God has told him to rejoin the world, and to work toward making it a better place to live in, which is why he wants to create a program or a foundation that

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will help kids stay away from the gangs, drugs, and violence that he was exposed to as a teenager.

"E" talked about his pride at having achieved the attainment of a responsible position at his office, in which he helps other consumers. He feels that he made this achievement on his own, and that has been the most important part of his recovery and has given him confidence he has never had before.

"F" feels that his involvement with the world makes his painful journey worth the effort it has taken for him to get there. He put it this way:

> You don't grow if everything is easy in your life. What better obstacle on your path to have to work through, and to be victorious over. It is like "yeah, I did that!" But the other thing, you know, is that my...uh... sensitivity and compassion for people who have mental illness has grown, and I feel compassion for them when they are sicker than I have been, and I...um... feel like I am part of a community of people in recovery, and I feel grateful that I can help others.

I asked "G" to tell me about the most important elements in reclaiming her life; she told me that it was "hope and support." She also told me that because she works at a place where she is accepted and respected, and because of the support she receives from her therapist and her psychiatrist, she has gained self-respect and confidence that continue to drive her hope. Another important element of her ability to be a part of the world as a productive person has been the strength of the relationships that she has with her children. She told me that the reason she wants to do this work is because she wants to “give back” for all she has received:

> ...I have always felt that I should give back all that I took. I think...uh... that that is one of the reasons I decided to go public with it. I...uh... had received so much that I wanted to give something back, and I decided that I should do that.

Cure or Ongoing Symptom Management

I asked the participants whether or not they believe that schizophrenia is a permanent condition, something they will continue to have to struggle with. Their responses fell into two categories: Cure and Ongoing Symptom Management.

Cure

“A” and “D” do not regard their condition as an illness. They believe that schizophrenia can be cured. When they speak of “cure,” it is with reference to a belief that an external force could cure them, and that it is connected with the “good” and “evil” dichotomy. Cure is dependent on their being good, removal of a punishment for being evil. They do not yet accept responsibility for the management of their symptoms. “A” and “D” do not think in terms of symptoms; they speak of cure as a possible result of changing their lives – becoming good, giving up cigarettes, etc., in which case, an outside power would intervene.

“A” believes that God has punished him with schizophrenia because he has been a bad husband and because he smokes. If he can become a “good” person, who "stays on the right path" and gives up smoking, he will be cured of schizophrenia.

"D" views his schizophrenia as both a "curse" for all his sins and as a "gift" of special powers that will allow him to "fix all the dysfunctionality in America." He believes that if he can be "righteous," quoting a Biblical source: "the prophets dictate that you can be healed." "D" struggles to understand his schizophrenia from his delusional perspective. He has evidently been told that one percent of the population of the United States is diagnosed with schizophrenia. He uses this information to explain a lot of the evil in the world. He seems to believe that the world is "sick" in some way, which suggests that he believes that schizophrenia is a bad thing. No wonder he does not want to accept that he has schizophrenia:

> I believe...um... that the one percent of people who suffer from schizophrenia, from psychosis, that as time goes forward, and that it is prophesized that the whole world will become sick and suffer from a psychosis (he clears his throat. I believe that I am part of that. I...um... don't choose it myself (he takes a deep breath), but I believe that that is the prophecy.

It is following this statement that I asked him if he thought that his schizophrenia is a permanent condition. He responded then with his idea about a prophecy that he can be healed. I asked him for confirmation that I understood his meaning – that his schizophrenia was not permanent. He answered, "Yes."

"A" and "D," who believe that cure is possible through intervention by some external force, also feel the most helpless in the face of their illness. They want the illness to "go away" and are waiting for God to remove this burden/curse from them. They believe that the cause of their schizophrenia is a punishment for their wrongdoings, and if only they can make amends, or live life "on the straight path," they will be cured.

"C," who has told me that he has a lot of delusional thinking, became somewhat delusional when I asked him whether or not he thought his condition would be ongoing. He told me that he believes that his schizophrenia can be cured some time in the future by medical intervention, but he does not want that for himself at this time and prefers to continue to work on his recovery:

> Part of my schizophrenia is that they can...uh... operate on my brain, and that they can like add things in, and they can delete things, but I...um... personally want to build on to my own personality and my own intelligence right now.... Maybe later, I maybe will get some brain implant or something like that.

Ongoing Symptom Management

The other five participants strive to work on managing their illness rather than concentrating on the possibility of a cure. They prefer to work on making their lives as normal and productive as they can within the limits they have accepted that they need in order to stay stable. They have come to some acceptance of this and moved on beyond being victims of their condition.

"B" spoke movingly about her acceptance of her responsibility to manage her symptoms and her realization that she may have to do so for a long time to come. She believes that it is worth it, because it has given her sobriety, reunion with her family, and a measure of independence in her life:

> It will be with you for life, even though your medications help you, there is not a cure. The medications help me to settle delusions and it helps me fight against the voices. It has also given me sobriety, and serenity being away from drugs and alcohol... I can't stop it. It will just have to be God and the spirit. I hope that I can do it.

"E" also accepts that he will continue to have to manage the symptoms of his schizophrenia. He uses the term, "signal anxiety," to define his paranoid fear. He also believes that people who have schizophrenia are being punished because they are bad people. However, he sees it differently than do "A" and "D":

> I...um... still have the schizophrenia because I still have the signal anxiety, and I still have all the experiences, and I have lived with it (he sighs, and takes a deep breath). But I think I am better, and I am stronger. I...um... think that a psychiatrist would say that I still have schizophrenia, but I think I have less schizophrenia, with the life that I live now... I think that a lot of people with schizophrenia can't face themselves. I think a lot of people have in the back of their minds that they are bad persons. I...uh... I think for myself,

> one of the most important things is that I tell myself that I am me and that I am...uh... a good person, and I have done some bad things, and I have done some embarrassing things in my life, but I am worth fighting for myself, because I am worthwhile, and no matter how bad things get in life, I am not going to commit suicide, and I am not going to end my life, and I...uh... may give up some things in my life, but I am not going to give up on myself.

"F," in spite of the fact that he told me he has not heard voices in some time and does not feel the paranoia he once felt or have delusions of grandeur any longer, still has symptoms that he has to deal with.

> I don't think that I will ever not have schizophrenia. I don't know if my brain will ever be healed. It seems that my concentration and my ability to maintain a coherent thought and express myself is sometimes difficult. It...uh... may be that if a certain pathway in the brain goes down, perhaps it can find another way, because the brain is a very flexible organ... I am not sure that it is just in the brain, but I think that learning to love life again is important. Going through this is very tragic, and you...um... have to do a lot of self-healing, and it is an ongoing process, and it doesn't end. I am not done with it. Maybe down the road, I, I will be done with it, but I still have further to go. I think hope is very important. When I came to my partial hospitalization program, I...uh... didn't have any hope, but it didn't matter. I was able to get my hope back and I got my

> life back, and people believed in me. I was...um... able to look forward, and begin to see, you know, the beauty in life. Some guy told me to go out and look at the beautiful sunlight and to look at all the colors and the trees. The little joys of life.

"G" told me that she has tried trials off of medications from time to time, but that she continues to need medications to stay stable. She also indicates in this quote how much she believes that her ability to reclaim her life is due to more than just being on the right medications. She believes firmly that people with schizophrenia need some form of psychotherapy to help them to cope with the effects of the illness on their lives and their relationships with others:

> I am on a lot of medications, but we...uh... have tried me off them, and it just...uh... doesn't work, so I guess it is just not going to happen. I finally just decided that I did not want my life to just be hospitals and illness... I have been very lucky. People need support, and, and the medication alone and therapy alone do not do as well as the two of them together. And anyway, a lot of people with schizophrenia get their medication, and there is not therapy or counseling, and they have no support. Sometimes I...uh... feel guilty that I was able to get that, and a lot of people do not get that support.

"C," who told me earlier that he thinks that schizophrenia can be cured with a brain implant, becomes less delusional. At the end of the interview, when

I asked him if he had some thoughts to share with people who work with or are related to someone who has schizophrenia, he said:

> I think that schizophrenia cannot be cured, but treated. People with the right medications and with the right, like, support can do just about anything they want to. I...uh... have gotten a lot of support and help and I am very thankful for that (he laughs). Nobody can do it alone.

I am not sure why he changed his thinking here. Perhaps it was because the first question was too personal, or perhaps it was too painful for him to acknowledge that his condition may be ongoing, that he drew upon his delusional system for protection from the pain. The second question was not about him personally, so perhaps he was able to answer in a more realistic way to a less intrusive question.

Attributing Meaning to the Experience of Schizophrenia

In my concern to understand the meaning of their illness for the participants, I asked each of them to give me a definition of schizophrenia, which is something that I have done often as a clinician. It is noteworthy that all gave a description of their schizophrenia rather than a definition. I find this an interesting phenomenon and one that I have often encountered in my clinical work. For both my participants and the clients with whom I work, schizophrenia is not a condition to be defined, but an experience being lived. In Kleinman's terms, it is the "lived experience" of this condition.

I proceeded to ask them to reflect on the meaning of schizophrenia in their lives. I had imagined that this would be difficult for them; however, all have thought deeply about it. Their responses fell into two categories that were congruent with their descriptions. They either perceived it as a burden ("A" and "D") or as an opportunity for growth; for some, it is a "test" of their ability to overcome obstacles in their lives ("B," "C," "E," "F," and "G"). In addition, all but one of the participants, "G," ascribed a spiritual significance to their experience. All seven of the participants agreed that part of the meaning they ascribe to their experience lies in its usefulness in helping others.

I will present the data on descriptions of schizophrenia followed by categories of meaning: schizophrenia as a burden; schizophrenia as an opportunity.

Descriptions of Schizophrenia

All of the participants described their schizophrenia either within the context of the interview or in response to a direct question from me. Their descriptions fell into two categories: an experience to be borne or an illness to be managed. The idea that schizophrenia can be overcome through management of symptoms rather than merely borne seems to be an important element in finding hope and rebuilding one's life. These two themes are then repeated in the way they speak about the meaning of schizophrenia as will be seen below.

Schizophrenia as an Experience to Be Borne

"A" defined schizophrenia as follows:

> I think they [people with schizophrenia] have a problem talking to people. People who hear voices (mumbles) can't have a voice without a mouth... Paranoid means that you notice a lot of people, and you want to be like them, have the things they have, feel angry that you don't have the things they have, and you smoke cigarettes because you don't have the things that other people have, and you feel (mumbles) suicidal because you have to wait so long for God to bless you... that's why I am schizophrenic.

At first, I thought he was referring to his isolation when he said that people with schizophrenia have "trouble talking to people," but he was referring to the invisible voices that he hears. He has trouble talking to them because he cannot see them, and they have power over him as a result. Then he goes on to describe schizophrenia in terms of the things he had not been able to have in his life because of his condition and calls this "paranoia." "A" has probably heard this word used in reference to his symptoms by his treatment providers, but he seems to use the word without really understanding what it means, although he does refer to the anger that many paranoid people feel. People with paranoia, I know from my clinical experience, often attribute special gifts or powers to other people as well as to themselves, and the sense of helplessness and powerlessness that results creates a good deal of anger. Lastly, because he is not "blessed" with a release from his schizophrenia, he feels suicidal. His last thought is that, because God does not bless him since he may be "bad" in some way or, perhaps, for something he may have done, he is punished with schizophrenia. This is one of the few places in the interviews where he admits to being schizophrenic. The pain and powerlessness that he feels, as he struggles with his schizophrenia is evident. No wonder he too has trouble accepting that he has schizophrenia.

"D's" description of schizophrenia is delusional and grandiose, as is typical of most of the thinking he has about his illness:

> I believe that it...um... is the accumulation of spirits in the air, combined in the intellect of one person, so it can be many persons... like a clash of personalities (he swallows). I also believe that certain people are chosen to have gifts and to suffer a curse. Mine...um... happens to be a psychosis to my eyes... I see little specks, and I have constant focusing on my eyes, and I...um... have pain.

He describes schizophrenia first an external power that inhabits a person's mind and makes him into more than one person, similar to the concept of the Trinity, or Dissociative Identity Disorder. Perhaps he has been told that the word, schizophrenia, is made up of the two Greek words, "schizo" – "split" and "phrenia" – "mind." The definition was used to describe the confusion that results from the loss of reality-testing that ensues during psychosis, splitting the reality-testing part of the self from the psychotic self. He then goes on to describe schizophrenia as a gift (of special powers) and a curse (a punishment, a burden). He seems to believe that the specks that he sees are an indication of his psychosis. It is not clear if the pain he experiences is physical or psychological. I do know that from my clinical experience that many people with schizophrenia attribute their physical pain to sources outside of the body, which is why many people that I work with have had so little medical care.

Schizophrenia as an Illness

The other participants all gave some variation on the description of schizophrenia as an illness in the sense that they experience symptoms that have affected their lives and their self-concepts in important ways. When I first asked "C" for a definition of schizophrenia, he answered as follows: "It is having delusions, believing things are true when they are not true." Later, he referred to it as a "brain disorder," when he was talking about the possibility of having a brain implant.

"F" talks about the schizophrenia entirely as an illness from which he is in "recovery." He has emotional and physical experiences that he attributes to his psychosis. After he told me that he believes that the reason why he had so much trouble accepting the diagnosis of mental illness was because of the stigma and because his judgment had been affected by a "chemical imbalance" in his brain, I asked him if he ever felt as though he were "sick" in some way. He agreed that he did not experience his psychosis as feeling ill in a physical sense, but then he added:

> But it is also...um... is not a comfortable feeling. In the period before I was hospitalized, it was a gradual decline for me. It was

> really intense... I was going with it, but it was a pretty demanding experience to go through. It is like...um... being on 24 hours a day. It was like being on stage all the time... with all the brain chemicals going off all the time; it was like being on a non-stop LSD trip.

"G" spoke of her schizophrenia strictly in terms of an illness that she treats with medication and support from her psychiatrist and therapist. As I have described earlier, she works daily to control her symptoms and to recognize when she is having stress. She talks about her illness in terms of any other physical illness which needs to be monitored daily, such as diabetes or heart disease. Perhaps this is so because she has experienced this condition for so long.

"B" describes her illness as a "brain" disorder that has affected her whole life:

> Schizophrenia to me is a disease, which is brain damage, loss of reality, a change of mind spiritually, a brain disorder of coming back to reality, of not collapsing, of not having communication with eternal life without medication.

"E" gave me a description of schizophrenia in terms of the experience of its effect on his life:

> I would define schizophrenia as helpless aggression. Feeling helpless. Feeling like you...uh... just don't have what it takes to survive in this world. The feeling that you don't have the control to shape your life, so you feel defenseless. There may be better

> definitions of schizophrenia, but that is how I define it for myself (he takes a deep breath). I have been helpless in my life; there is not much I can do about my life; that is a large part of schizophrenia in my life... Another part of schizophrenia I would define as aggression turned on myself. Part of the anger is directed at me...

He describes schizophrenia as a struggle with powerlessness, hopelessness, and depression. He spoke poignantly throughout the interviews of his loneliness and isolation from others. It is clear that he continues to have a lot of anger about having to live with schizophrenia.

Schizophrenia as a Burden

"A" and "D" often feel helpless and powerless in their struggle to gain control over their symptoms. As a result, the meaning of schizophrenia for them takes on the nature of a burden and a punishment to be endured until some force outside themselves lifts the burden from their lives. As a result, they remain victims to their symptoms, though neither has given up trying to cope. Both in very good treatment programs, and have people who care about their well-being and who work with them every day. While I was meeting with them, I was able to talk with some of the people at their treatment programs, and I was impressed with the quality of the care they are receiving.

"D," whose life struggle has been to overcome the tremendous guilt he feels for having murdered another teenager, continues to see his schizophrenia in terms of a punishment for that. He copes with this burden by his delusional belief that he has been given a gift of special powers and must right the wrongs of the world. This delusion helps to offset the heavy burden of punishment that he carries. His spiritual understanding of this experience is also described as a burden given by God for him to carry:

> Until I...um... entered back into the world, I believed that my plan would have worked (he clears his throat), and I am still gaining understanding about it. I...um... believe that it has been necessary for me to fulfill all the amends that I have had to make for all the sins and crimes that I have committed over the past 25 years of my life. I believe that it was the will of God (he clears his throat).

I am not sure what his plan was, although I think he is referring to the plans he made when he believed that he was a member of the CIA on secret missions to deal with some of the evils in the world. Here he describes his effort to accept that he is a person who does not have special powers but then avoids this painful realization with a delusional statement about his special status in God's eyes, as a person who must atone for his sins.

Schizophrenia as an Opportunity

The other participants described the meaning of schizophrenia as an opportunity. For most of them, it was seen as a "test" or an "obstacle" to be "overcome." It is in the ability to "win" the struggle to regain control of their lives that they found the most meaning and the most self-respect.

"B" described the meaning of her experience as a test that she hopes that she has passed and that now she can begin to accomplish more of her goals in her life. She also hopes that what she is telling me will also help me in some way that she does not define:

> ...If my schizophrenia is true, that I hope this will be a blessing of myself to you, and I hope that I can help other people to know that, if you have schizophrenia, that you can't always be down, and... that people who have this are being tested, and I know that I have been tested in hospitals, and now I turn around, and I take my medication. I now hope and pray that I can resolve a lot of things in life.

In another interview, she tells me the meaning she has ascribed to her experience of living with schizophrenia:

> Schizophrenia means to have patience with their psychiatrist, with their medications, with their friends, with their families, and believe that there is no cure, but there are medications and that a person can talk about it with another person and share their emotions and their ways of growing and their tears about schizophrenia. Sometimes you can explore your mind and about what your goals are, even though you are disabled.

She describes the struggle she has had to come to terms with the limits of her illness, but believes that, even though she is limited, she can still have hopes and dreams like everyone else.

"C" described the meaning of his experience as a "labyrinth" that hopefully will lead him to a higher state of consciousness. He describes this in somewhat delusional terms, but what he says is clear. He knows he has a long way to go, and he still believes that some of his hallucinations are true, which might indicate that, from time to time, he questions whether or not he has special powers or whether he has schizophrenia. He does recognize that he needs to take his medications and continue his treatment in order to become a whole person and to "go to heaven," when the final judgment on him is passed:

> Well, I think it is the angels are, like, talking to me, telling me that there is a better place to live, but that I...uh... am not ready yet. I believe in a higher state of consciousness, but I am, like, a little baby, crawling out of... getting clean and sober. I...uh... I get a glimpse of the future here and there. I have seen people appear and disappear... I remember once talking to this guy at this cafe, and I...uh... looked down, and a piece of carrot cake like appeared. I have seen pencils appear and disappear; I have seen medications change overnight. I have seen miracles, and I have seen a glimpse of what can be. I think maybe they are trying to tell me that is how I should be raised (he pauses)... They say it takes a village to raise a person, and I...uh... have built this whole community with my parents, and I have been learning from my elders, like my family, and I am learning from everybody, and hopefully I will gain another state of consciousness and go to like heaven...

It is interesting that he should talk about going to heaven, since he told me that he and his family have never belonged to a church or been religious; yet he sees his journey in spiritual terms.

"F" described his experience as an opportunity for growth:

> I would say that the growth part is the most important. In a way, I feel privilege to have been given the opportunity to overcome something like this. I...uh... don't think that I can say that with as much conviction, because it is still happening. It is an ongoing process of asking "What is the meaning for me?" I have heard people say that they are grateful alcoholics, and I have said that I am a grateful schizophrenic, but I think it is more real because I just feel like it is a blessing. You don't grow if...um... everything is easy in your life. What better obstacle on your path to have to work through and to be victorious over. It is like, "yeah, I did that!" (he laughs softly).

"G" also spoke of her experience as an opportunity for growth:

> Well, you know, in some ways, I...uh... think it has made me a better person, because I have experienced something that could be very devastating, and I...uh... have always felt that I should give back all that I took. I think that that is one of the reasons that I decided to go public with it (she pauses). I had received so much that I wanted to give something back, and I decided that I should do that.

I asked her if she ascribes any spiritual significance to her experience. She responded that she does not really believe in God. She believes that the meaning of her life is in her work and the contributions that she is making to the understanding of schizophrenia.

"E," who defined his schizophrenia as "helpless aggression," attributes some spiritual meaning to this experience. He seems to believe that although there is a God, it appears that he was given the burden of schizophrenia by chance. When I asked him about the meaning of schizophrenia in his life, he responded in a very poetic way:

> There is a song by Garth Brooks, "I could have missed the pain, but then I would have missed the dance." There is an old cliché that whatever doesn't kill you, makes you stronger. That is true in my life. I feel like the schizophrenia, the pain, the delusions have made me stronger (he takes a breath). I am a person who has been willing to fight the battle, a person who is willing to do whatever I have to do to survive. I...um... won't do anything bad, but whatever I need to do good to help me survive, I will do. Even though the schizophrenia has caused me a lot of pain in my life, it has strengthened me to say, you know, there are people who laugh at you in life, there are people who feel that they can take advantage of you in life, and to these people, I say, "You know, if you want to fight me, don't sing it, bring it, you got to bring some to get some. Put it in a sock!" (he takes a breath). I think I do this

because of all the Karate and chess championships I was in... I believe that there is a God. I...uh... don't know if there is an afterlife or not. I really don't know. I kind of doubt it. I believe in myself. If someone is going to do something to benefit me, it will have to be me. I have received a lot of help, as well as a lot of disdain, but still, I believe that my higher power is me. I believe that I was the one who chose my job, and I was the one who stayed here and persevered. That was my choice and my perseverance. I hate to say this, nothing against God, and I do not want to take His name in vain, but it is me who got me here. I thank God for the fact that the world exists, and I believe that He created it initially. How He did it, I am not certain (he takes a breath). I am not certain how life came to be. I have some ideas, and I am doing some writing about evolution, and I have some ideas about how evolution took place. The point is that...uh... God sort of directed things in the beginning, but then He had nothing to do with life anymore. Like I said, if somebody gets me something I like, it was generally me. I have gotten a lot of help in life, and I understand that, and I acknowledge that, but the person who I ultimately have to rely on is me (he laughs).

Suggestions for Better Understanding and Treatment of Schizophrenia

One of the purposes for doing this dissertation was to find out first hand, so to speak, about the experience of living with schizophrenia. All of these participants are doing so successfully, and some of the participants have found a measure of self-respect, connection with other people, and renewed hope in life. They have found a measure of joy in the midst of so much sorrow and suffering. I wanted their stories to enlighten those of us who do not have schizophrenia, and who do not really know what they have been through. So I asked each of them if they would share some thought that they felt would be important for the rest of us to understand about schizophrenia, and perhaps thoughts they may have for those of us who work with people with schizophrenia, that might help us to help them in a better way. They each had valuable ideas about this and were anxious to share them with me. Several of the participants told me that this felt like the most important part of the interviews.

Here are some of their thoughts:

"A":

> When you have a very traumatic experience in life, you are not to let the doctor force you to accept your condition in life. Your life is very stable, and you make choices and decisions and you know how to make friends. My advice to other people with paranoid schizophrenia is simply not believe it. Because the doctor gives you meds, it doesn't mean that you are ill. He doesn't know what

your situation is. He gives you...uh... drugs to help your situation, but you don't always have to take the medicine.

"B":

There is wisdom, and there is serenity, and there is hope, and everything is not hopeless. There is always a chance that you can change your mind and your brain and, therefore, the results of your life. Follow the truth. Amen.

"C":

I just want to say that I am very thankful for the support systems I have now. That's why I want to give back for all the help I have gotten from the system. I have gotten so much help... Nobody can do it alone.

"D":

I think that schizophrenia can be helped and that you don't have to suffer. I would like to thank President Clinton, President Bush, and the whole mental health system for the help that they give to people like me.

"E":

I think I have relearned things that I knew before [speaking about our interviews]. One of the things that I have learned working with consumers that a psychiatrist needs to learn over and over every day, that when a client says that 2 and 2 is 5, that the psychiatrist should not immediately tell them that it is 4, because they need to understand why the client needs to say that 2 and 2 is 5. It is a relearning process, and I...uh... believe that it is important, for people who work with people with schizophrenia need to learn that every day. I guess that is what I want to add.

"F":

I would say that recovery is possible. Recovery does not mean that you have to go off your meds, nor does it mean anything on the outside. It is like treating the whole person, and finding value in the person. It is about empowering the person, and...um... giving them the tools that they need to get their recovery for themselves. They can use the tools of the doctor and the tools and support of the clinician, but ultimately, you know, they have to recover on their own. It is something that each person has to do for himself. It...uh... means having a meaningful role, having a structured daytime activity that feels like it has substance to it. It can be volunteer, but it is something to do, some place to go, and a meaningful niche. It can mean connecting with your church, having meaningful hobbies that you enjoy, whatever it is. It is about doing something that gives you a sense of purpose and a sense of being alive. A support network is very important, and asking for help when you need it is very important. It is about believing that you can get better. I believe that recovery is...um... a lifelong process.

"G":

> I want people to see people as human beings, and...uh... realize that they have needs and wants and opinions and attitudes, and that people need to ask them how they feel about this thing, or do you have an opinion on this? People don't often ask them about what they think about things that happen... I believe that people with mental illness, if you can improve the quality of their lives, their symptoms will...um... get better. They want all the things that any normal person wants, a job, a house, a relationship, and a car. People don't see that, or hear that, or the people who work with them don't believe that they can do it.

The study reveals the courage with which each of the participants has had to deal with the multiple and ongoing difficulties of living with a serious mental illness. All of the participants expressed a determination to find a way to heal from their experiences of confusion, fear, and loss. The most difficult experience to deal with, however, has been the experience of being stigmatized. Each of them spoke of this in various ways, but the universal experience was one of loss of respect and acceptance by those around them. Each of them was fully aware of the implication of being diagnosed as schizophrenic, and the effect that this diagnosis has on other people. They described the sense of stigma as feeling unheard, devalued, rejected, or incompetent to make decisions about their lives. They each experienced a sense of alienation from others, loneliness, and a sense of feeling different or apart from "normal" people. Yet each of them has made a decision to continue to try to improve the quality of his/her life, find a place where they “fit” into the world around them, and gain some measure of self-respect and dignity.

CHAPTER FIVE: DISCUSSION AND IMPLICATIONS

This study explored the subjective experience of living with schizophrenia. Specifically the study focuses on how people diagnosed with schizophrenia cope with the ongoing nature of this condition and the consequences of being diagnosed and identified as schizophrenic. The study was designed to explore the common features of the experience of living with schizophrenia, while at the same time offering participants in the study an opportunity to tell their own unique stories.

The study conceptualizes schizophrenia as an ongoing illness that affects the mind. Using Kleinman's (1980) conceptual framework, illness is defined as the lived experience of the person, occurring in a specific cultural context that affects that person's understanding of a condition or diagnosed disease and the meaning attributed to it. It is considered to be ongoing because the symptoms continue over time. Lieberman (1998) describes schizophrenia as an "illness of the mind" because it affects the whole person, "the self," who lives with this condition. Though, in our culture, schizophrenia is defined as an "illness" or a "disease" to be treated medically, in other parts of the world it may represent a gift of special powers (Fabrega, 1989). Manifestations of the condition itself are difficult to separate from the way it is perceived. Acceptance of their condition as a disease or "illness" on the part of each of my participants and me indicates our culturally biased understanding. For the participants, this is probably essential. The way they accept and live with schizophrenia is the subject of this research. My task has been to remain as faithful as possible to their stories, while at the same time applying a perspective that attends to the psycho/social meaning of their situation.

The concept of "self" as described by Mead (1934) and elaborated upon by Blumer (1969) and the "symbolic interactionism" school of sociology were particularly useful with regard to this study. They describe the "sense of self" as a process of evaluating oneself in terms of the environment and construing meaning to the events in one's life in relation to social norms and expectations. The participants in my study are keenly aware of how they are perceived by the larger society in which they live. This has affected their sense of self, their understanding of the world and of their condition, and their attribution of meaning to the experience of their condition.

A primary finding is that the men and women who participated in this study, all of whom are struggling with the symptoms of a psychotic condition – schizophrenia – as well as from the complications of being identified as mentally ill, all actively think about and seek ways to live with their condition. Reestablishing self-respect is a large part of their concern and effort. The diagnostic and labeling processes that are embedded within the social response to what we call schizophrenia, though rising partially from a desire to help, inevitably contain, more or less, an undertow of fear and revulsion. The social mirror reflects back upon the sufferer an uncomfortable if not frightening picture of self. Thus, the very disturbing symptoms they experience are magnified by a loss of social identity. Though initially they all respond by denial of their condition, and some try to escape through using alcohol or drugs, the experience they described includes seeking to gain control of their symptoms and regain an identity – a way of being in the world. Although other researchers have described many of their strategies, each focusing on specific aspects of the trial of schizophrenia, an advantage of the narrative approach used in this study is that the stories are fulsome and contain multiple aspects of their experience, revealing a level of consciousness about their situation that is not often attributed to those suffering with this condition.

Three elements in rebuilding a life and an acceptable identity appear to be as follows: the ability to face one's fear; the acceptance of help and support; and acceptance of limits placed on the person by the condition. The 12-step model has been a useful tool for many of the participants. It has helped them to live more effectively within the context of ongoing psychotic experiences.

The components of this experience have been described and illustrated in Chapter 4 within five categories which emerged from the data: "Reclaiming a Sense of Self-Respect"; "Finding and Maintaining Values and Goals"; "Reconnecting with Others"; "Rejoining the World"; and "Finding Meaning in the Experience of Schizophrenia." They describe a journey from loss and isolation to developing a renewed sense of self-esteem and, for some, reconnecting with the larger community around them. These components are interrelated and can be assumed within an overarching theme: "The struggle to reestablish a viable way of being in the world: living with schizophrenia."

In this chapter I will discuss the findings in terms of this overarching theme and then in relation to the literature, including a section on the healing nature of personal narratives. The Chapter will end by addressing the contributions of this study, its limitations and directions for future research.

Living with Schizophrenia: The Struggle to Reestablish a Viable Way of Being in the World

Each research participant described a difficult journey of self-discovery and self-reconstruction, in narrative form, that began with childhood memories, many of which were painful (see Chapter 4). The data reveals that all the participants believe that these early experiences either contributed to or predicted the development of their schizophrenia. The influence of their early lives seems to have played a role in how they have understood and coped with their schizophrenia. Specifically, the presence or absence of significant supportive others seem to have contributed to their ability to rebuild their lives and find hope again. The ongoing support of others who cared for them after their first psychotic experience appears to have been critical to their ability to face their fears about being diagnosed with a mental illness and to accept help sooner than those who did not have that level of support. Regardless of the level of support that these participants have received, regaining control of their lives and reconstructing a sense of self has been arduous, filled with confusion, fear, and loss.

All of the participants have experienced both “felt stigma” and “enacted stigma” (Scrambler, 1984). They are fully aware of the social implications of being diagnosed with schizophrenia and the stigma attached to this diagnosis in our culture. The experience of stigma has contributed more than any other factor to the difficulties that they have encountered as they have sought to find a place in the world where they can feel socially acceptable and useful. The internalized stigma - felt stigma - and the rejection or condescension of others (particularly by those in the mental health profession) - enacted stigma - have contributed to the denial of the illness and the resistance to accepting help. In this regard, the experience of hospitalization was felt, for the most part, as a negative experience. The participants have all been hospitalized more than once, and they appear to associate this experience with loss of time, loss of progress, loss of self-esteem, and loss of self-respect. For these reasons, they are all striving to stay out of the hospital as much as is possible.

The participants have all thought deeply about living with schizophrenia, and they have all ascribed meaning to this experience. Some perceive of their schizophrenia as a burden, and others as an opportunity, still others as a gift. The nature of this perception helps determine the meaning of each person's experience. Some describe this meaning using religious terms, others philosophical terms, still others in the recovery language used in twelve step or mental health recovery programs. All believe that schizophrenia has a purpose in their lives. It may be that it offers them a chance to grow personally, to help others, or to teach them something about themselves that they could not learn another way.

Those participants who speak about their schizophrenia in religious terms seem to conceive of their struggle as one between good and evil, between God and Satan. This conception of schizophrenia as a struggle of such immense proportions seems to have made the task of accepting responsibility for managing the illness more difficult. They feel powerless over their symptoms and unable to live up to the expectations they feel have been placed upon them. Those who relate this sense of their condition appear to have made the least progress toward taking back control over their lives. This experience of schizophrenia seems to be prominent in those participants whose backgrounds are most closely identified with more fundamental Christian views of the world.

The journey of self-discovery, of learning to live with the ongoing condition of schizophrenia, began, as Bury (1982) has described it, with a “biographical disruption” of the trajectory of their lives, breaking continuity with the past. They lost their place in the world, their identities as “normal” persons. They lost jobs, time, and their place in the family, schooling, or social position. The first hospital experience reinforced this loss of identity with the prior self-image, as the people around them told them that they were mentally ill with a disease for which there is no known cure. This was devastating and frightening. All of the participants went through a period of denial, refusing to believe that they were ill, and refusing to comply with the medication regimen that had been prescribed.

The participants could not understand their psychotic experiences. They entered a period of confusion, fear, and unwillingness to accept their condition or to accept help. They continued to try to “overcome” or escape from it in various ways. They describe developing delusions to explain their experiences, to explain their voices, to rebuild their self-esteem, or as an escape from the emotional pain they were feeling. Some escaped into drugs and alcohol or used drugs and alcohol to self-medicate. Eventually, these strategies failed, and they were hospitalized again, sometimes many times. This course of repeated failure to "overcome" or "defeat" the condition they were in led to loss of hope, to a sense of defeat.

However, each participant has found the courage to go on, to find a way back, so to speak. Some have come further than others, but they all have continued to try to rebuild their lives. It appears that the most important factor in this effort has been the willingness to accept responsibility for themselves within the limits of their condition. They continue to have psychotic experiences, but they have come to recognize that help is available in the form of treatment with medications and support. Consciousness of this gives them some distance from their psychotic experiences.

The themes that have emerged are consistent with the findings of other researchers (Estroff, 1989; Davidson & Strauss, 1992; Dawson, 1994) who describe a similar process of reconstructing an enduring sense of the self as an active and responsible agent. According to Davidson and Strauss, persons living with schizophrenia can rebuild "a functional self in the midst of persisting psychotic symptoms and dysfunction." This provides the person with an "enhanced sense of self," a "refuge from their illness and a foundation upon which they may then take up the work of recovery in a more active and determined fashion" (p.131). The reconstruction of a functional sense of self includes four aspects: discovering the possibility of a more active sense of self; taking stock of the strengths and weakness of this self, and assessing possibilities for change; putting into action those aspects of the self that reflect one's actual capabilities; and "using an enhanced sense of self to provide some degree of refuge from one's illness and the detrimental elements of one's social milieu (i.e., stigma) and to provide a resource with which to battle them" (p.134). The experiences of the participants in this study can be understood within this framework.

Contrasting with current emphasis on the medical treatment alone of schizophrenia, Fabrega (1989), Lieberman (1989), and Dowrick (2000) all emphasize that rebuilding of a positive self-image and a meaningful life includes more than the remission of symptoms with medication. It includes the support and understanding of caring others, the courage to realistically assess one's strengths and weaknesses, and the willingness to rebuild a functional sense of self within those parameters.

Discussion of the Findings In Relation to the Literature

Both the illness literature and the contemporary literature on schizophrenia, which I reviewed in Chapter Two, used the symbolic interactionist point of view. In this literature the center of investigation is the relationship between self and the world. Taking this approach, I neither looked for nor concerned myself with the etiology of schizophrenia, nor precisely what schizophrenia is. I will address my findings in relation to this body of literature. My findings will also be discussed with respect to the literature on the healing nature of personal narratives and on first person accounts of living with schizophrenia.

Symbolic Interactionist Literature: Chronic Illness and Schizophrenia

I will begin the symbolic interactionist research literature on chronic illness literature and then move to the literature on schizophrenia that also utilizes this point of view. Much of the research on chronic illness has been qualitative. These researchers argue that this approach is the most effective way to understand the subjective experience of those who suffer from a chronic illness. The same is true for the literature on schizophrenia. I will compare and contrast these findings with the findings of the data gathered from my participants.

Chronic Illness

The literature on chronic illness describes the experience of coming to terms with an ongoing condition. This "biographical disruption" of the expected course of a person's life history leads necessarily to a disruption of one's identity in the world. It separates the ill person from those around him/her, leaving that person feeling isolated from others (Toombs, 1992). This separation from others contributes to a sense of a "spoiled identity" as judged or defined by others. A person who is no longer perceived as "normal" is stigmatized or discredited by others, and thus his/her "life chances" are reduced (Goffman, 1963, 1964).

The literature on chronic illness describes the strategies that people use to come to terms with the diagnosis of an ongoing condition. These strategies generally include an initial denial or minimization of the severity, prognosis, or permanence of the condition. They attempt to explain their experience as transitory, as not being serious, a condition that can be "cured" (Kidel, 1988). However, as the persistence of symptoms begins to disrupt the structures of everyday life that underpin the expected course of life, expectations and plans for the future must be re-evaluated and changed (Bury, 1982).

The data gathered from my research suggests that my participants experienced a similar process of denial and rejection of the diagnosis of schizophrenia, a diagnosis that brings with it the stigma of being labeled with a mental illness. In an effort to avoid the stigma of being labeled “crazy” or “incompetent,” they sought to explain their symptoms in various, generally delusional, ways. They impute their experience to different sources, such as anxiety or depression or drug/alcohol use. As the ongoing nature of the symptoms became evident, the biographical disruption of the expected course of their lives and identities resulted in loss of the ability to function as they had previously. They experienced stigma, isolation, and finally a loss of a sense of self. They all have tried various ways to interpret their experience in order to deny indications of an illness, but they all have faced the ongoing nature of their symptoms and have, at least partially, come to terms with their condition.

Another strategy used to cope with the stigma imposed upon them by their illness is described in the literature as an “objectification of the body.” This strategy separates the diseased part of the body from the rest of the self, therefore permitting the person to experience the illness as outside of his/her control, as not a part of the self, as an “alien presence” in the body (Toombs, 1992). This permits the person to both preserve a sense of self-worth – illness and self are separate – and to reduce the sense of responsibility for the feelings of vulnerability, powerlessness, and loss of control that constitute an ongoing condition (Castro, 1995; Helman, 1985; Kidel 1988; Sakalys, 2000; Tatham, 1988). This strategy can be successful for someone coping with an ongoing physical condition, as it allows the person to experience the illness as only a part of the self and not the whole self.

This strategy of "objectification of the body" was used by most of the participants at one time or another to explain the experience of symptoms but is complicated by the nature of this illness. Schizophrenia, as an illness of the mind, reduces the capacity of the person to distinguish between self and symptoms. Identifying symptoms as an "alien presence" in the body has led, for some, to the development of paranoid delusions of being "taken over" or "controlled" by force outside of the self. The recognition of symptoms as symptoms and not as the whole self has given most of my participants some capacity to distance this core self from the symptoms of the illness, but it has been a more difficult process for them than for those who cope with an ongoing condition that does not affect the mind.

The process of developing a new identity that incorporates the limitations of the illness is not linear, according to Yoshida (1993). She describes this process as a pendulum swinging from denial of the illness, to total identification with the illness, to finding a supernormal identity, to identifying the ill parts of the self as a part of the total self, to finding a middle self that includes acceptance of the permanence of the disability and an acceptance of the limitations imposed by that disability. This allows the person to act upon both the disabled and non-disabled parts of the self and to perceive oneself as part of a larger society of individuals with disabilities. This description of the process of constructing a positive identity within the context of an ongoing condition fits well with the narratives of my participants, whose attempts to find a way to live with their condition have included all of these elements. At one point or another, they have all denied the existence of their illness, surrendered to it, developed delusions of supernormal powers as compensatory defenses, begun to incorporate their illness identity into their total identity, and searched for a self-image that could make meaning and use of this experience.

Identification with the illness, according to Scrambler (1984), affords the person the opportunity to try out new roles that may not have been available before the illness. For example, one might try out the role of "hero who emerges victorious against all odds." By facing illness the person may achieve some admiration from those around him/her (Charmez, 1999). Several of my participants have used this strategy to achieve self-respect and a sense of status in relation to others. They describe their struggle for control over their symptoms as a battle that they fight, and wear as a badge of honor any achievement of stability and control.

The literature on chronic illness also addresses some of the factors that impede progress toward reclaiming one's identity and self-respect. Specifically addressed is the development of the identity of the person as a "victim" in the deviant role of a "patient," who is dependent upon others, unable to care for himself/herself, as a way of coping with the stigma of the illness and the loss of status (Scrambler, 1984).

In my study, all the participants have been involuntarily hospitalized at one time or another and have experienced the loss of control and status that constitutes the patient role. As shown in Chapter Four, some have been more successful at struggling against this role than others. It does appear that those participants who have had the greater advantage of support, education, positive life experiences, and have a sense of competency, have also made the most progress at avoiding the "victim" role as the major component of their identity as a person living with an illness.

As described in Chapter Four, regaining control over one's life remains a central issue in coping with an ongoing condition for the participants in my study. The struggle to face the limitations imposed upon one's life, find a way to carry on daily activities, to maintain goals, and keep important values has been part of rebuilding and reclaiming one's life. Though the literature on chronic illness refers to maintaining a sense of personal integrity, of "effectiveness," and a sense of "being able" as essential ingredients in the construction of a new identity within the context of an ongoing condition (Leidy & Haase, 1999), it does not address the problem of an ongoing mental illness in which the person has first to find a core sense of self, not affected by the schizophrenia, that can become "the active and responsible agent" for coping with a mental illness. This process is described in the literature on schizophrenia by Davidson and Strauss (1992), but it is not described in the literature on chronic illness.

Leidy and Haase (1999) refer to "connectedness" or "being with" as a "sense of significant, shared, and meaningful relationships with other people, a spiritual being, nature, or aspects of one's inner self" as one of the strategies that people who cope with chronic illness use to maintain personal integrity (p.72). This is an important part of the process of rebuilding one's life. Participants all shared with me the isolation and loneliness they have experienced as a part of their illness. This has been reinforced by the intrusion of auditory hallucinations that are denigrating and which often tell them that they are unlovable, dislikeable, etc., or by the paranoia they experience that instills mistrust and fear of other people or of themselves. This has led to anger and anxiety, a loss of a feeling of comfort from others, and a sense of the loss of the understanding of others.

All of the participants spoke movingly of how important it is for them to be able to have relationships with other people in order to feel "normal," to feel "worthy," to regain self-esteem through the respect and caring of other people, to feel "accepted." As they have begun to take back control of their lives, and rebuild a positive sense of self, it is this connection with others that most indicates to them that they have succeeded in overcoming the stigma and shame that they have felt. The literature on chronic illness and schizophrenia that I reviewed used the "symbolic interactionism" concept of "self" as a "social self." One's sense of self is as much derived from others as it is from internal experiences and is an ongoing appraisal of one's place in the world (Blumer, 1969). The positive sense of self is thus closely related to how one is regarded by others and remains the most important element of reconnecting with others. It is also the most important element in dealing with stigma and the resultant isolation from others.

With the advent of renewed hope and the support of caring others, these participants continue to work toward becoming part of the world again. They all spoke of wanting to be useful in the world, of wanting a "job," the measure of success in our culture. Our cultural norms dictate that if a person does not have a "job," a function, or usefulness in the world, that person is a failure (Bury, 1982; Charmez, 1983; Helman, 1985; Scrambler, 1984).

As the participants in this study have traveled along the road toward regaining control over their symptoms, they have ascribed various meanings to these experiences. They have thought of their symptoms as special powers, as punishment, as a curse, as a burden, or as a random event in the universe; but all of them agree that the experience of living with schizophrenia is a "test." It is a test of their ability to "overcome" something difficult that not many people have had to face, and they take comfort from this idea, as it makes their struggle significant, even important. It has made them "stronger" for the experience, and offered them an "opportunity" to test themselves in an exceedingly difficult way. The ability to survive the struggle is a source of pride for them, a source of self-esteem, and for some has been the source of self-confidence that they do not know they would have had without this experience.

This is consistent with the literature on chronic illness. Chronic illness forces the person to look at life from a different perspective from others who take their health and well being for granted. It offers the person an opportunity to see life more realistically, and to learn to value what is most important (Toombs, 1992). Chronic illness forces the person to give up the "idealized, omnipotent self" for a sense of self that is both more humble, and yet more "transcendent." The person becomes both more willing to accept the strengths and weaknesses that he/she has. Also, in so doing, he/she is able to create beauty out of loss and despair, the existential freedom to demonstrate to the world the unique qualities of the ill person (Radley, 1999). This is the opportunity offered by any ongoing illness.

Yet another way to understand chronic illness is from the perspective of the Jungian concept of the "shadow." Facing the illness, the shadow side of the self, is an opportunity for personal transformation through a deepening of awareness of the previously unexplored or unknown aspects of the self (Kidel, 1988). Several of my participants made reference to this concept, speaking about their schizophrenia as a process of growth, of becoming more than they were, perhaps more than they might have otherwise been.

For some participants, this experience has been an existential struggle to acknowledge the unpredictability and the fragility of life and to understand why they were given the experience of schizophrenia to live. They struggle to accept the fact that, whatever the reason that they have schizophrenia, they must find a way to make meaning and use of this experience. They know how vulnerable they are, and how fragile is their well being. Perhaps they know this better than those of us who have never had to struggle with an ongoing condition (Kidel, 1988). They are aware that health and illness are opposite sides of the same coin (Groddeck, 1923/1977).

Schizophrenia

Psychosis represents a tremendous loss of control of the mind, of one's identity, and finally of one's life trajectory when one is hospitalized against one's will. The literature on schizophrenia addresses the potential for "engulfment" into the deviant role of "psychiatric patient" (Lally, 1989; Williams and Collins, 1999). Lally asserts that the trauma of more frequent hospitalizations, a more fragile ego, more negative life experiences, lower educational background, fewer number and competency of alternative roles available, and less support from caregivers and family may all contribute to a more difficult struggle for symptom control, for regaining a positive self-image, social competence and the ability to meet the social expectations of others. The data from this study suggests that these factors have contributed to the progress or lack thereof that these participants have made toward construction of a culturally acceptable identity within the context of their symptoms. It is interesting to note, however, that in spite of these factors, several of my participants have made significant progress along the road to rebuilding a positive self-image. This suggests that other factors inherent in each person, such as the capacity for tenacity or optimism, may also be at work.

Delusions are described in the literature on schizophrenia as serving the function of explanation for unusual experiences, such as auditory hallucinations, or to protect the person from the effects of stigma, loss of self-esteem, from isolation, and from fear (Dawson, 1994). However, in my study, I found that, when the delusions take on cosmic proportions in which the person is confronted with being responsible for the good or evil in the world, the delusions no longer seem to serve these positive functions. The delusion that schizophrenia is a punishment by God for past sins, as at least two of my participants believe or have believed at one time, increases, for them, the stigma, shame, isolation, and fear that they experience as part of their condition. To counter this overwhelming burden, they have developed delusions of grandeur that they are "superhuman" or have some role as a "savior." This delusion hampers the ability to find a "functional sense of self" while living with ongoing symptoms. A functional sense of self is the result of a realistic assessment of strengths and weaknesses (Davidson & Strauss, 1992). Instead, these participants retain a sense of powerlessness, of "ineffectiveness" in the world. Their identification with either the "savior" or "victim" role threatens to "engulf" them. They continue to struggle against this engulfment by "trying to stay balanced" – rejecting this overwhelming responsibility, knowing that they are unequal to the task. In order to do this, they must give up the identity as a "savior" and accept that they are only human. This threatens to plunge them back into the "victim" role once more. This struggle to find a sense of self that fits their delusional system remains an ongoing issue for these participants.

This ongoing struggle impairs the person's ability to gain control and mastery over these experiences or to let go of the panic and helplessness they feel in the face of their auditory hallucinations. The participants in my study struggle to ignore their negative and frightening auditory hallucinations. However, when these hallucinations are coupled with religiously based delusions about their role in the world, it can slow progress toward a sense of mastery and control. In this case, the person's goals and values continue to be centered on fulfilling the terms of the punishment or of "saving" the world and make finding meaning and value in the activities of everyday life difficult.

In this regard, those participants I interviewed who believe that their schizophrenia is a punishment from God, appear to be having the most difficult time rejoining the world. They are still looking for a niche for themselves, since they believe that they have the burden of tremendous responsibility on their shoulders, and they are trying to find a role that will fit that responsibility. When they are able to let go of the idea that they must somehow reduce the suffering in the world, they are able to focus on more practical ideas for making themselves useful, but this is not yet a consistent position for them. The research literature that I reviewed did not discuss this aspect of delusions.

All of the participants experienced limitations to how much they can do, since too much stress can trigger psychotic symptoms. They talked of strategies used to reduce stress in their lives, such as leaving plenty of time to go somewhere or finish a task, taking time out to rest or to replenish internal reserves, spending time alone, or reducing stimuli in their lives. Some indicated that it takes a great deal of emotional energy to be in the world and that they have to take good care of themselves in order to stay functional. The literature on schizophrenia emphasizes careful attention to the management of stress at all levels – physical, emotional, mental – as an important part of managing symptoms of this condition – more so than for the symptoms of other types of chronic illness (Carr, 1988; DeVries & Delespaul, 1989; Gross, 1987; Williams & Collins, 1999).

The importance of medications came up in conversation with my participants with regard to the management of symptoms. As described in Chapter Four, all of these participants take medications for their schizophrenia, and all of them indicated that their medications help to decrease some of the symptoms they experience, particularly auditory hallucinations, giving them freedom from such intense internal preoccupation.

It is this factor that has convinced several of them that part of their illness is organic in nature. The advent of more effective medications in the past several years, targeting specific symptoms, has helped many of these participants to be more functional in their daily lives, and to "objectify" their illness so that it is at some distance from who they are. They asserted that their medications have helped them to be more effective in their relationships with others by allowing them to behave more "normally." The literature that I reviewed on schizophrenia was concerned with the subjective experience of living with schizophrenia and did not directly address the effect of medications on coping with this condition. These researchers point out that more recent research on schizophrenia has been almost entirely focused on the medical aspects of the illness rather than the experience of the person who lives with this illness. For this reason, they chose not to address the subject of medications (Cutting & Dunne, 1989; Davidson, 1993, 1994; Davidson & Strauss, 1992; Dawson, 1994; Deegan, 1993; Dowrick, 2000; Estroff, 1989; Lally, 1989; Leete, 1989; Pollack, 1989; Romme & Escher, 1989; Strauss, 1989, 1994).

Spotnitz (1999), who asserts the schizophrenia is amenable to psychoanalysis, argues that as people with schizophrenia resolve some of their unconscious conflicts, medications may be necessary only in times of increased stress. Two of my participants talked about this issue. Although they continue to take medications, both of them have worked with their psychiatrists to either reduce or refine the dosage of the medications that they take when they are doing well, and increasing the medication in times of stress.

Each of the participants in this study has thought about the meaning of schizophrenia in their lives, and this meaning now guides their actions and goals. The meanings ascribed to this experience are a reflection of our cultural understanding of schizophrenia as an illness of the mind.

The meaning of schizophrenia as a "test" has determined the actions that my participants take in regard to it. This is in agreement with the literature on "symbolic interactionism" (Blumer, 1969). Without exception, these participants want to use their experience to help others, either in the mental health field or in some human services field. They want their struggle to be meaningful to the larger community. This desire to be useful helps them to become part of the community of other people who struggle with chronic illness and identifies them with other caring people, other people committed to helping those who suffer. It identifies them with the larger community of persons who work for the benefit of others.

The literature on schizophrenia I have reviewed does not address this issue directly. It addresses the problem of “adaptation” to the auditory hallucinations – the continual engagement of such people with their voices, unable to objectify them and understand them as something they can either accept or reject, and unable to find strategies for controlling their responses to (Romme & Escher, 1989). The literature deals with the meaning of the positive symptoms of auditory hallucinations and delusions and the negative symptoms of apathy, affect blunting, withdrawal and isolation (Dawson, 1994; Romme & Escher, 1989; Benjamin, 1989), but does not address the subjective meaning of schizophrenia to the person with this condition. For this, we will need to turn to the first person accounts. The existential meanings of this illness are also not explored.

The Healing Nature of Narratives

Pat Deegan (1993), who lives with schizophrenia, stresses in her account of her recovery how important it is for the person with schizophrenia to seek not to be “normal” but to be whom he/she is “called to be”: a “whole, healthy person with a psychiatric disability.” Telling one’s story can incorporate this experience.

My participants found satisfaction in telling their stories to me. They indicated to me that this made them feel important, that they had something to contribute to the field of literature on schizophrenia. The participants who work in the field of mental health or as advocates for people with mental illness have publicly acknowledged their illness, and in so doing, have found a sense of integrity for who they are: they are people living with the condition that is called schizophrenia. As many of them indicated to me, they are “people” first, and they are not “schizophrenics.” This is an important distinction because it identifies them as one of “us” and not a separate category of people. “Going public” with their illness, instead of hiding it from others, has given them a measure of self-respect and decreased the sense of shame about having a mental illness. This is consistent with the literature on stigma that asserts that public acknowledgement of one’s condition helps to reduce shame and isolation. It places the person in the category of “person with a problem” rather than in the category of “problem” or “deviant” person (Scrambler, 1984).

Perhaps due to my stance as an interviewer, interested in learning from them about schizophrenia, the participants felt that their stories had meaning to the larger community. They eagerly shared their stories with me, wanting to give me as much information as they could about the nature of their illness, their beliefs about it, their symptoms, and the meanings that they have given to this experience. I had worried that they would become upset or fearful of telling me about their symptoms and their struggles, as I have often encountered this as a clinician.

It may be that, since they felt that I was not interviewing them as a clinician, to diagnose and treat them for an illness, they were more open and willing to talk with me than I have experienced in other settings. Perhaps because I am accustomed to talking to people with schizophrenia, and felt comfortable doing so, they felt at ease talking about this with me. I am familiar with the communication problems that are often part of the illness and the delusional thinking that often intrudes into that communication, so I did not feel confused or uncomfortable when this occurred. I told all of them that their stories were important to me and to others who work with people with schizophrenia, because it offers us a chance to learn more about this illness from those who live with it. I believe this attribution of meaning to their narratives encouraged them to talk with me more frankly than they might have done otherwise.

The Healing Nature of Narratives

All participants expressed to me a sense of relief, of pleasure, of feeling "important," or of feeling worthy at the conclusions of the interviews. In this way, I believe these narratives served some healing function for my participants. This is consistent with the literature on both chronic illness and on schizophrenia (Bartz, 1999; Charmez, 1999; Kelly & Dickenson, 1997; Lang, Floyd, & Beine, 2000; Robertson-Malt, 1999; Sakalys, 2000, Thorne, 1999). As I noted in Chapter Four, the *Schizophrenia Bulletin* began printing the narratives of persons with schizophrenia as part of each issue. Prior to this, the prevailing belief was that persons with schizophrenia could not speak for themselves or tell their own stories, as they were perceived as "incompetent," "too confused," or "too psychotic" to be consulted directly about their experience. This is still a common belief, and I see it often in my work as a clinician. Many people who work in the mental health field still believe that people with schizophrenia are too ill for them to be considered a source for better understanding the nature and course of this illness. This has been true more for people with mental illness than for people with other chronic illnesses, and is particularly stigmatizing and denigrating. My participants shared with me some of these ideas, explaining to me how they had not been “listened to” in the past, or were dismissed as “too crazy” to be taken seriously by those around them.

The opportunity to share their stories and to be taken seriously by others who are seeking to understand this illness is a relatively new phenomenon in mental health. Since each of my participants has experienced this feeling of being unheard, I believe that the stories they told me were healing and undid some of the hurt that they have experienced in this area in the past.

The literature on chronic illness deals with the concept of healing narratives more directly than the literature that I reviewed on schizophrenia. Kleinman (1988) notes that personal narratives of the illness experience are integral to the legitimization of the person’s illness experience, and can contribute to insight, empathy, and understanding of the suffering by those around the person, and may help the person to live more fully within the context of the illness. Frank (2000) asserts that illness narratives are therapeutic and emancipating, allowing some distance and some disengagement from the illness, as well as building healing relationship with others. I am in agreement with this stance, and I believe that the willingness to listen to a person’s story with empathy and understanding is part of any good therapeutic intervention and can be healing for the person who is being listened to in a respectful way. In this study, I learned how important this is and how often my participants have been treated disrespectfully as they tried to tell others of their experiences.

First Person Accounts

The participants all shared that the onset of their psychotic symptoms was a devastating experience for them, whether it resulted in hospitalizations, in loss, in stigma, or in self-respect. The ongoing nature of this condition has been a factor in their continued struggle to understand the ramifications of their experience and to try to make meaning from this. In this endeavor, they remain "active agents" in their evaluation of the schizophrenic condition, using the strengths of the "core self" to find ways to cope with this significant disruption to the prior sense of self (Davidson, 1994; Davidson & Strauss, 1992; Estroff, 1989; McNally 1996; Phripp, 1995; and Roe, 1997). They have described their experience as a difficult journey from somewhere dark and frightening to a place of hope and strength. This metaphor is captured in some of the accounts reviewed in Chapter 2 of others who have struggled with schizophrenia (Deegan, 1993; Jordan, 1995; Leete, 1989; McGrath, 1984) and accounts written by/with treatment providers (Schiller & Bennett, 1996; Sechehaye, 1951).

The subjective accounts of living with schizophrenia often include descriptions of construction or reconstruction of a "new" definition of self, so important for a person with an ongoing condition (Launer, 1999).

Barnes and Berke (1972), Green (1964), North (1987), Perceval (1838/1961), and Vonnegut (1975) each give moving narratives recounting many of the same experiences as those reported to me by my participants. They describe the first frightening and confusing experiences of the onset of psychosis, with vivid tales of their responses to these experiences, interpreted as bizarre or frightening by those around them.

Mark Vonnegut (1975) gives a particularly vivid account of the onset of his psychosis that is similar to the experiences that participant "F" described. He recounts his confusion and fear as he becomes progressively more unable to distinguish what is real from what is not real and of the responses of those around him as they became more concerned and frightened by his behavior. My participants were not able to talk much about others' responses to their behavior, as they were so internally preoccupied. But they did glimpse the reactions of others from time to time and described their own confusion, anger, fear, and shame about the way others responded to them.

Carol North (1987) and Sechehaye (1951) both give graphic accounts of the visual distortion of reality that signals the onset of psychosis. Two of my participants also shared their experiences of visual and perceptual distortions that affected the sense of normalcy of the everyday physical world. This was also very frightening and discomforting.

Perceval's (1838/1961) narrative is a vivid description of the experiences that people with psychosis endured in the 19th century, before the advent of medications. They were locked up in an asylum and treated as though they were incompetent and hopeless. The account of his illness and recovery describes his journey to find the enduring sense of self from which to rebuild a viable identity. This account had much influence on amelioration of conditions and treatment of people with schizophrenia. Nonetheless, almost two centuries later, dehumanizing treatment of mental illness persists. My participants described some of their experiences as shaming, stigmatizing, and denigrating.

Other accounts (Barnes & Berke, 1972; Green, 1964; and Schiller and Bennett, 1996) offer vivid and moving descriptions of the struggle to come to terms with living with a mental illness, struggling not to become engulfed by the illness, finding a sense of self-respect and self-esteem in the capacity to overcome the effects of such a stigmatizing and devastating condition. My participants spoke of some of these aspects of their illness, although they were unable to be as graphic or as detailed in their accounts. I had the impression that some of my participants could not speak of some of their experiences in detail because the memories were either too upsetting for them to report or because they did not have words to describe these events more fully.

The first person accounts in the *Schizophrenia Bulletin,* that began to appear around 1980, tell more about the coping strategies people use to live with their schizophrenic condition. These accounts describe rediscovery of a sense of who they "really" are, the core self, and how they cling to that sense of self as they learn to live with their ongoing symptoms. They describe the loneliness, the isolation, and the stigma that they have experienced. But also described is the discovery of their uniqueness in the world and the strategies by which they take back power and control over their lives. These powerful accounts of recovery within illness are reflected in the narratives of my participants as well. They too have found strategies for overcoming many of the deleterious effects of their illness to find a renewed sense of self-respect and purpose in the world.

Summary

Although the literature I reviewed has explored the subjective experience of both chronic physical illness and ongoing mental illness, particularly schizophrenia, the contemporary literature on schizophrenia does not address some of the deeper meanings that people who live with the condition ascribe to this experience. The literature focuses more on those aspects that contribute to understanding the subjective experience and the strategies that people use to cope with their illness. The older literature on schizophrenia deals with schizophrenia within the context of a pathogenic family dynamic, and methods of treatment were fashioned to help the person to correct earlier concepts of self and other, but the recommendations for treatment are based in the mental health practitioners' perception of what was needed rather than in the point of view of the person living with this illness. My study is an attempt to hear directly from my participants their view of the illness and their own recommendations for what is needed in order for them to re-connect with themselves and others.

The findings of the researchers reviewed parallel most of my own. The experience of being labeled with a condition that is defined as a chronic illness is a devastating and frightening experience for anyone. The person experiences fear and anger at being faced with a condition that cannot be cured, that cannot be "vanquished" like an enemy, but which endures in spite of the person's best efforts to overcome it. The person so affected suffers a loss of a sense of self as they were and a loss of self-respect in the eyes of others, since they can no longer be "functional" or "carry their own weight." They are viewed as "deviant" and are stigmatized by themselves and others in this role. Persons living with a condition that has been defined as a chronic illness go through different stages of understanding and of taking responsibility for regaining control of their lives, and of beginning to build an identity that incorporates but does not overwhelm their core sense of self. The most important factors in this rebuilding of an acceptable identity are hope and support (Charmez, 1983, 1999; Kidel, 1988; Leidy & Haase, 1999; Lindsey, 1996; Morse & O'Brien, 1995; Scrambler, 1984; Yoshida, 1993). This is also in agreement with the literature on schizophrenia that the discovery of core aspects of the self that are untouched by the illness and can be used to rebuild an identity within the context of the illness is essential to being able to overcome the effects of this illness of the mind (Davidson, 1992; Davidson & Strauss, 1992; Estroff, 1989; Lally, 1989; McNally, 1996; Phripp, 1995; Strauss, 1989).

The potential for becoming "more" of a person than one might have been without the experience of the illness offers the possibility of imbuing the illness with the meaning of a "test" or even of a "gift." My participants talked about this meaning, and it is described in the research on chronic illness (Groddeck, 1923/1977; Kidel, 1988; Radley, 1999; Toombs, 1992), but I found little reference to this idea in the research on schizophrenia.

Contributions of the Study

This study explored the subjective experience of schizophrenia and offers some answers to the question of how people come to terms with this illness, which so profoundly affects the life and identity of those who live with it. The study expands upon and corroborates research in the field of medical anthropology, done both by others who have studied the experience of living with chronic physical illness and by those who have studied the experience of living with schizophrenia as an ongoing mental illness.

The literature reviewed makes it clear that illness is the lived experience of a disease, and in order to help people who live with any form of ongoing condition, it is important to understand their experience. Much of the contemporary research, therefore, consists of qualitative, phenomenological studies. There are few such studies in the research literature on schizophrenia. The literature reviewed suggests that an emphasis on the medical treatment of schizophrenia, the advent of newer, more effective medications, the belief that schizophrenia is not amenable to psychotherapy, and the dearth of funds in public mental health to offer more holistic treatment of this illness have resulted in less attention to the experience of persons who live with this condition. Early in his research on schizophrenia, Strauss (1989) was asked by one of his subjects why he/she had never been asked what he/she did to help himself/herself. This study sought to address this question and to add to the qualitative research on the subjective experience of living with schizophrenia.

The results of this study indicate that people who live with schizophrenia can and do come to terms with their illness. They describe it as a difficult journey of self-discovery in which they have learned to deal with a disruption in their lives, their relationships with others, stigma, and the confusion and fear that surrounds the psychotic experience, in which reality, one's judgment, even one's perceptions can no longer be trusted. It is a world that is different from the world as experienced by others, and they must find a way to come to terms with this experience. Delusions appear to be a way of explaining these experiences, although the delusions themselves can be an impediment to finding successful strategies for coping with the illness.

I sought to better understand why some people with schizophrenia cope better than others with their illness, and my study corroborates that of others. Those people who have the advantage of the support of caring others, better education, better earlier life experiences, the availability of alternative roles and skills, and the availability of effective medications as needed, do better than those without as many advantages. I also found that delusions that are religiously based might be an impediment to taking back control of one's life. This was not addressed in the literature.

It is the willingness and ability to take responsibility for the management of one's life and the acceptance of limitations imposed by the illness on that life that appear to be the most important elements in the ability to come to terms with and cope with the lived experience of schizophrenia. The same is true for all of us. The acceptance of responsibility for one's life as it is given to us and the desire to make the most of who we are and what we have is the most important factor in any life well lived. The difference for my participants is that they have had to live with loss that most of us have never had to face.

Limitations of the Study

The participants in this exploratory, phenomenological study were selected for their ability to communicate their experience, and as such, they represent only a small sample of those persons living with schizophrenia. In general, they are somewhat better educated and higher functioning than many of the people that I encounter in my clinical work. Many of the people with whom I work are not able to communicate their experience as clearly as these participants were able to. I believe, however, that their experiences match those of many I have encountered in my clinical work, as well as the experiences of those who have told their stories in recent editions of the *Schizophrenia Bulletin*.

Explanations or hypotheses that were generated by this study must be accepted or rejected on the basis of conjecture and subjective interpretation of the data. These explanations may not be generalized as representative of all persons living with schizophrenia, but the literature suggests that much of what my participants have experienced is common to others who live with this condition.

Directions for Future Research

As stated before, there continue to be few qualitative research studies of schizophrenia. Research emphasis is on the medical treatment of this disorder. From my own experience with working with people with schizophrenia as a clinician, they are often afraid to talk with me about their experience, denying that they have an illness or symptoms because they fear that I will judge them or perhaps send them to the hospital. My experience as a researcher was an entirely different one. It may be that other clinicians in the field are reluctant to try to talk with their clients about their experience because they too have encountered resistance to talking about the illness experience. I do not know how much this factor has contributed to the scarcity of other qualitative studies.

Another factor that might contribute to the paucity of qualitative studies of schizophrenia is the difficulty in communication that practitioners encounter in talking with people, whose speech or thought process interferes with their ability to clearly articulate their thoughts. The presence of intrusive delusions or hallucinations during an interview can be unsettling. My participants sometimes responded to internal stimuli while they were talking with me, and one participant's speech is noticeably affected by her schizophrenia. My familiarity with this phenomenon permitted my participants and me to overlook this difficulty in our conversations.

It would be interesting to explore the meaning of the presence or absence of internal stimuli when someone with schizophrenia is speaking with another. I noticed several things about their speech patterns. The participants would sometimes hesitate before speaking, clear their throats, take a deep breath, or sigh. I interpreted this behavior to mean that they were fearful that they would be judged for what they were saying, or perhaps because there is a lot of emotional pain associated with that content. I did not explore this with them, but it is clear that they have thought about their experience a lot, and have many feelings about it. The participants, and one participant in particular, sometimes spoke about their schizophrenia in the third person. It appeared that they might be trying to distance themselves from this experience, as though it were happening to someone else.

The participants I interviewed told me that the mental health professionals they have encountered are mostly interested in the amelioration of symptoms rather than the meaning of the experience. In the literature reviewed, I found little or no reference to meaning attributed to the schizophrenic experience. There is some reference to this in the literature on chronic physical illness, and this was the basis for my exploration of this subject with my participants. I was surprised by how easily they were able to talk about it, and I had the impression that no one had ever asked them about this before. They had thought about this a lot, and were quite willing to share their thoughts with me. I learned a great deal about the way in which meaning is made from an experience in which the sense of reality is lost or questioned, in which the mind can no longer be trusted. It takes a great deal of tenacity and courage to go on living in a situation where no experience can be taken for granted anymore, and one's senses can no longer be trusted. I believe that this is an avenue of further study into how the mind makes meaning of the psychotic experience, rather than of the psychotic symptoms alone.

The impact of stigma on persons who live with the condition of schizophrenia is well known. How they cope with that stigma and overcome it is addressed only in the first person accounts and in one study by Lally (1989). There is much emphasis in the literature on ways of coping with the symptoms of the illness and finding ways to rebuild a positive sense of self, to rebuild a useful niche in the world, but little mention of how people learn to cope with the stigma itself. There is some reference to this in the literature on chronic illness, particularly the study by Yoshida (1993). This study and that of Lally formed the basis of my inquiry into the subject with my participants. I believe that this too might be an avenue of further study.

The impact of culture on the understanding and treatment of schizophrenia remains an issue that I recognize as having often been overlooked both in my work as a clinician and in the literature on schizophrenia. Schizophrenia is assumed to be an illness that is incurable and that affects the competency of persons with this diagnosis. The label is laden with the connotations of “crazy,” “bizarre,” “different,” “fearful,” and each person who lives with schizophrenia must contend with all these cultural assumptions about the illness. Even those who work in the field accept as true many of these assumptions about schizophrenia. Of all the psychiatric illnesses that one can have, the diagnosis of schizophrenia is by far the most stigmatizing. There is some reference to it in the illness literature (Kleinman, 1988) but little reference to this issue in the literature on schizophrenia.

Another issue that has been overlooked is the issue of “chronicity,” and the use of this term when describing the experience of living with schizophrenia. Some researchers such as Harding, Zubin, and Strauss (1997) assert that the people who study schizophrenia come in contact only with those persons who need continual support and treatment, and they often see them only over short periods of time. Because their sample is thus skewed, they assume that schizophrenia is therefore a “chronic” illness – an illness whose course and outcome result most often in deterioration over time. Some longitudinal studies indicate that many people with schizophrenia get better over time. My study indicates that this has been true for most of my participants.

Dowrick (2000) questions the validity of the medical and psychiatric community’s adherence to objective, observable, scientific categorizations of mental illness. He asks whether the absence of mental health automatically means mental illness, and whether or not mental illness should be divided into discrete categories? When the symptoms of one disorder overlap into another disorder, how do we know that the patient has been put into the right category? I found no other reference to this concept, and I believe that this is a subject that warrants further exploration.

Fabrega’s (1989) cross-cultural study indicates that schizophrenia is not always defined as an illness, and in some cultures a person with extraordinary experiences may be considered as a resource for better understanding some of the larger questions of life. I believe that this concept also merits further reflection and study.

In the older literature that I reviewed on schizophrenia, there is much discussion about the etiology and nature of schizophrenia. As the theoreticians sought to understand this phenomenon, they described a set of observed behaviors that eventually became known as schizophrenia. The *DSM-IV-TR* (2000) lists criteria for the diagnosis of schizophrenia. And yet, it has been my experience that the diagnosis may vary from one psychiatrist to another. One psychiatrist may diagnose Paranoid Schizophrenia, another might diagnose Undifferentiated Schizophrenia, yet another might diagnose Schizoaffective Disorder, depending on the symptoms present at the time of the interview with the doctor. This presents, in my mind, a problem for both clinicians and patient as to the veracity of the diagnosis and its subsequent treatment, since that is based on the diagnosis.

The conclusions of the present study indicate that persons with schizophrenia are able to talk thoughtfully and informatively about their experience, given the right context. The experience of schizophrenia requires constant reassessment of fundamental beliefs about the world and constant reassessment of one's value in the world in the face of ongoing stigma. Coping with this condition requires courage, humility, integrity, reassessment of fundamental values, and coping with feeling different from others. I hope that this research study will encourage others to enlarge upon these findings.

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APPENDIX A

Priscilla Fleischer, L.C.S.W.
7200 Bancroft, Suite 133
Oakland, California 94605
Telephone: (510) 553-8500

RECRUITMENT LETTER

Date:

Dear___________________________________

I am currently involved in the dissertation phase of the doctoral program at the California Institute for Clinical Social Work, Berkeley, California. I would like people who have been diagnosed with paranoid schizophrenia to participate in my research project, and I am writing to you as part of my recruitment effort.

My study will examine the subjective experience of living with paranoid schizophrenia. Specifically, it focuses on coping with the chronicity of this condition and with the consequences of being diagnosed and identified as schizophrenic. Although the literature on schizophrenia is vast, covering etiology, treatment approaches, and medications to treat this condition, there is a limited amount of literature on living with this condition, written from the first person point of view. There are few qualitative research studies that explore the question of the illness experience – living with a chronic illness of the mind, and the ways by which a person comes to terms with this reality.

I will be conducting at least two, and possibly three tape-recorded 30 to 40 minute interviews with people who have been diagnosed with paranoid schizophrenia for at least two years who are not conserved, have had more than one psychotic episode, and who are at least 30 years old, thus having had to confront the issue of chronicity. I would like to have participants, both men and women, of varied backgrounds and experience, to offer as wide and rich variety as possible. Since people understand and interpret their experience differently, I would like to include people with varied outcomes to living with their illness.

These interviews will include an opportunity for my participants to get and give feedback on my interpretations of their experience. I hope to enter their worlds as fully as possible, and allow them to tell their stories in their own way, and to refine their responses, until they are satisfied that I have understood what they have to say.

If you have a client who, you believe, fits these criteria, and who would be available and might be willing to participate in this study, I would like you to speak to them, explaining the nature of the study, and ask them if they would like to participate. They can meet with me at their convenience, at a place of their own choosing that would feel as comfortable and safe for them as possible.

They need to know that they will be meeting with me at least twice, and that our interviews will be tape-recorded. If they are interested in doing so, I have enclosed a consent form for me to contact them and set up an initial screening interview, either by telephone or in person, which will take only about 15 minutes. At that time, I ask that you advise them that you will be mailing the consent form to me, and that I will contact them as soon as it is received.

Thank you for your participation in helping me to recruit participants for my study. If you are interested in receiving a summary of the results of this study, please add a note to that effect. I hope that this will be a useful and positive experience for the participants of my study.

Sincerely,

Priscilla Fleischer, LCSW

APPENDIX B

Priscilla Fleischer, L.C.S.W.
7200 Bancroft Ave. Suite 133
Oakland, California 94605
(510) 553-8500

CONTACT CONSENT FORM

I,____, give my consent to be contacted by Priscilla Fleischer, L.C.S.W, for the purpose of determining whether or not I would like to participate in a research study of people who have been diagnosed with schizophrenia, as part of a dissertation for the California Institute of Clinical Social Work. I understand that this consent does not obligate me in any way to participate in the study, and that if I decide I do not want to participate, I may withdraw at any time. I understand that Priscilla can contact me at a time and place of my own choosing, either in person or on the telephone, or I may contact her myself by telephone, should I prefer. Our initial interview will last no longer than about 15 minutes, and the subsequent interviews will be between 30 to 40 minutes and will be tape-recorded. These meetings will take place in a private, confidential setting to be arranged by the researcher, Priscilla, and myself. We will talk more at that time about the research study, and I can ask any questions I wish to ask about the study at that time.

Signature:________________________________Date________________________

Address:____

Telephone:___________________________

Witness:___________________________________

APPENDIX C

Priscilla Fleischer, L.C.S.W.
7200 Bancroft Ave. Suite 133
Oakland, California 94605
Telephone: (510) 553-8500

TELEPHONE CONTACT FORMAT

Hello, my name is Priscilla Fleischer. I am a social worker who works with people with schizophrenia. I am working on a dissertation for the California Institute for Clinical Social Work, and am conducting a research study of people who have been diagnosed with paranoid schizophrenia. I believe that it is very important for the people like me, who work with people with schizophrenia, to listen to the stories of people like you, who can help us understand more about this illness.

Therefore, I would like to talk with you about your life, in order to better understand what this experience has been like for you, and what it has meant to you to have schizophrenia. I would like to talk with you for about 30 to 40 minutes at least twice maybe three times. We could meet at your convenience, at a place that you choose, such as your case manager's office, your home, my office, or someplace quiet where we can talk privately. If it becomes too stressful for you, we can stop at any time, and you are free to withdraw from the study any time you wish.

Since I believe that everything you say is important, I want to tape record our interviews, so that I can play it back and make notes about it to share with you later. I want you to give me feedback about my interpretation of what you have said, and to help me understand it accurately. When I am finished with the tape recordings, I will erase them.

Everything you say to me will be held in confidence, and when I share the results of my study with the people who will read my dissertation, I will not use your name, and I will disguise your personal information so that you cannot be identified to protect your confidentiality.

When we are finished, I would like to know about how you felt about being a participant in my study, and if you learned anything about yourself by talking about your life. I am hoping that it will help us both to learn more about you.

Do you have any questions about this study for me? Do you feel as though you understand what I am asking you to do? If so, would you like to participate in my study? You can think about it if you are not sure, and talk it over with someone and call me back to let me know later. I can be reached at (510) 553-8500 during the day. I hope you will be willing to participate in my study, and I look forward to talking with you again. Thank you.

APPENDIX D

Priscilla Fleischer, L.C.S.W.
7200 Bancroft Ave. Suite 133
Oakland, California 94605
Telephone: (510) 533-8500

SCREENING INTERVIEW FORMAT

I am Priscilla Fleischer, and I am the person who spoke with you on the telephone about participating in my study of people who are living with paranoid schizophrenia. Thank you for meeting with me, and I hope you will feel free to ask me any questions you may have about my work, or about my study. As I told you on the telephone, I am a licensed clinical social worker, and I am the team leader for a case management team that works with people who have been living with a psychiatric disorder like schizophrenia for some time. I want to know more about what it is like to live with this problem, to help those of us who work in the field to listen and learn from the experts like you. I am hoping my study will help other people who are in mental health learn better ways to help people with problems like yours. Do you have any questions about that?

I would like for us to meet at least twice, and maybe three times, for about 30 – 40 minutes each time, at a quiet place that you can choose, that feels comfortable and safe for you. I will ask you questions and maybe make some notes while we are talking, so I don't forget any important things we talk about. I will also tape record the interviews, so that I can listen to them to make notes about it later. At the next time we meet, I will bring those notes and share them with you, and you can tell me if I got the information you gave me accurately. You can also add more or make changes to what you have said as we go along. After we are finished with our interviews, if you have more to add, you can call me and we can meet again. When I am finished with the tape recordings, I will erase them because they are confidential. Do you have any questions now?

During the interviews, I will be asking you about your life, both before and after your schizophrenia began. I hope you will feel free to talk with me about whatever is important to you.

If you feel ready to agree to participate in the study, let's set up a time when we can begin. I am going to read the consent form to you now, and ask you if you would be willing to sign it at the time of our first interview. If you don't feel ready to decide, here is my card, and you can call me, or I can call you at another time. You can make your decision then. Thank you for your time. I hope you will agree to participate in my study. I think your story will be important.

APPENDIX E

Priscilla Fleischer, L.C.S.W.
7200 Bancroft Ave. Suite 133
Oakland, California 94605
Telephone: (510) 553-8500

INFORMED CONSENT FORM

I,_______________________________________, hereby willingly consent to participate in an exploratory study of the narratives (stories) of people who have been diagnosed with paranoid schizophrenia. This research project will be conducted by Priscilla Fleischer, L.C.S.W., under the direction of Sylvia Sussman, Ph.D., Principal Investigator and research faculty member, and Cynthia O'Connell, Ph.D., faculty member at the California Institute for Clinical Social Work.

I understand the procedure to be as follows:

1.) At least two, and possibly three, 30 to 40 minute audio-taped interviews will occur in a private, confidential setting to be arranged between myself and the researcher. I will be talking about my experience of living with schizophrenia, and what this experience means to me.
2.) I am aware that there may be some risk for emotional discomfort involved in participating in this study. If this should happen, we can stop and meet at another time. I can also withdraw from the study at any time. If the experience has been stressful for me, I will be able to contact the researcher who will make provisions for me to receive professional help from someone with whom I feel comfortable talking, at no cost to me, for a reasonable and limited time.
3.) I understand that I may withdraw from this study at any time. I also understand that this study may be published and that my anonymity will be protected. No names or individual identifying information will be used in any oral or written materials. The audiotape will be erased at the completion of data analysis.
4.) I understand that I will have the opportunity to give and receive feedback from the interviews, and to refine any of my answers. I also understand that I have the option to received feedback from the results of the study. Please send me a summary of the results at the address below.

Yes__________No___________

Signature:________________________________Date:________________________

Address:____

Witness:_______________________________________

APPENDIX F

Priscilla Fleischer, L.C.S.W.
7200 Bancroft Ave. Suite 133
Oakland, California 94605
Telephone: (510) 553-8500

INTERVIEW GUIDE

Introduction

"First, I want to thank you for helping me with my research. Your story is important because it will help me to better understand what it is like to live with the diagnosis of schizophrenia. We will talk for about 30 to 40 minutes, each time we meet, but we can stop or take a break at any time. I would like to learn about you, your life, and your experiences. I hope you will feel free to talk with me openly and honestly about yourself. Please ask me about anything you do not understand. If it is okay with you, let's begin with your telling me something about your early life: where were you born and where did you grow up?

Background and History

Probe Questions:

1.) Tell me something about your family.
    a. How many people are in your family, and where are they all now?
    b. Who was the most important person for you in your family?
    c. What made that person so important?
2.) Can you remember some of the events that you think were important? (school)
3.) Can you describe the kinds of things you enjoyed (or did not enjoy) doing the most as you were growing up?

4.) Where there some things you learned as you were growing up that are important to you now?

Experience of the Diagnosis

Why don't you tell me about your early experiences of schizophrenia – what was it like, and what happened to you? (experience and events)

Probe Questions:

1.) How old were you the first time you had psychiatric problems?

2.) Do you remember feeling different in some way that you later associated with your illness?

3.) Did you go to the hospital?

4.) Can you tell me about whom you saw at the hospital and how they treated you? (hospital or clinic)

5.) What do you think caused the problem?

6.) Why do you think it started when it did?

7.) What do you think schizophrenia is?

   a. Does it have anything to do with your life?

   b. What does this problem do to you and to your body?

   c. How does it work?

8.) What are the chief difficulties your problem has caused for you?

   a. How severe do you think your problem is?

   b. Do you think it will have a long or a short course?

8.) What do you fear most about your problem?

Relationship to Other People

What has it been like with your family since all the problems began, and how do they respond to you now?

Probe Questions:

1.) Who are the other people in your life? (friends, coworkers, people you live with, people you encounter)

2.) Is it different than it was before your problem began?

3.) Do you have people in your life who understand and help you with your problem?

Coping with the Illness

Probe Questions:

1.) What sorts of difficulties do you encounter in your everyday life that you associate with your illness?

2.) What have you done to deal with these problems so far?

3.) What do you think might help (has helped? not helped?)

4.) What kind of treatment do you received? What treatment would you like to receive?

5.) What are the most important outcomes you want to receive from this treatment?

Meaning of the Experience

Probe Questions:

1.) What do you think having schizophrenia means?

2.) What has it meant to you?

3.) Has it had an impact on you spiritually?

4.) How does your illness affect what the future holds for you?

Sense of Self

Probe Questions:

1.) How do you think being diagnosed with schizophrenia has affected the way you see yourself?

2.) How would you describe yourself now?

3.) How would your family describe you?

4.) How would other people describe you?

5.) Is there anything you would like to change about yourself or your life?

6.) What do you like best about you?

Conclusions

Probe Questions:

1.) Finally, are there parts of your story that I may have not covered with you that you think are important and that you would like to talk about?

2.) Do you have any thoughts about the experience of the interview?

3.) Did you learn anything about yourself that you did not know before?