Living with Schizophrenia: A Phenomenological Investigation

Andri Yennari

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LIVING WITH SCHIZOPHRENIA: A PHENOMENOLOGICAL INVESTIGATION

By

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ABSTRACT

LIVING WITH SCHIZOPHRENIA: A PHENOMENOLOGICAL INVESTIGATION

By

Andri Yennari

August 2011

Dissertation supervised by Russell Walsh

This study investigated the experience of living with schizophrenia through seven participants’ accounts of the way they have been perceived and treated by others, as well as the way they viewed themselves after having been identified with the diagnosis of schizophrenia. Participants were recruited through psychologists at the mental health facility in which they received treatment and were interviewed by the researcher in that facility.

To analyze the data of this study, an empirical phenomenological method was used to explicate the meaning of schizophrenia as it was experienced and lived by participants. In addition, this work included a hermeneutic component to interpret the data and explore implicit dimensions of the experiences described by participants. To make the approach as explicit as possible, the researcher employed reflexive procedures
of acknowledging a priori assumptions, expectations, and presuppositions forming the
frame of reference from which the phenomenon was understood.

The aim of this empirical qualitative research was to explicate the “lived
meaning” of the diagnosis of schizophrenia for particular individuals and then across the
individuals. Though the original objective of the project was to focus on the impact of
diagnostic labeling on individuals’ lives, some of the themes that emerged addressed the
experience of living with the mental illness of schizophrenia more broadly. Themes were
grouped under two clusters to reflect the complexity of participants’ experience. One
cluster pertained to the issue of living with the diagnostic label of schizophrenia. Integral
themes included the impact of diagnostic labeling on identity, concealment of the label in
interactions with others, and facing ignorance and stigma. The other cluster was specific
to schizophrenia as a disorder with which participants struggled. This cluster included
themes pertaining to the frightening onset of the illness, the role of spirituality in coping
with the illness, tension between trust and mistrust in interpersonal relationships,
medication side effects and non-compliance, and perceptions of unhelpful and beneficial
aspects of treatment.

Findings of this study have important implications for research, clinical practice
and public policy. Congruent with prior literature, findings indicate the positive impact of
spirituality on coping with schizophrenia, treatment adherence and satisfaction, and self-
efficacy. Furthermore, participant accounts demonstrated that the illness of schizophrenia
has personal and interpersonal consequences beyond those resulting from diagnostic
labeling. Findings also highlight the need for education and research to combat ignorance
and stigma regarding schizophrenia. Moreover, negative and positive treatment
experiences provide feedback on potentially effective and ineffective aspects of treatment. This information can help mental health professionals become more aware of how they might improve the quality of care in order to facilitate patients’ growth and recovery.
ACKNOWLEDGEMENTS

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Introduction

In Western culture historically society has marked out the different, the deviant, the dangerous, the mad (Harman, 2003). This marking has had both helpful and harmful potentials. Psychiatric diagnosis is a form of marking that when applied in a careful, non-abusive manner, increases clients’ chances of being helped. It should be acknowledged that there exist several benefits to applying a diagnosis. According to the DSM-IV-TR (2000):

The purpose of the DSM-IV is to provide clear descriptions of diagnostic categories in order to enable clinicians to diagnose, communicate about, study and treat people with various mental disorders (p.xxxvii).

The diagnostic process offers many advantages. Besides its utility for treatment planning and communication among clinicians, it provides information about prognosis, contributes to protecting mental health services consumers, and facilitates the communication of empathy of mental health professionals and others toward patients (McWilliams, 1994, pp. 7-10). Also, receiving a schizophrenia diagnosis can be a relieving experience in that individuals are provided with an understanding of what is happening to them as they suffer psychotic symptoms. Also, receiving a diagnosis can lead individuals to receive treatment and support in dealing with the illness.

However, diagnostic labeling can also be a form of stigma:

Stigmatizing involves projecting onto an individual or group judgments as to what is inferior, repugnant, or disgraceful. It may thus translate disgust into the disgusting and fears into the fearful, first by singling out difference, next by calling it inferiority, and finally by blaming ‘victims’ for their otherness (Porter, 2002, p. 62).

Stigma has been and continues to be part of the lives of individuals with serious mental illness. Psychiatric labeling can have harmful consequences for the diagnosed
schizophrenic. According to research evidence [see Wahl (1999), Whitaker (2002), Harman (2003)], once the psychiatric label has been applied, an individual’s name, reputation, and dignity are severely damaged. The diagnosis of schizophrenia may injure many areas of life as it can ostracize and defame a person, maybe for a lifetime. As Harman (2003) observed, applicants for college enrollment, life insurance, officer candidacy, graduate training and other special privileges, can be quickly blacklisted based on severe psychiatric diagnoses like schizophrenia (p. 1). In addition, diagnostic labeling has an effect on individuals’ interpersonal relationships with others who may fear, distrust or avoid living, socializing, working with or relating to people with schizophrenia.

Makal (1999) noted the interrelationship between stigma, mental illness and culture. Each culture has its own value system which defines what is good or bad, normal or abnormal, accepted or rejected, desirable or repulsive. The value system in which each one of us is embedded inevitably influences how mental illness will be lived and experienced. As Makal postulated, “Mental illness does not take place in a vacuum. It is rather lived out within various layers of a socio-cultural dialectic which gives meaning to that experience.” (p. 7) As it is explicated in the pages that follow, schizophrenia is in part a culturally and socially co-constituted story, as the individuals’ lived experience is influenced by our cultural stories; but also goes beyond them. Also, there are biological factors to schizophrenia as well.

Harman (2003) offered a historical account of how the treatment of individuals considered “mad” changed as a result of changes in the way serious mental illness was viewed, storied, and understood. Madness for the ancient Greeks was the result of
humoral imbalance. During the Middle Ages and the Reformation, delusions and hallucinations were indicators of sin and diabolical possession; thus the insane were hanged, tortured and persecuted. During the “great confinement,” the mad were denied reason, treated as wild beasts and shut away in asylums to be restored to health through barbaric treatments such as bloodletting, trephening and physical restraint in chains and straightjackets. In the 19th century, the goal of emerging psychiatry was the classification of symptoms into medical entities. Schizophrenics were mainly treated as inferior diseased creatures with hopeless prognosis. The Nazis employed psychiatry to justify killing schizophrenics and other mentally ill individuals as they were considered biologically unsatisfactory and devoid in value (Harman, 2003). The psychiatric diagnosis of schizophrenia led many to extermination in gas chambers. Other schizophrenics lost the right to marry and were subjected to forced sterilization.

Today, even though the treatment of the mentally ill is more humane, individuals with schizophrenia still face involuntary commitment and continue to be prejudiced against and isolated on the basis of unfavorable stereotypes of mental illness that have survived through the years. Media portrayals of schizophrenics are oftentimes demeaning, false and misleading and reinforce the public’s ignorance and prejudices against individuals with schizophrenia and other serious mental illnesses (Harman, 2003). Stories based on the history of mental illness have changed and have been told over and over throughout the years, and implicitly influenced the way schizophrenics and the mentally ill in general are understood and treated. Entranced by stories about severe mental illness, many in the fields of psychology and psychiatry seem uninterested in learning what schizophrenia is for the schizophrenic person.
Stories in the Western world portrayed mental illness as a “chronic” and “disabling” condition. However, cross-cultural studies of schizophrenia indicated different understandings and treatments of mental illness in Non-Western cultures. For instance, Makal (1999, p. 8) stated that in some developing countries like Sri Lanka, it is a common belief that mental illness is troublesome but curable. Western societies commonly classify delusions and hallucinations as primary symptoms of schizophrenia. In some other cultures, however, these symptoms are considered God-given gifts and common thus normal experiences of shamans. Thus, how mental illness is storied and understood is relevant to the culture in which one lives. Interestingly, a cross-cultural study of schizophrenia conducted by the World Health Organization (1979) supported that the prognosis of schizophrenia is better in developing than developed (i.e., industrialized) countries. In this dissertation, the focus is placed on how schizophrenia is storied in the Western world and experienced by those living with schizophrenia.

In the mental health professions, the most prominent attitude toward schizophrenia is that of the medical model. According to the medical model of mental illness, schizophrenia entails the existence of genetic abnormalities and various neurochemical and physiological defects. Schizophrenia is deemed a neurological brain disease associated with dopamine imbalances in the brain and defects of the frontal lobe caused by genetic or other factors. The DSM-IV-TR (2000) characterized schizophrenia by impairment in reality testing, disorganized speech, thinking, and behavior, illogical thinking, delusions, hallucinations, and other emotional, behavioral, and cognitive disturbances (pp. 153-165). Schizophrenia continues to be considered a primarily
biological phenomenon; psychological and social meanings and experiences associated with schizophrenia continue to be relegated to the background (Makal, 1999).

The medical model approach minimizes the importance, or even the very possibility, of comprehending schizophrenic psychological experiences. This position was taken early on by Karl Jaspers in the early 20th century who claimed that it was “A fool’s errand to penetrate the essential obscurity of the schizophrenic world. Schizophrenia, the result of some as-yet undiscovered physiological abnormality…cannot be understood psychologically from the perspective of a normal mind” (Jaspers, 1964, pp. 577). For Jaspers, schizophrenia’s bizarreness and incomprehensible symptoms were beyond the scope of a Verstehen (understanding) approach. Assuming the biological nature of the illness, the medical model supports a biomedical treatment of schizophrenia to diminish symptoms. Based on this perspective, any attempt to understand the life-world of individuals with schizophrenia through phenomenological methods would be futile.

Numerous studies published over the past three decades have cited growing research evidence supporting the biological model of mental illness adopted by psychiatry. Those studies pointed to the structural and neurochemical abnormalities present in schizophrenics which are believed to account for psychotic symptoms as well as social and emotional-processing deficits. For instance, McCarley et al (1999) reviewed several research studies supporting the position that schizophrenia is a brain disorder with altered brain structure such as third ventricle enlargement, immaturity of dentate gyrus, and volume reduction in medial temporal lobe structures. Also, Carpenter & Buchanan (1994) characterized schizophrenia as “arguably the worst disease affecting mankind…a
personal tragedy which attacks the human properties considered most precious and distinguishing.” (p. 681) These authors, therefore, viewed pharmacotherapy as essential to effective treatment. Corcoran et al (1995) stated that certain schizophrenic symptoms reflect a “deficit in the ability to appreciate other peoples’ mental states,” and that many patients with schizophrenia lack a “theory of mind” which hinders the capacity to infer others’ intentions behind indirect speech (p. 5). It is argued that differences in brain function make it hard for schizophrenics to accurately interpret and recognize other peoples’ feelings. However, despite the aforementioned research findings, the brain mechanisms of schizophrenia remain largely unknown and research evidence inconclusive.

In the past two decades, even though interest in the biological aspects of schizophrenia continues to grow, there has been increasing interest in the social and psychological aspects of living with schizophrenia and other mental illnesses. This is demonstrated by the development of rights advocacy organizations like National Alliance on Mental Illness (NAMI) and Psychiatric Survivor/Mental Health Consumer Movement (or MAD Movement), and widely accepted journals like the Schizophrenia Bulletin and Psychiatry which regularly include articles detailing the experience of mental illness written by current and former psychiatric patients and their families (Makal, 1999).

The primary purpose of this dissertation is not to offer an explanation of the etiology of schizophrenia. Rather, while acknowledging the role of genetic and other biological factors in the development of schizophrenia, I chose to focus on the understanding of schizophrenia as a story or social psychological creation, co-constituted
and lived out by unique individuals, who make sense of and give meaning to their experiences.

Diagnostic labeling and its consequences have been studied by the social sciences for decades. However, very few studies have researched the psychological impact, both positive and negative, of mental illness from the point of view of the affected individuals. Their life-world can be understood through the phenomenological point of view, which respects and seeks to learn and understand persons’ lived experience. What is the experience of living with the diagnostic label of schizophrenia? This question is the central focus of this work. In an effort to be faithful to participants’ lived-meanings, data were analyzed using an empirical-phenomenological method.

One study researching the stigma of mental illness from the point of view of the individual being stigmatized, which also served as the stepping stone for this project, is a dissertation by Michael Makal (1999) entitled The Experience of Living with the Stigma of Mental Illness. I started where Makal left off and addressed what he identified as the limitations of his study or directions for further research. Makal’s study explored the experience of being seen, (supposedly) known, perceived or storied by others as mentally ill in the context of the Western value-system and particularly DSM diagnosis. His study illustrated the negative impact of stigma and explicated the experience of living with the stigma of mental illness. The constituents he discovered to be key in the experience of being stigmatized with mental illness were: Being Found Unacceptable as a Human Being, Being Feared, Being “Diseased,” Being Found Less Than a Full Person, Being Discounted, Being Doubted, Being Laughed At, Being Talked About, Being Non-Existent, Sadness, Separation and Self-Worth, Feeling Misunderstood, Entering the
World, Estrangement, Paranoia, Desire for Acceptance, To Reveal or to Conceal, Finding Acceptance, and Coming to Terms.

This present study, like Makal’s, relied on first-person narrative descriptions of individuals living with the diagnostic label of schizophrenia and employed an empirical-phenomenological method to explore and interpret these descriptions. However, Makal’s study sought to illuminate the general structure of the experience of living with the stigma of any mental illness. It focused on the negative experiences associated with carrying any diagnostic label. In contrast, this present study focused on deepening our understanding of a specific mental illness; schizophrenia, while being open to the consequences, both positive and negative, of carrying that label. Furthermore, this present research study addressed the experience of living with the diagnosis of schizophrenia within a developmental and historical/biographical context.
Literature Review

The Diagnosis of Schizophrenia: A Brief History of Madness

Since the beginning of time, humans have tried to understand and treat madness. Trephined skulls datable back to at least 5000 BC, unearthed by archaeologists, contain holes believed to have been created to allow demons that possessed subjects to escape (Porter, 2002). Archaic Greek myths viewed madness as a visitation from the gods and ascribed illnesses to spirits.

Hippocrates (460-357 BC) was the first to separate medicine from religion and magic, and one of the earliest to point out that different diseases can be distinguished by specific symptoms. Hippocrates developed a comprehensive naturalistic explanation for health and illness, which he thought resulted from the shifting balance between four “humors” or fluids: blood, yellow bile, phlegm, and melancholy. In health (both physical and psychological) these four elements were seen as balanced whereas in disease were believed to be out of proportion (Porter, p. 41). Galen (130-200 AD), another Greek physician whose writings and ideas continued to dominate medicine and psychiatry for the next 1000 years, took over Hippocrates’s humoral pathology and claims that mental diseases could be the result of a disorder in the brain (Harman, 2003).

The middle ages were noted primarily for religious superstitions. In 15th century Europe, hallucinations and delusions were seen as proof that someone was possessed and that madness was a trial or a punishment from God (Kyziridis, 2005). Witches and heretics were accused of causing natural disasters, crop failure, sudden death, and other misfortunes. During the Reformation an estimate of 200,000 people, mainly women accused of rebelling against God, were burned or executed by religious authorities.
The fear and hatred of the mad thus have some of their roots in religious belief and superstition.

In the period between 1656 and 1660, with the rise of absolutism in France and later in the whole of Europe, the mad and the poor were shut away in lunatic asylums during the “great confinement.” Madhouse inmates were deemed to be without rationality and reason, and were treated as wild beasts in a cage. Chains and whips masqueraded as therapeutic (Porter, 2002, pp. 17-25). Asylums served as machines to restore the insane to health through brutal treatments such as seclusion, physical restraint, and bloodletting.

The modern era was marked by the beginning of the so-called moral treatment in Europe. Philippe Pinel (1745-1826), a French physician and one of the founders of modern psychiatry, inspired by the spirit of his time and the Revolutionary ideals of liberty, equality, and fraternity, in 1793 struck off the chains from inmates. Embracing the progressive thinking of the Enlightenment, he postulated that it was a “Supreme moral duty and medical obligation to respect the insane individual as a person… madness is a breakdown of internal rational discipline in sufferers whose moral and psychological faculties needed to be rekindled” (Porter, 2002, pp. 104-105). Pinel and the reformers that followed placed great emphasis on classifying various types of disorders according to detailed descriptions of symptoms to inform appropriate treatment and care for each patient.

In the 19th century, the main goal of the emerging discipline of psychiatry was the scientific grasp and treatment of mental illness. Psychiatry mainly adopted organic etiologies for mental illness and separate disorders were identified. German physician Emil Kraepelin (1856-1926) attempted to make sense of the bizarre behavior he observed
among the inmates of asylums in Germany during the late 19\textsuperscript{th} and early 20\textsuperscript{th} centuries. In 1878, Kraepelin combined the various symptoms he had observed into a single disease entity he termed dementia praecox or “Dementia of early onset”, characterized by a decline in cognitive process, hallucinations of hearing, sight, smell and taste, delusions, slow social decline, and negativism (Harman, 2003). More specific symptoms were divided into 11 subtypes of dementia praecox, described in Kraepelin’s book Dementia Praecox and Paraphrenia (1919).

Kraepelin’s most important achievements were differentiating dementia praecox from dementia in elderly persons (now called Alzheimer’s) and paranoia (today called delusional disorder) as well as providing the foundation of today’s DSM diagnosis of schizophrenia. However, as influential as Kraepelin’s work was, over time it has elicited criticism from various authors such as Harman (2003), Andreasen (2001) and Laing (1960, 1967).

Harman (2003) criticized Kraepelin for not reporting the number of those who conformed to the descriptions he presented, and for focusing exclusively on sufferers’ symptoms or psychopathology without attempting to understand through in-depth interviews with patients what symptoms meant for them or how they experienced their disorder. According to Harman, Kraepelin also failed to give any information about how he arrived at the diagnoses of dementia praecox (i.e., descriptions of how data were acquired, whether other medical and neurological conditions were ruled out, etc.), and he had strong negative prejudices about the people under his care, evidenced by his defamatory remarks about patients. At one point, for example, Krapelin described inmates as “inferior creatures with a hopeless prognosis” (Harman, pp. 91-127). For
Harman, Kraepelin’s biggest failure is that he did not look at individuals holistically, as persons with unique personalities, abilities, interests, and feelings.

In the book *Brave New Brain* (2001), Nancy Andreasen emphasized the “downsides” of Kraepelin’s diagnostic classification as well as of DSM diagnostic criteria. A main criticism is that DSM definitions and criteria dehumanize clinical care. She encouraged mental health professionals to stop thinking of patients as “cases of disease” or “packages of signs and symptoms” without taking adequate time to get to know them as unique individuals who happen to have a medical and/or psychological concern of some type (Andreasen pp. 183-184).

Along the same lines, R.D. Laing offered a powerful critique of Kraepelin in his books *The Divided Self* (1960) and *The Politics of Experience* (1967). In *The Divided Self*, he stated: “It is possible…to know just about everything that can be known about the psychopathology of schizophrenia or of schizophrenia as a disease without being able to understand one single schizophrenic” (p. 33). In their attempt to be “scientific” and “objective,” many mental health professionals try to analyze and classify schizophrenia patients’ speech and behavior into isolated clinical “signs.” However, Laing stated that “To look and listen to a patient and to see ‘signs’ of schizophrenia and to look and listen to him simply as a human being are to see and hear in radically different ways” (p. 33). Looking at patients’ actions solely as ‘signs’ of a disease and imposing our categories of thought on patients limits the *possibility* of understanding and seeing patients as persons.

Eugene Bleuler (1857-1939) criticized Kraepelin’s use of the term dementia praecox, arguing for an absence of evidence supporting a global dementing process (Kyziridis, 2005). Therefore, in 1911 he coined the term “schizophrenia” coming from
the Greek terms schizo (split) and phrene (mind) to describe the fragmented thinking of people with the disorder, with symptoms including alogia, affective blunting, anhedonia, avolition, and attentional impairment (Harman, p. 125). Bleuler was also the first to categorize schizophrenic symptoms as “positive” and “negative,” terms still used today.

The next historical phase in the treatment of the mentally ill was described by Albert Deutsch in his book *Shame of the States* (1948). Deutsch wrote a vivid expose of the disturbing and dehumanizing conditions of America’s State hospitals in the mid-twentieth century. He explained that the treatment of the mentally ill deteriorated to an “animal-like level” (p.28). Mental patients of all diagnostic categories and ages were thrown together in overcrowded cells, often unclothed and not permitted eating utensils. Windows were broken, through which cold blasts came through in winter, endangering the physical health of patients. There were not enough attendants to serve all cells and not enough beds for everybody in each room, forcing many to stand all day or sleep on the ground.

Deutsch also addressed the problem of stigma in his 1937 work, *The Mentally Ill in America*. Here he addressed the question, what follows after mental patients are discharged from State hospitals to normal community life? Harman (2003, pp. 138-139) cited a relevant quote:

> Once discharged as cured … a patient was invariably burdened with new handicaps, one of the heaviest being the “stigma of Insanity” with which the ex-patient of a “mad house” was burdened. The patient cured of pneumonia or appendicitis might return to take up his affairs at the point where his temporary illness had interrupted his normal routine. But not so the recovered mental patient. He was a marked man. He had been “crazy, and didn’t the popular saying go “once insane always insane”? His relationships with family or friends thereafter were likely to be strained, at least for some time; his “term” in a mental hospital stood as a serious obstacle to re-employment. Under these added strains
many a mind gave way again, rendering the individual socially inadequate. (Deutsch, 1937, p. 28)

Many would argue that the above description, even though written 72 years ago, still describes the effects of stigma on psychiatric patients even today. Once a mental illness label is attached to a patient, he or she is likely to carry it for a lifetime.

In the 1930s and 1940s, Nazi psychiatry deemed schizophrenics ripe for elimination. Killing off the “insane” was considered an “act of mercy to shorten the lives of these miserable creatures” whose “lives were not worth living” (Harman, p. 138). Porter (2002) reported that approximately 70,723 mental patents were gassed between January 1940 and September 1942 (p. 187). Before 1940, the insane lost the right to marry and were subjected to forced sterilization.

Partly in reaction to asylums and Nazi psychiatry, a new era of psychiatry began in the 1940s and 1950s focusing primarily on medical treatments. Electric-shock treatments were employed against schizophrenia with some mixed results. Psychosurgery, aiming at behavior modification achieved through surgical intervention into the brain, brought good results to some patients and disastrous results to others. Another type of treatment carrying great expectations was psychopharmacology. Antipsychotic and antidepressant medications made it possible for many patients to leave the psychiatric hospital; however, many studies report devastating side effects. Whitaker (2002) offered an account of those side effects through ex-mental patients’ oral testimonies. Patients complained that neuroleptic medications turned them into “zombies” or made them feel “closed-in,” “mummified,” “confused,” and “fearful.” They reported unpleasant physical side effects such as blurry vision, irresistible sleepiness, constipation, weight gain, and psychomotor retardation (p. 176).
In the 1960s and 1970s, the anti-psychiatry movement questioned the values that drive our care of the mentally ill, and urged offering a caring, humane and responsive environment to their needs, as well as treatment based on dignity and respect. Existential-phenomenological psychiatrist R.D. Laing, while disavowing the label anti-psychiatry, offered an alternative view of madness questioning the merits of neuroleptic medication and the usefulness of psychiatry. His different theses on schizophrenia demystified, normalized, and humanized a condition that was associated with “madness” and stigma. According to Laing, schizophrenics are individuals with extraordinary struggles of living, but are not different qualitatively than individuals without schizophrenia.

Laing viewed schizophrenia as a symptom of what he called extreme “ontological insecurity” where the individual fears being engulfed by others, experiences a sense of unreality, lacks the experience of his or her own temporal continuity, and whose identity and autonomy is always in question (Laing, 1960, pp. 40-43). Laing defined ontological insecurity as an intense dread that one’s ongoing existence is imminently endangered—the absence of a basic trust that one can go on being. Furthermore, he perceived schizophrenia as an adaptation to prolonged and profound miscommunication in the family system. Using a methodology he termed “social phenomenology,” Laing sought to “bracket” or temporarily suspend psychoanalytic interpretations and biological-psychiatric diagnosis, to avoid influencing the behaviors observed. In the book *Sanity, Madness and the Family* (1964), Laing and Esterson employed “social phenomenology” to study how diagnostic symptoms of schizophrenia make sense or become intelligible in the context of experiences and communication in the family system. Finally, Laing (1967) viewed schizophrenia as an inner journey, a voyage of self-recovery and
reintegration, or an attempt at self-healing and rebirth of the self. As he stated, “madness need not be all breakdown. It may also be a breakthrough” (Laing, 1967, p. 133). Looking at psychosis as a healing process that shouldn’t be pharmacologically suppressed, Laing and his associates established “therapeutic communities” to assist this potential liberation from existential death.

The development of therapeutic communities was based on the principle that in the absence of labeling, stigma, psychotropic medications, involuntary treatment, and professional and patient roles, along with the presence of staff that provide support, caring, respect, and appreciation, patients would find a sanctuary to facilitate the journey toward the restoration of their sanity. However, evidence confirming the success of therapeutic households in fostering patients’ journey to self-recovery is elusive. Due to the absence of rules and regulations and structure giving direction to residents’ everyday lives, the atmosphere of these households was often anarchic and chaotic. Furthermore, great tension was observed between residents and between residents and local citizens. Residents would intimidate local citizens by their strange behavior, and citizens would laugh at, ridicule, and stigmatize residents. The project was abandoned due to the aforementioned problems as well as limited funding.

Today, mainstream psychiatry remains committed to Kraepelian description and classification of symptoms into diagnostic categories. However, while treatment of individuals with mental disorder has actually become more humane, there is still progress to be made.
Theories of Mental Illness and Stigma

Social Labeling Theory - Scheff, Sarbin and Mancuso

Social Labeling Theory, a controversial perspective based on Hughes (1945) social status theory and Becker’s (1969) deviance theory, became widely known in the early 1970s through the work of Scheff (1974, 1984) and the social constructionists’ Sarbin’s and Mancuso’s (1980) work on mental illness. The Social Labeling Theory viewed mental illness as a social role. It is a controversial theory as it explicitly challenged the psychiatric view that mental illness is a medical condition that affects individuals from within, and should be treated and alleviated through psychiatric intervention.

Social Labeling Theory claimed that mental illness does not stem from within the person but is a socially constructed category or a role created for individuals in a particular society. Each society is comprised of agreed upon norms, mores, rules, and expectations that define normal or acceptable behavior and dictate what is called deviant, abnormal or pathological behavior. Those norms are implicit or taken for granted by members of a society, and since they are socially constructed, their meaning changes or becomes relative depending on different social contexts. What are considered delusions and hallucinations or pathological thoughts and voices in one society might be culturally acceptable imaginings in another. For instance, a shaman is able to hear the voice of God or see an image of God, or a religious person might feel the presence of Christ in the room with her or him when she or he is praying. These experiences isolated in the context of a mental health interview would support a diagnosis of schizophrenia in that they represent delusions and hallucinations. The same experiences would be considered
“normal” or desirable in a cultural context that valued the experiencing of such thoughts and fantasies. According to Social Labeling Theory, there is not one reality but many depending on relative rules and norms of each society.

Society enforces homogeneity and conformity in its members by rewarding or punishing those who meet or fail to meet normative expectations. As Scheff (1984) postulated, behavior falling outside societal norms is deemed “deviant” and threatens socially constructed reality. Therefore, society does not tolerate and seeks to control behavior that threatens its balance. According to Scheff (1984), society controls deviant behavior through a three-step process: stigmatization, segregation and labeling. A behavior that becomes stigmatized might not be inherently bad or wrong but it is stigmatized and rejected because it is peculiar or different, or lies outside a society’s norms and mores. The actor of a threatening behavior is subsequently segregated and labeled as deviant. Therefore, mental illness is simply an official label applied to, and aiming to control, behavior that violates societal rules and norms. One such violation or form of deviance is mental illness.

The social labeling process does not end with the application of a label or an individual violating societal norms. Official labeling of a diagnosis can trap an individual in a “self-fulfilling prophecy.” Scheff (1984) maintained that official labeling causes a “crisis” in the deviant person who, being in a highly suggestible state begins to act as a mentally ill individual conforming to others’ expectations. When every attempt to escape his or her ascribed role is punished, eventually the deviant person usually succumbs to the role of the insane and begins a career as a mental patient. In Scheff’s words: “The more the rule-breaker enters the role of the mentally ill, the more he is defined by others
as mentally ill, but the more he is defined as mentally ill, the more fully he enters the role, and so on” (p. 72). Thus, mental disorders could be seen as social roles created and maintained by this dynamic and reciprocal social labeling process.

Sarbin and Mancuso (1980) offered a similar point of view on mental illness as a social role or category, and made a strong statement about the stigma accompanying mental illness. If an individual engages in deviant or unusual behavior, then society attempts to label, explain, and control deviant behavior by assigning a label to it. This position is controversial because it challenges psychiatric diagnoses and the role of psychiatry in general. For Sarbin and Mancuso the disease model and psychiatric diagnoses are used to legitimize control and to contain undesirable or socially unacceptable behavior. A label of mental illness, such as schizophrenia, may lead to stigmatization and rejection by society. For these authors, the disease model should be “replaced by a contextualist model that does not have the moral valuations that are disguised by the mental illness concept” (Makal, p. 55).

Scheff’s (1984) critique of Social Labeling Theory was that it is a limited and one-sided perspective. It is overly focused on portraying deviants as powerless victims unable to escape from or reject the role ascribed to them by society. Furthermore, as Gove (1975) argued, the social labeling perspective ignored research regarding the genetic and biological factors that may underpin psychiatric disorders. Also, the social labeling perspective grouped all undesirable and deviant behavior together and avoided looking at the meaning of this behavior from the perspective of the “deviant” or mentally ill individual.
Michel Foucault

Michel Foucault provided a historic-cultural perspective on mental illness or “madness” that social labeling theory lacks. Makal (1999) and Porter (2002) offered a comprehensive overview of Foucault’s interesting and provocative historiography of mental illness and stigma. Foucault asserted that psychiatric concepts and labels are not scientific and objective, but moral concepts disguised in medical terminology. Mental illness diagnoses are just another way to subjugate or bring under control what he calls madness or “unreason.” Foucault in the 1960s argued that the history of madness dated back to the mid 1600s when during the rise of absolutism the King of France Louis XIV inaugurated a “Europe-wide great confinement” of the country’s mad and poor (Porter, 2002, p. 92). In the period between 1656 and 1660, 6000 criminals, streetwalkers, vagabonds, beggars, the insane, and all tainted by unreason were gathered and confined in Paris’s Hospital General. By the end of the 17th century, such hospitals were common in each city of France and throughout Europe. Apparently, the purpose of these houses of confinement was to gather and provide what was considered necessary, from the perspective of those in power, for the health, welfare, maintenance and protection of those who could not provide for themselves.

However, Foucault saw a very different motive behind the establishment of such hospitals. For him, houses of confinement arose out of “condemnation of idleness and a repression of those who might rise up against the State” (Makal, p. 60). Foucault claimed that a political reason behind the great confinement of the mad and the poor was the ascendance of the bourgeois value system. Madness and unreason became associated with idleness, social uselessness and immorality and therefore confinement in lunatic
asylums was considered “therapeutic.” Foucault famously argued that placing the mad and the poor away in hospitals was a tool for social control used by the bourgeois to smooth the running of emergent industrial society.

According to Porter (2002), for Foucault institutionalization was not therapeutic but essentially a police measure or a State’s attempt to solve the social problems spawned by demographic change and industrialization. The mad were deprived of all their legal and human rights, were denied reason and treated as wild beasts in a cage. Even during the period of moral reform in the 19th century associated with Pinel and Tukes (who introduced humane treatment of the insane) madness and unreason was still repressed by a different kind of morality. Even though they literally struck off the chains from the mad, guilt and shame often served as internal chains confining them from the inside. The responsibility for madness was shifted to the insane themselves. Physicians gained a prominent role in the treatment of the mad. Medicine (and today psychiatry and psychology) as power and authority represented the ideal of reason, and madness became equated with stigma and unreason. In this power structure “Madness would henceforth be structured as a microcosm of bourgeois society, and the bourgeois ideal of reason” (Makal, 1999, p. 63).

Foucault’s work generated both praise for its historiography of mental illness and wide criticism among historians (Porter, 2002). He wrote a poetic, rhetorical, account of how mental illness came to be stigmatized and linked to idleness and animality.

Thomas Szasz
Like Foucault, Thomas Szasz (1961, 1987), a psychiatrist, challenged the moral underpinnings of the concept of mental illness (Makal, 1999). In his 1961 seminal work, *The Myth of Mental Illness*, he postulated that mental illness was a “myth.” Szasz argued that mental illness is unlike medical illness for several reasons. First, he claimed that there was no evidence to suggest that mental illness is a brain disease demonstrated by an observable lesion in the anatomy or physiology of the body (at the time Szasz wrote, such evidence did not exist.) Second, unlike other medical fields, which use proven scientific methods to justify their findings, psychiatry bases its diagnostic classification system on political and not scientific grounds. For instance, once viewed as an illness, homosexuality was added to the Diagnostic and Statistical Manual for mental disorders, only to be later removed from it (and thus cease being an illness) in 1973. Szasz saw psychiatric diagnosis as a form of social control that labels norm-violating or disturbing behavior as an illness, and thereby provides justification for psychiatric treatments. Finally, whereas typically a medical patient voluntarily visits a doctor and chooses whether to accept or refuse proposed treatment, this is not the case in the psychiatric relationship where the psychiatrist has the power to force treatment upon a patient, as in involuntary commitment. For Szasz, the distinction between the medical and psychiatric situations is that the former is typically cooperative, whereas the other is coercive. “The physician controls diseases, not persons, whereas the psychiatrist controls persons, not diseases” (Szasz, 1987, p. 127).

The mentally ill, for Szasz, are persons who violate social norms and are then categorized as having a mental illness for several reasons. First, by claiming that mental illness is a disease, society has the legitimate right to control socially undesirable
behavior. Second, if mental illness is classified as a disease, then psychiatrists reap financial benefits. Last, both doctors and some mental patients may benefit from the mental illness claim. Psychiatrists may feel powerful by imposing their authority and infantilizing patients, while on the other hand, certain patients might benefit by being absolved of legal and moral responsibility for their actions (Makal, 1999). Szasz suggested that psychiatry should abandon the medical model as a means for explaining human behavior. Instead, psychiatry should try to understand all behavior as meaningful and intentional.

Szasz’s work is important because it offers a critical view of the moral and scientific foundations of psychiatry, and the social ramifications involved in receiving a mental illness diagnosis. In doing so, it invites the question of how the “myth” of mental illness impacts those subjected to its consequences. However, the effectiveness of medication as well as research indicating genetic and biological components to schizophrenia, have been used as arguments against Szasz’s assertion that mental illness is a myth.

Erving Goffman

American sociologist Erving Goffman, in his seminal work *Stigma: Notes on the Management of a Spoiled identity* (1963), offered a sociological perspective on stigma. For Goffman, stigma is “The situation of the individual who is disqualified from full social acceptance” (Porter, 2002, p. 62). As expressed by Porter (2002), “Stigmatizing – the creation of spoiled identity – involves projecting onto an individual or group judgment as to what is inferior, repugnant, or disgraceful. It may thus translate disgust
into the disgusting and fears into the fearful, first by singling out difference, next by calling it inferiority, and finally by blaming “victims” for their otherness” (p. 62).

Goffman defined stigma and described its impact on the relationship between individuals carrying the stigma and those who do not. For Goffman, society teaches us to categorize people we interact with in terms of their “social identity” and attributes that define it. These assumptions are implicit, so individuals are not explicitly aware of them when in their everyday interactions they encounter and categorize others. Goffman distinguished between two types of social identity. Individuals in a society typically assign or attribute certain characteristics to a person, which form the person’s virtual social identity. However, an actual social identity refers to the qualities or characteristics that the person actually possesses. Even though actual and virtual identities often coincide, sometimes they do not. Someone with a particular social identity may possess an undesirable attribute that sets him or her apart from others in the same social category. This discrepancy between virtual and actual social identity is called stigma.

In *Stigma: Notes on the Management of a Spoiled Identity*, Goffman distinguished between three types of stigma:

First there are abnormalities of the body – the various physical deformities. Next there are blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction alcoholism, homosexuality … Finally there are the tribal stigma of race nation and religion (1963, p. 4).

In these types of stigma, attributes possessed by an individual in a particular context usually elicit discomfort from others who tend to reject or turn away from the stigmatized person. In all societies, individuals seem to have the psychologically driven or unconscious need to order the world in an attempt to distinguish and demarcate self
from others. According to Porter (2002), the construction of polarizing distinctions drawn between insiders and outsiders, “them-and-us,” reinforces our fragile sense of self-identity. Diagnosis is an obvious example of this need to order the world into categories, and psychiatry contributes to the stigmatizing enterprise through its diagnostic classification system. It sets the sick or insane apart from the normal or sane.

Stigma exerts a great influence on its carrier’s interpersonal relationships and has negative psychological impact on the stigmatized. The world becomes polarized between one’s own group (i.e., others possessing the same stigma) and others who do not share the stigma. Identifying with the stigmatized group, the person may feel understood and gain support, guidance, and empathy from others, whereas refusing to do so may cause shame, resentment, and self-hatred for not being able to meet normative expectations.

Goffman’s work is a sociological study of the process whereby stigmatized persons as a social group acquire a new social identity. Even though it touches upon some of the psychological effects of stigma such as the stigmatized individual’s ambivalence, self-derogation, and shame about his or her new identity, it does not explore in depth the individual psychological experience of living within the stigma of mental illness. The present study attended to this lack by exploring how individuals that carry the label of severe mental illness experience stigma and its lasting psychological effects.

Studies supporting the consequences of psychiatric labeling

Next, different types of studies on the impact of psychiatric labeling will be briefly reviewed. These include experimental research, autobiographical accounts and attitude surveys. These types of studies are described in greater detail by Makal (1999), Whitaker (2002), Porter (2002), and Harman (2003).
Experimental Research

The Rosenhan study (1973) is one of the most well-known studies investigating stigma as it is related to psychiatric diagnoses. *On Being Sane in Insane Places* led to a public outcry and concern about the reliability and harmfulness of psychiatric diagnoses. In this research study, eight “normal” subjects posing as patients with a single symptom were admitted to various psychiatric hospitals. Their presenting complaint was hearing voices which said such things as “thud,” “empty,” or “hollow.” Once admitted into the hospitals, all but one were diagnosed with schizophrenia (Harman, 2003).

Once admitted, the pseudopatients stopped complaining of symptoms. They then started openly writing notes on their observations. During their hospitalization no staff member suspected their pseudopatient status. Length of hospitalization ranged from 7 to 52 days and during that period of time the eight pseudopatients were given 2,100 neuroleptic pills, which they hid or flushed in the toilet. The majority of them were discharged with a diagnosis of schizophrenia “in remission” (Whitaker, 2002). Interestingly, many of the patients suspected that the researchers were not “real” patients but “journalists or professors” checking on the hospital (Makal, 1999).

Rosenhan and his associates also discovered some aspects of what it was like to be a schizophrenic in the eyes of others. They wrote in detail about the relationship between staff and patients. According to Whitaker, doctors and nurses spent almost no time with patients and avoided interacting or even making eye contact with them. They did not offer meaningful responses to any of the patients’ questions. Often, attendants would wake patients up in the morning screaming “come on, you motherfuckers, out of bed” (Whitaker, p. 170).
The Rosenhan study was important in that it exposed the unreliability of psychiatric diagnoses and raised questions about the treatment of patients within psychiatric hospitals. Once the schizophrenia label was applied, the staff tended to treat patients in ways that confirmed their status as mentally ill.

Autobiographical Accounts

A famous example of an autobiographical account of the experience of stigma comes from Clifford Beers in his 1908 book, *A Mind that Found Itself*. His book had a significant impact in the struggle for better treatment of individuals with mental illness. In his book, Beers described his involuntary commitment and the mistreatment of patients and the living conditions in the mental hospital. Like many others, Beers was subjected to such cold in his cell that he had to keep moving to keep warm. He portrayed most attendants as “ignorant brutes” physically assaulting and yelling at inmates. The mail Beers sent to his family was discarded, and mail sent to him was never delivered. Beers wrote about the cruelty and violence inflicted on patients (e.g., they were beaten with rods, chained, humiliated) and how his suffering was aggravated by his almost continuous confinement (pp. 132-136). After his recovery, Beers recalled that the treatment he received seemed like “malicious torture, which would drive a sane man to violence,” (Porter, 2002, p. 169).

Another example of an autobiographical account is that of Patricia Deegan, a psychologist who wrote extensively about her experience of living with the diagnostic label of schizophrenia. Having first been diagnosed with schizophrenia at age 17, Deegan rejected the “prophecy of doom” associated with her diagnosis, that she would never get well and that the best she could hope for is “cope” by taking medication for the
rest of her life. She went on to earn her doctorate in clinical psychology from Duquesne University in 1984, lectured, published, and consulted on recovery and the empowerment of people with psychiatric disabilities throughout the U.S. and internationally. As an activist, she has spoken around the world about her personal and professional experience of recovery and continues to inspire and speak to many people’s experiences through her powerful testimony. In her work, she talked about the impact of diagnostic labeling on one’s self sense of self, dreams, and future goals. She spoke of recovery as a transformative, self-directed process through which a new sense of self emerges. She challenged the medical model’s reductionism and pessimistic prognosis on schizophrenia, and offered suggestions that mental health services can implement in improving the quality of care offered to individuals with schizophrenia.

In her 2001 article “Recovery as a Self-Directed Process of Healing and Transformation.” Deegan shared her personal experience of being diagnosed with schizophrenia. She stated that before being diagnosed with mental illness, there was a basic congruity between how she understood herself and how others perceived her as a whole and unique individual with a promising future. However, the way she was viewed by people around her drastically changed after being diagnosed. As she described:

> It seemed that everything I did was interpreted through the lens of psychopathology. I was always quiet, shy and introverted. Now I was guarded, suspicious and had autistic features. When growing up, my grandmother used to say I had ants-in-my-pants. Now, in a mental hospital, I was agitated … in a classic double-blind, if I protested these pathologized interpretations of myself, then that was further proof I was schizophrenic because I lacked insight! (p. 5)

Once diagnosed, Deegan felt that her identity had been reduced to an illness in the eyes of those interacting and working with her. She vividly recalled the event of her
diagnosis. The psychiatrist compared schizophrenia to a disease like diabetes for which she had to take medications for the rest of her life and go into a halfway house to be able to “cope.” Deegan refused to accept this hopeless prognosis and started fighting for a life that had meaning and hope. “I am more than a schizophrenic. I am a person of worth and dignity,” (p.5) she felt. Deegan saw this incident as a turning point in life. She organized her recovery around a dream: to become a psychologist and transform the mental health system so it helped instead of hurt people.

Deegan’s case explicated the painful consequences of diagnostic labeling as well as recovery as a process of transformation of the self and regaining control over one’s life, hopes, and dreams. Receiving a diagnosis of schizophrenia was a life-shuttering, spirit-breaking experience for Deegan. Friends and strangers were frightened of her or overly careful when near her. She described feeling helpless and powerless, and the “dehumanizing” transformation from being a person to being an illness.

For Deegan, recovery meant to overcome and reject the shame and stigma she internalized. Recovery was a process of healing and transformation for her. In this process, she realized that she was not simply passive victim of her illness, but could play an active role in the management of her illness. For her, recovery did not mean “cure” but “a transformation of the self wherein one both accepts limitations and discovers a new world of possibility, it is a self-directed process of reclaiming meaning and purpose in life” (p. 19).

By reducing patients to an incurable illness with a hopeless prognosis, many doctors and others in patients’ lives tend to ignore the resilient strengths, as well as the hope for recovery, of labeled schizophrenics. Many supporters of the medical model
often overlook the context of individuals’ lives and fail to recognize the intensity of the existential struggles of those individuals with schizophrenia. Those human experiences include loss, grief, shock, fear, loneliness, abandonment by friends and relatives, and abandonment of dreams and hopes. Due to the pessimism and “prophecies of doom” that surround the diagnosis of schizophrenia, patients suffer the effects of poverty, stigma, dehumanization, and degradation. They cease to be the experts of their experience.

Deegan offered suggestions that mental health professionals can implement in improving the quality of care and facilitating the recovery of those labeled with schizophrenia. These included: teaching tomorrow’s mental health professionals not only clinical and diagnostic skills, but the necessity of seeing patients as human beings with psychiatric disabilities; viewing patients as active agents in their recovery rather than passive victims of their illness; sharing power with rather than having power and control over patients; and creating hope-filled care-filled environments that nurture and invite growth and recovery in those who have lost hope.

Surveys

Makal (1999) and Harman (2003) cited various attitude surveys supporting the existence and importance of psychiatric stigma. There are two kinds of attitude surveys: attitude surveys of the general public, and patient attitude surveys. The first type of survey was described by Makal as distributing a list of statements or questions to a random sample of the population. Examples of survey items included: “I would not hesitate to work with someone who had been mentally ill,” “I would be willing to room with someone who had been a patient in a mental hospital,” and “I can imagine myself falling in love with a person who had been mentally ill” (p. 19). Participants were asked
whether they agreed or disagreed with items and how strongly, and on the basis of the mean of scores, researchers concluded whether the public accepted or rejected individuals with mental illness. An example of this type of survey comes from Bentz and Edgerton (1971) who distributed “social distance” questionnaires to a random sample of 1,405 rural North Carolina respondents. Participants were willing to tolerate relationships with mentally ill individuals as long as the relationship was not extremely personal. Results of this survey indicated that the rural North Carolina respondents were more accepting than rejecting of the mentally ill (Makal, pp. 19-20).

Harman offered a review of the most extensive patient attitude survey focusing on the responses of those most affected: the mentally ill themselves. This research was conducted by Otto Wahl, his graduate student at George Mason University, and NAMI (National Alliance for the Mentally Ill) in 1999. Respondents were people diagnosed with a serious mental illness including schizophrenia, bipolar disorder, and major depression. The goal of this research was to look at the consumers’ reactions to stigma experiences, as well as how consumers coped with stigmatizing experiences. Participants described how they were rejected by friends and families, how stigma experiences often led to isolation from others, their sensitivity to some who were unreasonably concerned or fearful by possible dangerous behavior, and their experience of being appalled by some who considered them as lacking in intelligence or responsibility. Sometimes they reported that they were disregarded and ignored or treated as incompetent (pp. 35-37).

Thus far, I have attempted to provide a concise review of existing literature on how mental illness or “madness” has been and continues to be viewed in Western societies, and how those deemed “mad” have historically been treated—or rather
mistreated. I have examined various theories of mental illness as well as studies supporting the negative consequences of psychiatric labeling. The specific focus of the present project is to study the experience of living with the diagnostic label of a specific mental illness: schizophrenia. What is unique about this study is the emphasis on the experience of living with the diagnosis of schizophrenia from the perspective of the patients themselves. Michael Makal’s (1999) dissertation served as a stepping stone for this project. However, whereas Makal explicated through first-person narrative descriptions, the experience of living with the stigma of any mental illness, the objective of this present study is to use first-person accounts to deepen our understanding of schizophrenia, a condition most commonly associated with “madness” in Western culture. One appropriate method for explicating the psychological experience of living with the diagnostic label of schizophrenia is the empirical-phenomenological approach. This method emphasizes participants’ lived meanings, allows for their voices to be heard, and can hopefully contribute to changing how we understand, view, and treat them.

Non-Biomedical Views of Schizophrenia: Nature and Treatment

Harry Stack Sullivan: Interpersonal Theory and Psychotherapy

Harry Stack Sullivan was a U.S. Psychiatrist who developed a theory of clinical psychiatry based on interpersonal relationships. Sullivan postulated that personality develops through our interactions with others, and that psychiatric symptoms arise as a result of fundamental conflicts between the individual and his or her human social environment. While acknowledging the genetic contribution to mental illness, he emphasized psychological and social factors rather than neurobiology as bases for psychiatric disorders. His work on interpersonal relationships was revolutionary in that it
extended Freudian psychoanalysis to the treatment of patients with severe mental disorders, particularly schizophrenia. He believed that, though impaired, the mental functions of schizophrenics were not beyond repair. Through his clinical work, he demonstrated that it is possible to understand schizophrenics and aid in their recovery.

Harry Stack Sullivan was critical of Kraepelian psychiatry’s emphasis on classification of disease entities and pessimistic prognosis. He felt that interpersonal social and cultural aspects were ignored. Contrary to the hopeless and pessimistic customary view, he maintained that mental disorders are not predestined and inexorably fixed, but preventable and curable. He demonstrated that the occurrence of mental illness could be explained primarily on the basis of experiential factors rather than by reference to a primarily organic disorder.

In his developmental theory of personality, unfulfilled basic social needs such as communication, friendship, and sexual expression may result in feelings of inadequacy, severe loss of self-esteem and self-worth, and may precipitate a schizophrenic break from reality. Sullivan characterized schizophrenia as a “peculiar disorder of social or non-social activity” (Sullivan, 1962, p.221) and saw individuals suffering from schizophrenia as extremely shy and sensitive. Their social vulnerability “naturally erected enormous defensive machinery between themselves and intimate contact with other people” (Sullivan, 1962, p.223). These characteristics have not been recorded in diagnostic manuals and textbooks, but can be evident to those intimately involved with schizophrenic individuals in clinical practice.

Sullivan developed the technique of “participant observation” in which the psychiatrist was not just an observer of patients’ behavior, but became a “significant
other” in their lives through their interactions. Therapy thus provided a sympathetic, supportive environment. He saw the clinical interview as a special instance of all interpersonal situations. The psychiatrist is not distant and detached from appreciating the interaction, but involved, interested, respectful, genuine and tolerant. The relationship in itself was therapeutic, facilitated the development of interpersonal intimacy and helped in the re-development of self-esteem and eventually the readjustment of the general structure of personality. Unconditional acceptance and prizing facilitated the development of trust in individuals who “learned long before admission that there is no-one in the wide world who can be trusted to value and to love” (p.318). Most importantly, patients were appreciated and treated as persons striving to live among persons, “very human” whose complexity cannot be grasped. Sullivan maintained that “we are all more alike than different” (p.235) recognizing the basic humanity of all individuals, including those who are most deeply psychotic.

Specially trained ward attendants worked with patients in Sullivan’s treatment ward at the Sheppard Pratt hospital to provide meaningful relationships with patients, treating them as humans beyond their clinical label. Sullivan (1962) reported that a significant proportion (70-80%) of patients treated under these conditions improved to the degree of “social recovery,” or improvement to the point of functioning in society without requiring active institutional supervision (p.284). The therapeutic environment provided by the psychiatrist was crucial in patients’ progress and recovery.

Frieda Fromm-Reichmann: Principles of Intensive Psychotherapy

Frieda Fromm-Reichmann succeeded in using intensive psychotherapy to treat schizophrenic patients who were previously considered unsuitable for psychoanalysis.
Her perspective was revolutionary because she introduced modifications to the classical psychoanalytic model of the time, treating patients face-to-face, focusing on the here-and now of the therapeutic situation in order to understand patients’ past relationships, and attempting to assist psychotic patients to integrate rather than reject their illness.

A highly gifted clinician, Fromm-Reichmann maintained that the development of a trusting therapeutic alliance with individuals having difficulty trusting others in their interpersonal relationships was a key aspect of treatment. This realization was based on her observation that the tendency of schizophrenics to withdraw reflected an ambivalent conflict; they were torn between intense longing for and an equally intense fear of symbiotic merging with another (Cohen, 1982). She considered patients extremely sensitive and was attuned to their fear of closeness. She perceived the therapist’s role as making up for patients’ inadequate mothering through constant warmth and continuous effort to reach a harmonious relationship. Fromm-Reichmann emphasized basic therapist attitudes such as humility and willingness to learn from patients, respect, listening, and communication of understanding in successful psychotherapy. She saw patients as “tending toward health, growth and independence” (pp.13-14).

Like Sullivan, Fromm-Reichmann emphasized that emotional difficulties in living are difficulties in interpersonal relationships. An individual is not mentally healthy if he or she is not aware of or able to handle his or her interpersonal relationships (Fromm-Reichmann, 1960, p. xiv). By virtue of our common humanity, Fromm-Reichmann believed that the emotional difficulties of mental patients, neurotics and psychotics, are rather similar to one another and also to the emotional difficulties in living from which we all suffer at times. However, a person becomes a mental patient in need of
psychotherapy if those difficulties are so great that he or she is unable to resolve them without help. (p. xi). Like Sullivan, Reichmann also saw therapy as an interpersonal process aiming to help patients clarify the troublesome aspects of their lives and ultimately to resolve their symptomatology.

Bertram P. Karon and Gary R. Vandenbos: Psychotherapy of Schizophrenia

Karon and Vandenbos (1981) demonstrated that psychotherapy, including some versions of psychoanalytic therapy in particular, is the effective treatment of choice for schizophrenic patients. These authors outlined empirical data coming from 6 major studies showing that even a small amount of psychoanalytic therapy (i.e., an average of 70 sessions over a 20 month period) produced changes that medication alone could not produce. Patients who received psychotherapy as compared to those receiving medication alone showed less thought disorder, spent much less time in the hospital, and improved in overall functioning, and psychotherapy proved to be less costly in the long run (Karon & Vandenbos, 1981, p.371). Furthermore, individuals who received psychotherapy demonstrated an increased ability to be economically self-sufficient (pp. 442-443)

Furthermore, Karon & Vandenbos offered insights regarding the prognosis, nature, and treatment of schizophrenia. First, they emphasized an optimistic perspective demonstrating that the schizophrenic individual might not be easy to treat, but is not impossible to treat (Karon & Vandenbos, 1981, p.33). The authors sited several examples of well-known psychoanalysts who successfully treated schizophrenic patients, such as Carl Jung, Alfred Adler, Harry Stack Sullivan and Frieda Fromm-Reichmann. From these examples they conceptualized effective treatment as getting the schizophrenic patient to
build a relationship with the psychoanalytic therapist, and then using the therapist as a bridge to the external world.

Karon and Vandenbos described the nature of schizophrenia as experienced by patients. In their clinical experience, schizophrenic patients are frightened, confused, usually lonely, and often angry human beings. They know they are different from other human beings and that they have different experiences. They notice that frequently others do not react kindly towards them and may stigmatize them because of these differences (p.3). They do not understand what is happening to them and what has caused it, and typically they do not know what to expect of the future. And even though the genetic and physiological evidence is still questionable, they were led to believe by professionals and popular culture that they suffer from a genetic-physiologic “disease” that is incurable and with which they must live forever (p.3).

A basic conflict frequently faced by individuals with schizophrenia is that of feeling lonely and moving toward people, then feeling scared and moving away from them. They cope with a “terrible world” filled with “terror.” Yet, they are human like you and me. There is nothing in the schizophrenic reactions which cannot be found in the potentiality of all human beings, and any one of us could develop so-called schizophrenic symptoms under enough stress of the right kind (p.43). According to Karon and Vandenbos, while symptomatology and degree of impairment vary across schizophrenics, they all have in common that they are very ill, their reactions to normal life are impaired, and their symptoms can be understood as defences against terror.

In light of the literature reviewed, the current study sought to explicate the experience of living with schizophrenia from the point of view of the individuals carrying
the diagnosis. Specifically, the psychological impact of living with schizophrenia and the impact of carrying the psychiatric label of schizophrenia were addressed.

**Method**

The study investigated the experience of living with the psychiatric label of schizophrenia through participants’ accounts of the way they have been perceived and treated differently by others after having been identified with the diagnosis of schizophrenia.

**Participants**

Individuals recruited to participate in this study met the following criteria:

1. They were diagnosed by a psychiatrist or psychologist as having schizophrenia based on having met DSM-IV-TR criteria.
2. They were adults of any age, both men and women, born as American citizens or individuals who reside in the US coming from Western Culture backgrounds.
3. Participants agreed or disagreed with their diagnosis, but were aware that they have or had been perceived by others as mentally ill.
4. Participants were able to participate comfortably in all phases of research, including: interacting with the researcher, having interviews tape-recorded, and talking about their experiences of the impact of diagnostic labeling. Participation was voluntary, informed, confidential, and participants were made aware that they had the freedom to withdraw their participation at any time.
5. Range of participants included individuals diagnosed with both Reactive and Process schizophrenia types.
6. The Psychologist inviting clients to participate in this study made the determination that potential participants were not cognitively impaired based on clinical judgment and diagnostic skills.

Participants were recruited through mental health professionals working with individuals with schizophrenia. These professionals were contacted directly by the researcher. The professionals provided information about the purpose of the research project as well as copies of the research request to participants. As mentioned above, to
address the concern or question of cognitive impairment in participants, it was important that the psychologists inviting clients to participate in this study made the determination that potential participants were not cognitively impaired based on clinical judgment and diagnostic skills. These professionals were asked to announce the research project and provide brief information about the nature of the study or display copies of a flyer describing the study and including contact information. In addition, the researcher asked mental health professionals at different “partial hospitalization” and inpatient programs to allow her to present the research project in person to groups of clients. Participants who expressed interest were provided with a guide that reiterated the nature and purpose of the study. Participants were informed about precautions taken to safeguard their confidentiality, as well as that their involvement was voluntary and could be withdrawn at any time. Finally, participants signed a consent form agreeing to participate in the study.

This study made an effort to include a range of participants at different levels of functioning. Toward this end individuals with diagnoses of either Reactive or acute and Process types of schizophrenia were included. Those participants diagnosed with Reactive schizophrenia had developed schizophrenia suddenly, in reaction to some life crisis, and had good premorbid history. On the other hand, those diagnosed with Process schizophrenia had a slow, insidious onset at a young age.

**Research Question and Data Collection**

The following is the question that was posed to interested and qualified participants:

*Please describe your experience of living with the diagnosis of schizophrenia. How has the diagnosis affected your self-image? How has the diagnosis influenced the attitudes and responses of others?*
Please describe your experience as fully as possible with specific examples

The question posed is similar to that posed by Makal (1999) in his investigation on the stigma. However, unlike Makal who investigated the stigma of any mental illness diagnosis, I was interested in explicating the structure of living with schizophrenia. Stigma was only one dimension of the experience of living with schizophrenia.

Participants were interviewed at the mental health facility in which they received treatment. First, the researcher and participants met briefly so that participants were provided with the research question and consent forms. Then signed consent forms were acquired, and in response to the question, participants were interviewed. Personal interviews allowed for a conversation between participants and researcher. Originally, the researcher intended to meet twice with each participant for audio taped interviews, with the purpose of the second to allow participants to clarify or expand on selected areas and to ask the researcher questions about the research process in general. However, due to lack of participant availability the second interviews were not performed. Nonetheless, at the end of the first interviews each participant was encouraged to ask questions, elaborate their accounts, and note if any concerns arose. After the interviews were completed, accounts were transcribed verbatim and identifying information was removed. Consultation with mental health professionals working with participants regarding background and treatment history was utilized as a supplementary source of data.

Data Analysis
To analyze the data of this study, I used the empirical phenomenological method developed by Amedeo Giorgi (1970). This method helped explicate the meaning of the diagnostic label of schizophrenia as it was experienced and lived by participants. In
addition, this work included an interpretive component—going beyond description of participants’ experiences to explore implicit dimensions of those experiences.

Fischer and Wertz (1979) provided a definition and overview of an empirical phenomenological method as developed at Duquesne University. Phenomenological psychology explores human behaviors, psychological experiences and situations as those are lived by the individual. This is done by researchers “bracketing,” or setting through a process of rigorous self-reflection theories, constructs, prior knowledge, and presuppositions about the phenomenon under investigation in front of us for critical reflection. According to the authors, phenomenology studies a person’s life world as it is experienced and formed by the person who lives it. By the term “empirical” Fischer and Wertz referred to reflection upon actual events and providing “data and steps of analysis that lead to findings so that other researchers can see whether and how they could come to similar findings” (p. 277). The aim of this empirical qualitative research was to explicate the “lived meaning” of the diagnostic label of schizophrenia, for particular individuals and then across those individuals.

In the present study, general themes observed across different descriptions were characterized as the shared constituents of the phenomenon under investigation. Emphasis was given to commonality that was present in the many diverse appearances of the phenomenon, and to reliance on the actual words of participants. The empirical phenomenological method appreciates that reality is multiperspectival and thus experienced differently by different individuals, and yet unitary in that researchers can come to a consensus about its essential aspects or constituents. “A rose may be a
different rose to each of us, but we all recognize that it is indeed a rose (Fischer & Wertz, 1979, p. 277).

Empirical phenomenological research is reflexive in that it “turns back upon” or “takes up again” what has been experienced pre-reflectively (Walsh, 2003, p. 52). Phenomenology and hermeneutics play a foundational role in practices of reflexivity. Phenomenology highlights the importance of experiential accounts and is concerned with explicating a priori assumptions and presuppositions. Hermeneutics emphasizes the interpretive and perspectival nature of all understanding, underscoring that research findings are shaped by and comprehended through researcher presuppositions. Therefore, explicating one’s approach is important.

In empirical phenomenological research, researcher expectations and presuppositions are not viewed as obstacles that hinder understanding, but integral to research results and useful in forming the ground or frame of reference from which the phenomenon can be understood. The qualitative researcher’s main aim is to make his or her approach as explicit as possible. Walsh (2003) spelled out the reflexive procedures of acknowledging researcher a priori assumptions, researcher reflection, and explicating implicit assumptions or approach. During the procedure of acknowledging a priori assumptions, researchers articulate in written form their interest in the phenomenon under investigation as well as their expectations for the project. In addition, researchers may reflect on and note down their impressions and reactions during the research process, in order to access and become aware of implicit assumptions they hold. Finally, researchers scrutinize their findings in light of the a priori assumptions identified and their own
reflections. Thus, maintaining a progressive reflection journal before, throughout and after the research process was an important part of the present study.

After gathering and reviewing background literature, the researcher using the empirical phenomenological method first asks participants to write about or orally describe an experience. Based on a preliminary interpretation of those initial accounts, the researcher asks participants to elaborate and clarify specific points. Then, the transcribed interview becomes the text for analysis. Researchers immerse themselves in the data and by reading and rereading the text several times, and then identify and thematize statements relevant to the phenomenon under investigation.

As a next step, edited descriptions are organized to form a “general structure” of the phenomenon across participants’ accounts. Here the researcher notes aspects essential to all cases and how descriptions reveal the meaning of this experience. Following this rigorous process, verbatim passages from participants’ descriptions illustrating each identified aspect are presented to readers, who can agree with or challenge the researchers’ descriptions and interpretations.

For the present study, a basic description of the complex and extensive process of arriving to the “general structure” or basic constituents of the phenomenon of living with schizophrenia follows (pp.46-49). The research question posed to participants contained three elements or dimensions. First, it asked about the experience of living with the diagnostic label of schizophrenia more broadly. Second, participants were asked to reflect on the impact on their self-image of receiving a schizophrenia diagnosis. Third, participants were asked about how the diagnosis influenced the attitudes and responses of others. Therefore, the research question inquired about three dimensions of participants’
experience: The contextual dimension referring to the broader context of participants’ experiences, the personal dimension regarding the psychological impact of schizophrenia, and the interpersonal dimension concerning participants’ relationships with others.

Bearing these three broad categories in mind, the interviewer highlighted on each participant’s transcript sentences relevant to each dimension. Throughout the process, marginal notes regarding recurrent ideas or points, as well as reactions from the interviewer were made next to highlighted quotes. Then, demonstrative quotes corresponding to the three dimensions were clustered (i.e., copied and pasted) for each of the participants. Those quotes were read, reread and reflected upon to the point where specific themes under each dimension cluster started to be identified for each of the participants, and those were noted. Identified themes later formed the individual interpretive summaries detailed in the results section. Themes for each individual participant were noted and were compared across participants. Following, common themes across participants were identified. Those themes later formed the general interpretive summaries resulting from the study. A flow chart describing the reflexive and rigorous process of arriving to the particular themes for the participants is found on page 51.

It is hoped that information obtained in this study will offer the psychology community knowledge about the diagnosed individuals’ concerns and perspectives of how they are, have been, and would like to be treated by others in a mental health setting, as well as in their personal life, as a result of their diagnostic label – information patients might not otherwise be given the opportunity to disclose in their everyday lives. This information can help mental health professionals become more aware of how they might
improve the level of care in order to create a nurturing and supportive environment that will facilitate patients’ growth and recovery.
Living with Schizophrenia

3 Dimensions

- Contextual (e.g., social context, hospital, media, stigma)
- Personal (e.g., psychological, self-image, fear, self-acceptance)
- Interpersonal (e.g., trust and mistrust in relationships, others’ reactions)

Preliminary analysis:
Quotes pertaining to each dimension highlighted on each participant’s interview transcript

Demonstrative quotes clustered (i.e., copied and pasted) for each dimension for each of the participants

Specific individual themes identified under each dimension cluster for each participant (i.e., individual interpretative summaries)

Common themes across participants are identified (i.e., general interpretative summaries)
Results

I. Individual Interpretative Summaries

Devin’s Experience of Living with the Diagnostic Label of Schizophrenia

Devin is a 26-year-old, single, White, middle-class man. He was diagnosed with schizophrenia at age 21 and has received psychiatric treatment at both the inpatient and outpatient levels of care. He is currently unemployed. While in inpatient treatment at 2 state mental hospitals, he received multiple ECT treatments and several trials of various psychotropic medications. Over the past 2 years, he participated in outpatient treatment at a hospital’s Intensive Outpatient Program, and has been seeing a psychiatrist for pharmacotherapy once a month. He is on disability support and now lives alone in an apartment. During the interview he appeared to be shy (e.g., no eye contact,) reserved, and concrete (did not offer elaborate answers to questions). He avoided offering details of his personal experience with schizophrenia and emphasized the desire to be “normal,” his current state of well-being, and ambivalence about the usefulness of treatment.

For Devin, living with the diagnosis of schizophrenia entailed several dimensions. First, with respect to his self-image, while Devin recognized that he has a mental illness, he did not identify with the diagnostic label of schizophrenia; he did not seem to identify with the role of a mental patient, and described his illness as an event of the past. Devin kept emphasizing that he was “fine” and that he would like to be “normal.” Second, with regards to his view of the attitudes and responses of others, Devin stated that those did not change in response to receiving a psychiatric diagnosis. However, Devin offered some contradictory responses. On the one hand he expressed that his relationships were “better than ever” and that he was now closer to his family, but on the other he said that
he lost some friendships and did not like to depend on others after he was diagnosed with mental illness. Finally, Devin spoke about his negative treatment experiences in the hospital.

Based on the interview content, Devin did not seem to accept the diagnosis of schizophrenia or his role as a patient. However, an interesting contradiction is that Devin had been compliant with treatment as he still maintained monthly appointments for medication management in a schizophrenia treatment program. Even though he refused to offer details on the experience of the onset of schizophrenia, Devin looked scared and visibly anxious when he stated that being “sick” and feeling that he “couldn’t control” his “mind” was “rough.” He also mentioned that receiving a diagnosis “was not good” in terms of the way receiving the label of schizophrenia impacted his life, but did not elaborate in his responses. He quickly, however, counteracted those responses with several statements affirming that he was “fine” and was “feeling good.”

Devin did not seem to identify with the diagnostic label of schizophrenia or the role of a patient, despite being in treatment. He denied ever experiencing symptoms (“No I never really heard voices”) despite receiving several ECT treatments. Also, he attributed being “sick” to taking medications (“Yeah. I am doing fine! I mean before I was really sick…I don’t know if it is from the medicine… I am doing fine now.”) He said that he was relieved his illness belonged to the past and that he preferred being “normal” (“…I would rather not be sick…I’d rather be normal…that’s why I feel better now, I am glad it’s over…”). In addition, he could faintly recall his treatment location/the location of our meeting (“I can’t remember…I came out and went to a place in X location, X hospital I think it was called”). Finally, he assumed the role of a “visitor” instead of a patient (“I am
pretty much out of the loop now so I am on my own so I come to visit every once in a while”) when he was asked about what type of treatment he was receiving at the hospital.

Second, Devin offered some contradictory responses with regards to the attitudes and responses of others who know that he had been diagnosed with schizophrenia. Devin initially mentioned that having been diagnosed with schizophrenia had no impact on his interpersonal relationships. On the one hand he expressed that his relationship to his parents improved and was now “better than ever;” he said that since he got diagnosed his family seemed to show more attention towards him and spent more time with him. However, he disclosed that he did not like to depend on them, for instance, for transportation. Furthermore, Devin stated that since he got diagnosed he lost some of his friendships. However, he felt that the reason he did not have friends anymore was that he now did “not go out as much” and that his friends were now busy “doing their thing.”

From the beginning of the interview, Devin appeared guarded, avoiding eye contact, looking down or straight forward, away from me. Devin seemed to relate to me similarly to how I imagined he related to other authority figures/treatment team members at the hospital, oftentimes telling me what he thought I expected to hear. At other times, he seemed to relate to me as a young woman close to his age, answering in an honest and forthright manner. The way Devin related to me may provide useful information about the way he probably related to mental health professionals in a position of authority. He was compliant and provided answers to all questions. However, he seemed to often minimize the impact of his illness/symptoms, probably to avoid consequences such as re-hospitalization, medication increase, etc. He denied experiencing symptoms, but stated that receiving a diagnosis helped him understand his illness (e.g., “I think it helped I
guess at least I know what was wrong or something,”) and indicated that receiving treatment was helpful (e.g., “So it was good in that way [i.e., others making decisions for him] but it’s better than being sick though I guess. You know what I mean? At least you are getting help anyway”). Perhaps he refrained from elaborating on responses, especially those concerning treatment effectiveness and experiencing symptoms (e.g., “Treatment was fine! It was nice! What else?”) for fear that I might have relayed that information to his treatment providers (Devin might have perceived me as having an evaluative function or role). Given that he expressed that he disliked the hospital, admitting to difficulties or the experiencing of symptoms could have meant a return to intensive treatment if I relayed that information to Devin’s providers.

Finally, Devin spoke about his negative treatment experiences in the hospital. His responses seemed honest, even though after each response he made sure to counteract it with something positive about treatment (e.g., “Being sick was bad and being at X Hospital made it worse. I mean, it was better that I was getting help, but I didn’t want to be there.”) Devin stated that receiving a diagnosis had a negative impact on his life, even though he did not elaborate on this point. In addition, Devin found ECT (“ECT is electric? ... I had that. It didn’t do anything”) and pharmacotherapy unhelpful (“Not really [i.e., taking meds as having downsides] well, I mean it made me sleepy and a little bit drowsy all day, every day, but it was better than having racing thoughts”) and complained about the rigid rules of the hospital as well as his lack of freedom to behave the way he wanted.

Even though Devin was not very elaborate in his descriptions (reflected in my continued effort to actively engage with, support, affirm and encourage Devin to respond
to questions) he did provide some honest responses to questions. For instance, when I asked Devin how receiving a diagnosis impacted his life, Devin answered: “It wasn’t good…I feel right now I’m not really good at explaining.” He also mentioned that treatments like ECT were ineffective. Interestingly, Devin was attuned to my disappointment and frustration when I gave up trying to extract information (Devin did not elaborate and kept stating that he was “fine”) and apologized for not being detailed in his responses (e.g., “Sorry I did the best I could; I am sorry it wasn’t more information.”)

It is important to consider possible factors influencing Devin’s comportment including: Devin’s possible perception of my role as an authority figure when thinking about his responses, as well as factors like personality (e.g., shyness or introversion), and interview time limitations.

**Barry’s Experience of Living with the Diagnostic Label of Schizophrenia**

Barry is a 27-year-old, single, White, lower middle class man. He was diagnosed with schizophrenia at age 21 and has received psychiatric treatment at the inpatient and outpatient levels of care. In treatment, he addressed psychotic illness as well as alcoholism, which developed as a coping strategy. At the time of onset of psychotic symptoms he was subjected to 12 ECT treatments, which erased some early memories, and multiple psychiatric medication trials that elicited numerous unpleasant side effects. Although he has learned to cope with symptoms and was stabilized on meds, Barry continues to meet with an outpatient psychiatrist for medication management. Prior to the onset of illness, Barry attended Law School. He is currently unemployed, receiving disability and social security, and living in government-funded housing. During our
interview Barry was talkative, established good rapport, and exhibited great effort to answer questions and elaborate on responses. He appeared to trust me and was eager to share his experiences. Reportedly, he has shown the same comportment with his psychiatrist and treatment team.

For Barry, living with the diagnosis of schizophrenia entailed several dimensions. First, with respect to his self-image: (a) Barry recognized that he has a mental illness, and embraced and integrated the diagnostic label of schizophrenia as well as his role as a mental patient as part of his identity. (b) An additional aspect which developed when Barry was diagnosed with schizophrenia is that of a spiritual life. At the same time, a main conflict for Barry seemed to be that between self-acceptance and spirituality, and feeling “shattered,” “self-judgmental” and “less self-centered and self-confident” since diagnosed with schizophrenia. Also, Barry developed a present orientation (“I try to have an optimistic life outlook—which is hard”) rather than having regrets over frustrated career opportunities and focusing on future goals. Second, in regards to attitudes and responses of others, being diagnosed with schizophrenia confronted Barry with others’ lack of acceptance of his diagnosis, which has led him to conceal or be less open about disclosing his experience. On the other hand, Barry expressed that he felt gratitude and trust towards his doctors as well as some family members and friends for their support, and also spoke about some benefits of treatment. Other features of Barry’s experience included negative treatment experiences such as dealing with serious medication side effects, and developing various strategies to cope with the illness.

Barry acknowledged that he has a mental illness for which he is in treatment, and accepted the diagnosis of schizophrenia as part of his identity. He spoke extensively
about the onset of his illness, which caused a lot of confusion, fear and distress, and led him to seek treatment. He indicated that overall he was grateful for the help and support he received since diagnosed and defended his need for treatment against his brother’s insistence that Barry was not a “textbook schizophrenic” and did not need medications. Barry accepted that he had benefited from treatment, despite the severe side effects he had to endure.

In addition, Barry spoke about an aspect of his self-image that developed after he was diagnosed with schizophrenia, that of spirituality. In the quotes below, Barry described how spirituality helped him accept himself and his new reality of living with a serious mental illness, as well as how it served as a great source of strength.

... The only thing that opened completely was a spiritual life. That didn’t exist prior... Certain things just made sense... or I might have been a questioning person prior, but for some reason, whatever happened and things were just completely understood to me now. At least in the way I see it. I don’t overly discuss it with people where it hasn’t become the focal point in my life like trying to proselytize something but it’s definitely, it’s been a solace and I think that was a gift.

… it gives me strength and stuff that’s almost inconceivable...I feel very... constant gratitude for that...For having that sort of belief or understanding or spiritual aspect that allowed me to understand where I am at or what happened... in a certain way or to be able to not to blame myself entirely. Because I don’t know if that’s something I can do! I never have. I mean, thoughts never crossed my mind.

At the same time, Barry seemed to be conflicted between two aspects of his self-image: that of a spiritually self-accepting individual and that of a “shattered,” “self-judgmental” and less self-confident person. Barry appeared to be disconnected from his past in focusing on the present. For instance, he stated, “…sometimes I have difficulty assessing before and after…like looking at a photograph from childhood and I try to see it. Sometimes it’s there, sometimes it isn’t.” Furthermore, he continued, “Sometimes I
don’t even really remember what my goals and aspirations or what my self-image was…I was probably a pretty confident person…it’s not that I live with no confidence now. Sometimes I just have difficulties I guess.” He also stated that, even though he did not like to dwell on “what if’s” and frustrated goals and aspirations such as having a job (i.e., before he was diagnosed, Barry was in college studying Law) and being “successful,” leading a “normal life” is difficult for Barry as he tends to be “down on” himself. For instance, Barry stated that he is sometimes self-judgmental when he blames himself for possibly exacerbating his illness by “drinking too much.” Even though he said he tries to maintain an “optimistic life attitude,” it is often “hard.”

This contrast was also evident during the interview. Throughout, Barry seemed unhappy and in a lot more emotional pain than he was willing to admit. Though very engaged, his way of relating contradicted his appearance and body language. Barry wore black sunglasses, and was turned toward gazing at the wall ahead of us throughout most of the interview. One could sense fear and despair in Barry as he spoke about confusion, inability to control voices and using alcohol to cope, and being overmedicated and experiencing serious medication side effects while at the same time being “so vulnerable but having faith and trust in doctors even if they weren’t the right ones.” However, on different occasions he tried to counteract that through the use of humor.

In regards to the interpersonal dimension of Barry’s experience, being diagnosed with schizophrenia confronted Barry with different reactions from others. Barry had to face his brother’s lack of acceptance of his diagnosis. Barry admitted feeling “angry” and “really upset” in response to his brother’s reaction (e.g., he called Barry “lazy” and “afraid to grow up”). As he stated, “I told him why would I want, why would anybody
want to live on disability and social security from the age of 22? ...is that the secret of getting ahead?” Barry did not seem to feel understood or accepted; he felt blamed for having an illness. However, he also seemed to justify his brother’s lack of understanding by explaining how ignorance about mental illness may lead others to mistake mental illness, and in this case schizophrenia, with “laziness” or “immaturity.”

On the other hand, Barry expressed that he felt trust and gratitude towards his physicians as well as some of his family and friends for being supportive. In particular, he attributed good will to others trying to help him. For instance, he expressed that he always had faith in treatment, even though it did not always lead to a positive outcome: “I was so vulnerable and I had faith and trust in my doctors, even if they weren’t the right ones you know? Like I have now… I was certainly as open-minded as a patient could be…the faith (i.e., in doctors) aspect was always there but it didn’t always lead to a positive result. It was just the constant attempt… which is good.” (p.5) He continued to say that he felt fortunate to be able to address his symptoms in a timely manner before the illness was exacerbated, and that he felt “lucky” to have people to “care about” and “listen” to him and be in a position to get help with medication. In addition, Barry spoke about the support he received from his parents, especially his father, by whom Barry felt understood and supported, given that he too had to deal with serious mental illness.

Finally, despite talking about the benefits of treatment, Barry was candid about negative treatment experiences such as dealing with serious medication side effects and coping with the illness. He characterized medication side effects as being “worse than the actual illness.” He spoke of feeling “scared” about having difficulty breathing and swallowing, and feeling “uncomfortable” by salivating and having to use the restroom
too often. He disliked being “sedated” and having his “motor functions all messed up” to the point he sometimes “walked into walls.” He added that sometimes he wished he could go on a “break” or a “vacation” from taking meds from time to time.

As a final point, Barry offered insight into various strategies he used to cope with the illness. First, he spoke about using avoidance as a coping strategy. He mentioned how he used drinking in order to “tone down” voices and other symptoms, acknowledging that abusing alcohol was not a healthy or adaptive strategy. Second, at various points throughout the interview, Barry used humor as he was recollecting the onset of the illness. Last, he spoke about not dwelling on “what if”s” and having regrets about the past, but trying to focus on the present moment and taking each day as it comes as he went on with life.

Daniel’s Experience of Living with the Diagnostic Label of Schizophrenia

Daniel is a 33-year-old, single, African American male who is unemployed, and currently in the process of applying for Social Security for the third time. He lives in government-assisted housing. He was diagnosed with schizophrenia 15 years ago, and was mandated to treatment by his parents who were concerned because Daniel was “isolating.” He is currently in outpatient therapy. He meets with a psychiatrist once ever 2 or 3 months for medication management. Prior to his first hospitalization, Daniel was in college, aspiring to become a computer scientist. His passion for computers led him back to college 3 times, but due to subsequent hospitalizations and financial difficulties, his dream was never realized.
During our interview, Daniel was talkative and engaged, but even though some of his responses were directly about his personal experience, he mostly addressed the broader context such as the politics of the mental health system and the negative impact of the media on public opinion on generating stigma, ignorance and fear. He openly spoke about accepting his diagnostic label while simultaneously concealing it in his interpersonal interactions to avoid rejection and discrimination.

For Daniel, living with the diagnosis of schizophrenia entailed several dimensions. First, with respect to his self-image, Daniel accepted that he suffers from schizophrenia and integrated the label and role as a mental patient as part of his identity. He mentioned that since he was diagnosed, he still saw himself as the same person even though his future goals have changed. He dispelled negative stereotypes, affirming that individuals with schizophrenia are different neurochemically but not qualitatively, and that they can be successful and charismatic. Second, in regards to his view of the attitudes and responses of others, Daniel spoke about “stressful,” one-sided interpersonal relationships and concealing his diagnostic label to avoid stigma and discrimination. He also spoke about others’ invalidation as well as lack of empathy and understanding. Furthermore, a central conflict for Daniel appeared to be the dynamic between trusting and mistrusting others. Other features of Daniel’s experience included negative hospitalization experiences and learning to cope with symptoms (often without medication), learning to navigate the politics of the mental health system, and his view on media as generating ignorance, fear, and negative stereotypes about schizophrenics.

Daniel seems to have accepted his diagnostic label and role as mental patient as part of his self-image. He acknowledged that sometimes when he is “delusional” his
“perspective on reality is not clear.” This awareness was reflected throughout the interview as Daniel stated that he has a “mental disorder/illness” and described symptoms he experienced. He mentioned how he is in the process of applying for social security for the third time, recognizing that dealing with serious mental illness is the main reason he abandoned his future career goals. He stated that he saw himself as different neurochemically (“chemicals in the brain that other people might have less”) and having to deal with “internal voices and confusion” others do not have to deal with. In addition, he said that receiving a mental illness label has not affected his self-image, even though his career goals have changed (“I am so far in debt I don’t think about school anymore”). He mentioned that it is hard to focus on the distant future and instead developed a “here and now” orientation, focusing on the present and taking it “one day at a time.”

Furthermore, Daniel embraced his difference and expressed that accepting the label of schizophrenia did not make him inferior or defective in any way. Being schizophrenic, contrary to the “misconceptions” of those around him (family especially) did not mean that Daniel is of inferior intelligence. In fact, Daniel demonstrated with examples of famous geniuses that individuals with schizophrenia can be gifted and charismatic. In his own words: “… There is a lot of famous people like great artists like DaVinci was a schizophrenic…You know? It doesn’t mean that you are stupid. It just means that your mind works differently than others.”

Second, regarding the attitudes and responses of others, even though Daniel accepted the label of schizophrenia as part of his identity, he admitted concealing the label in his interpersonal interactions and especially romantic relationships, mainly to
avoid rejection, stigma and discrimination. His reasons for this concealment are summarized in Table 1.

Possibly, invalidating and “stressful” family and interpersonal relationships (e.g., being “belittled,” perceived as less intelligent, etc.) led Daniel to avoid talking about his feelings and to conceal his diagnostic label in his relationships. He disclosed that most of his family believed that schizophrenia is not “real” and since it did not exist, Daniel was not “sick.” Ignorance and lack of education led Daniel’s family to equate mental illness with mental retardation. Daniel suspected that some of his family members have a mental illness themselves, but because they did not seek treatment, they expected Daniel to do the same. Furthermore, Daniel disclosed that his romantic relationships tended to be one-sided, usually focused on the other person’s needs. He mentioned that he did not like to be “self-absorbed” and did not care about himself and his own problems. He stated that in his relationships he hid that he had schizophrenia and tended to focus on his romantic partner’s feelings and needs, to avoid dealing with his own feelings. Also, he spoke about others’ lack of “real compassion” or understanding of what he went through when he was “symptomatic.” Daniel stated that he believed that it is hard for people who do not have to deal with “internal voices,” “confusion” and other symptoms to comprehend what it meant to live with schizophrenia.

Moreover, a central conflict for Daniel appeared to be the dynamic between trusting and mistrusting others. This dynamic also played out in the way Daniel related to me.
Table 1. Daniel’s Reasons for Concealing the Diagnostic Label of Schizophrenia

1. **To avoid ridicule**
   
   “In most cases yeah (i.e., chooses to remain quiet than telling others when symptomatic. People look at you funny when you say you hear voices.”

2. **To avoid feeling badly about self**
   
   “It only brings me down more.” (i.e., trying to “block out” discrimination)

3. **To avoid invalidation**
   
   “A lot of people don’t even believe it’s a real illness.”
   
   “People are entitled to their opinions. I try to block it out. What doesn’t kill me makes me stronger (smiles).”

4. **To avoid being belittled**
   
   “Hmm… I found that if you go back that route (i.e., express how he feels to others) they try to belittle you, they think that you are less intelligent and stuff like that and I’m not stupid.”

5. **To avoid eliciting fear in others**
   
   “Yeah usually they go to the extreme. When you are afraid they usually go to the extreme. Like, I don’t know what’s going to happen, I don’t know if you are going to hurt me or whatever but you know so am I go on the extreme side rather than me be not so cautious and get hurt.”

6. **To avoid differential treatment**
   
   “Yeah but… just because you were diagnosed, other people that know is the ones that you tell. The doctor can’t tell anybody. So just because you are diagnosed, nobody else is going to know unless you tell them.”
   
   “I don’t think I should be treated special. I’d like to be treated like everybody else.”

7. **To avoid stigma**
   
   “You know, I just have a mental illness. But you know if you tell someone you are schizophrenic first thing they think the way you say mental illness they think that you are stupid.”
Daniel spoke about the negatives of his experiences in the mental hospital as well as in stressful interpersonal relationships, but at the same time, he seemed to attribute good will to others by blaming the media for misinformation and promotion of mental illness stereotypes. He spoke about negative medication side effects and restriction of freedom in the hospital, but at the same time he perceived doctors as willing to help (“I work with my doctors and try to do what’s right.”) Negative and stressful interpersonal experiences, which seem to have been hurtful to Daniel, led him to mistrust others and keep to himself in order to avoid being hurt again. He also expressed that he sometimes did not allow others to be helpful because he was not willing to talk or seek help in dealing with his illness. (“…I can’t put all the blame on others; you know a lot of the problems were unique. I am working on it.”) At the same time, he expressed his disappointment about others’ uncaring attitude (“…People don’t treat each other good. Nobody wants to help everybody…”).

This relational dynamic of trust versus mistrust was also exhibited in Daniel’s interaction with me. On several occasions during the interview, Daniel showed through his disclosures that he felt comfortable enough to disclose and trust me with personal information such as his reactions to the onset of his illness, his past career aspirations and frustrated future goals, learning to cope with symptoms and not taking medication as prescribed, his family history and family members’ relationship with him since diagnosed, and stressful interpersonal relationships. Yet, in other ways he appeared distant, as he did not disclose much about his personal emotional reactions to issues he described, such as how he saw himself, and how he felt when discriminated against by others. Talking about emotions did not seem easy for Daniel, and this reaction of
avoiding being vulnerable made sense partly given past experiences of invalidation from others. Even though Daniel’s tone was confessional, he tended to talk in global terms, often in the second person narrative. The use of second person could also be understood as a way Daniel distanced himself from his feelings and experiences.

Finally, Daniel spoke about negative treatment experiences such as losing a sense of freedom in the hospital, being on several different medication trials and enduring numerous medication side effects. To avoid unpleasant side effects, Daniel confessed that over time he learned to cope with symptoms on his own instead of taking his medication as prescribed. His introduction to the mental health system occurred when he was involuntarily hospitalized by his parents upon onset of his illness. Once he was “caught,” he was marked out and labeled with schizophrenia and had been inducted into the mental health system ever since. In his own words: “But this is how society is…it is hard to catch people that are schizophrenics. There are a lot of people walking around with lots of illnesses that aren’t diagnosed.” Daniel spoke about the process of learning to navigate the politics of the mental health system and the “stressful and confusing” process of receiving help. Daniel argued that the system was designed to discourage many people who compete for resources from receiving benefits such as disability, social security, treatment, and housing, and to differentiate those who legitimately need assistance by virtue of suffering from a serious mental illness (“The underlying secret debate.”) In addition, Daniel spent a large part of the interview talking about how the media was responsible for generating fear, ignorance, and negative stereotypes about schizophrenics. Daniel believed that the media, being the sole (mis)educator of the public about mental illness, portrayed individuals with schizophrenia as violent and responsible for serious
crimes, instead of showing how those individuals can also be gifted and charismatic. The media, in Daniel’s view, not only defamed schizophrenics, but by focusing on pathology dehumanized and portrayed them as a list of symptoms.

**Shawn’s Experience of Living with the Diagnostic Label of Schizophrenia**

Shawn is a 40-year-old, White, single, middle-class man. He was mandated to treatment by his father 18 years ago upon onset of the illness, was diagnosed with schizophrenia, and has received treatment at both inpatient and outpatient programs ever since. Prior to his first hospitalization, Shawn attended 2 years of college studying Finance. However, his college education was interrupted by illness. He had several subsequent involuntary hospitalizations over the years, but has reportedly been compliant with treatment and his condition has remained stable over the past 6 years. Shawn continues to meet with an outpatient psychiatrist once a month for medication management. He is currently unemployed, receives disability benefits, and lives in an apartment with his brother.

For Shawn, living with the diagnosis of schizophrenia entailed several dimensions. First, with respect to his self-image: (a) While he recognized that he has a mental illness, he did not identify with the diagnostic label of schizophrenia as part of his identity. (b) He saw diagnosis as a way in which he was “marked out,” lost his freedom and subsequently mistreated by the mental health system as well as relatives who mandated him to treatment. (c) Shawn seemed to be split between viewing himself as “sick,” scared and helpless, insecure about others’ liking him, and being a “nice guy” with a “great personality” and future goals. Second, with regards to his view of the
attitudes and responses of others, Shawn stressed that he typically concealed his diagnostic label in his interpersonal relationships in order to avoid rejection, discrimination and abandonment from others. Finally, other features of Shawn’s experience included trying to understand his illness (e.g., struggling between assuming the responsibility for the onset of his illness versus assigning responsibility to extraneous factors) and the struggle between trusting and mistrusting others.

First, with respect to Shawn’s self-image, it became apparent that, even though Shawn has been actively participating in treatment in a schizophrenia outpatient program, he did not identify with the diagnostic label of schizophrenia. For instance, throughout the interview he used different terms to describe his onset of schizophrenia, such as: “feeling really depressed,” “having symptoms,” “having weird thoughts,” “strange, racing type of thoughts,” “fixations,” “being sick,” “being sick,” “having a chemical imbalance in the brain.” He even challenged me by asking, “What is a psychotic episode and what does it mean?” For the most part, he avoided using the term schizophrenia to describe his experience.

Furthermore, Shawn saw receiving a diagnosis and subsequently being mandated to treatment as an unfair punishment imposed by others who misunderstood his intentions. For instance, he stated that he was hospitalized by his father because he “wrestled” with his brother and “drove his car fast”, and was subsequently hospitalized by his cousin because he was not taking his medications. He did not seem to understand that his behavior, however deviant or different, was of concern to others. From his perspective, Shawn saw himself as singled out and labeled (punished) whereas other people “way, way sicker” and “way worse” than him that “did not have to go to the
hospital.” He saw being hand-cuffed, placed in a “paddy wagon,” and confined in a hospital as punishment for his deviant behavior, and it was an experience which caused him to “hate the mental hospital and not want to be in the hospital ever again in my life.”

Given those experiences, he did not seem to see any helpfulness to treatment, other than medication management, which seemed to help him participate in the reality of the majority by not obsessing over “paranoid” ideas such as others’ ability to read his mind.

However, even when talking about the helpfulness of medication, he seemed ambivalent. This ambivalence is reflected in the statement: “Honestly, I take them (i.e., medications) and they work but I don’t notice differences at all.”

In addition, in regards to Shawn’s self-image, he seemed to be split between two views of himself. The first one could be inferred by Shawn’s detailed description of his feelings during the onset of schizophrenia symptoms and in his description of his relationships with others. Shawn spoke about feeling helpless, scared and as if he was “losing” his “mind” when he experienced unexpected schizophrenia symptoms. With regards to his interpersonal relationships, he expressed concern about the possibility of others not liking him if they knew that he has a mental illness. The other view is the view of himself as a “nice guy” with a “great personality,” a view he derived from the feedback of others who know him as a person and not as someone carrying a psychiatric diagnosis.

Second, with regards to his view of the attitudes and responses of others, Shawn stressed that he typically concealed his diagnostic label in his interpersonal relationships in order to avoid rejection, discrimination and abandonment from others. He mentioned the only occasion in which he would have felt comfortable revealing his diagnosis was
when he knew well and trusted the other individual, and that that individual knew him as a person and as a friend so that he would not be judged solely based on his diagnostic label.

Below are quotes in which Shawn described concealing his diagnostic label from others in his interpersonal relationships:

…It’s almost like, say you are dating someone but you never told them you had an illness, and when they found out they might actually, you know, leave you!

… It’s almost like, he (i.e., friend) got rid of me because he found out I had this illness.

…You gotta make sure that they are into you, what I’m saying is, you meet a girl right now and you tell her oh, I have psychosis you know, she might go the other way. But what I’m saying, you have to know these people, and then tell them, down the road.

…At this bar everyone likes me down there, I’m almost positive they don’t know about my illness. I’m wondering if they’d still like me if they found out.

Other features of Shawn’s experience included trying to understand his illness, and the struggle between trusting and mistrusting others. Shawn expressed that upon the onset of schizophrenia symptoms, he originally thought that he “messed up” his “brain by drinking,” but later on came to believe based on an explanation by his medical doctor, that he “inherited” his illness from his mother who was also mentally ill. A key aspect of receiving a diagnosis of schizophrenia seemed to be wondering about what triggered onset of symptoms. Another feature of Shawn’s experience of living with the psychiatric label of schizophrenia is the struggle between trusting and mistrusting others who know of his diagnosis. Shawn seemed to separate people into two categories; those who “misunderstand” him, mandate him to treatment, reject and discriminate against him, and those who value him, reassure, support, and try to understand him. Given the loss of
relationships with those who learned he has schizophrenia, and the stigma and rejection he experienced, Shawn’s cautious attitude is understandable.

**Jack’s Experience of Living with the Diagnostic Label of Schizophrenia**

Jack is a 28-year-old, single, lower middle class, African American man. He was mandated to treatment 4 years ago by his mother who was worried about what was “wrong” with him after he started to “isolate” and disclosed to her that he had been experiencing psychotic symptoms. Jack received treatment at both inpatient and outpatient levels of care. He currently sees an outpatient psychiatrist once every 2 months for medication management. Prior to his hospitalization, Jack was a college student working on his Associate’s degree in Business Administration. Jack now works part-time, and lives alone in his own apartment in a government-assisted facility. He currently has no plans to return to college. He expressed that his extended family was supportive. During our interview, Jack was talkative, engaged, and appeared genuine in his reflections. For the most part, he avoided using the term schizophrenia in talking about his experience with the illness, and spent the majority of the interview time talking about negative hospitalization experiences and medication side effects. He spoke about concealing his diagnostic label from others, and expressed that even though he saw his illness as “slowing” him “down,” it did not get in the way of his optimistic life outlook.

For Jack, living with the diagnosis of schizophrenia entailed several dimensions. With respect to his self-image: (a) While Jack recognized that he has a mental illness, he did not seem to fully accept his diagnosis, and did not use his diagnostic label to describe himself. A main conflict seemed evident in Jack’s descriptions: accepting the diagnosis
of schizophrenia as part of his identity and rejecting it as something that “gets in the way” of his daily living and something that could be “overcome.” (b) Another central conflict was between dwelling on “what if”s” and frustrated future goals and expectations, and pushing through difficulties by maintaining an optimistic life outlook.

With regards to his view of the attitudes and responses of others, Jack spoke about concealing his diagnostic label from others to avoid discrimination and being “made fun of,” to avoid making others uncomfortable, and to avoid re-living bad memories related to his hospitalization. Other features of Jack’s experience involved negative treatment experiences such as dealing with uncaring hospital staff members and coping with serious medication side effects.

While Jack acknowledged that he has a mental illness for which he is in treatment, he did not seem to fully accept the diagnosis of schizophrenia as part of his identity. Jack spoke about his illness as something that gets “in the way” of his daily living and something that could be “overcome” or something that he expected to eventually recover from. Throughout the interview, Jack used different terms to describe his illness. He would sometimes call it “depression,” a “condition,” a “mental disease,” a “disease,” an “illness”, a “chemical imbalance,” having an “episode,” but would rarely call it psychosis or schizophrenia. For the most part, he avoided using the term schizophrenia to describe his experience.

Another conflict central to Jack’s experience was between wondering about what his life would have been like had he not been diagnosed with schizophrenia, and maintaining a hopeful and optimistic life outlook. Jack stated that at the back of his mind he always wondered “what if it [schizophrenia] never happened” and “what if” he “did
things differently?” Jack saw having a “condition” as potentially getting in the way of maintaining a full time job, as he feared that having another “episode” could “interfere” with his work. He disclosed that he often saw schizophrenia as holding him back from meeting his goals and aspirations. However, he also said that receiving a diagnosis had not affected his self-image and that he still had goals for the future. Even though the illness affected his motivation and mood, Jack said that he was “not giving up” and that he wanted to “beat this.” For instance, he stated that despite having an illness he went on to earn his Associate’s degree, and he continued to remain optimistic that his condition will eventually improve.

Jack explained that in his interpersonal interactions, he tended to conceal his diagnostic label from others to avoid discrimination and being “made fun of,” to avoid making others uncomfortable, and to avoid re-living bad memories related to his hospitalization. He mentioned that the only exception could be in a situation where he completely trusted the other person. Jack’s reasons for this concealment are summarized in Table 2.

Other features of Jack’s experience included negative treatment experiences such as dealing with uncaring hospital staff members and coping with serious medication side effects. He described the majority of staff members at the first hospital where he was committed as uncaring and as having a “nasty attitude” towards patients. Those staff members’ indifference was striking for Jack, who described this as a very unsatisfactory treatment experience. He stressed that the experience made him “want to get out of the hospital the soonest possible.” Jack also described a positive treatment experience at his
current facility, where he felt that his doctors had real concern for patients and took them seriously.

Table 2. Jack’s Reasons for Concealing the Diagnostic Label of Schizophrenia

1. *To Avoid being Made Fun of and Taken Advantage Of*

Hmm… well, at first you know, they didn’t like it because the *depression* thing, I really didn’t like talking about it because I didn’t know if I told certain people they would take advantage you know… *take advantage of* me for having a certain condition, or even to a point even trying to *poke fun at me* because I have like a *mental disease* so…

2. *To Avoid Making Others Uncomfortable*

Well… I haven’t experienced anything like (i.e., people making fun of him) that but, it’s always at the back of my mind, you know, I really don’t want to tell this person that I have such and such disease, you know, because they may feel a certain way or they may feel *uncomfortable*, you know, to know that I have a mental disease or something like that so… knowing me I just really don’t bring it up until I feel like, 100% comfortable with that person that, you know, that they know me well enough and then I might bring it up. But, even then, it is kind of hard for me to bring it up…

3. *To Avoid Re-Living Bad Memories*

Ah some days when, you know, when I do talk about it, I can talk about it for a minute and it doesn’t bother me but, the longer I talk about it I don’t want to talk about it anymore because, it just feels, I don’t know it just feels like I just *break up all the bad memories* and start *re-living* certain things you know how I started and everything like that, you know…

Lastly, Jack spent some time during the interview talking about his experience with antipsychotic medication, focusing on his suffering caused by medication side effects. Even though he admitted that medication was helpful in eliminating symptoms like delusions and auditory hallucinations, he stopped taking them to avoid experiencing side effects. He spoke about feeling extremely drowsy to the point that his work
performance was impaired. In his own words, “The side effects pretty much had me
drowsy to the point where I couldn’t really do anything…it felt like someone hit you with
a tranquilizer dart…your body just start shutting down, the only thing you wanna do is
lay down so it will wear off.” These side effects caused Jack to discontinue taking
medication for a period of time. As a final point, Jack did mention that he had one
positive treatment experience in a group therapy setting where he was relieved to learn
that he was not alone in what he was experiencing. Receiving some advice and
information on how to cope with his illness was another benefit Jack identified.

Beatrice’s Experience of Living with the Diagnostic Label of Schizophrenia

Beatrice is a 53-year-old, married, African American female, coming from a low
socioeconomic status. She has two daughters aged 32 and 27. She receives disability
benefits, but for the past few years she has been employed part-time by X hospital as a
peer support counselor/community aide. As a child, she was raised in foster care and has
a history of mental illness beginning in her late teenage years. Throughout the years, she
has received various formal diagnoses including major depressive disorder, schizo-
affection disorder and schizophrenia, paranoid subtype. She has had numerous
hospitalizations over the past 30 years, and received treatment at both the inpatient and
outpatient levels of care. She is seeing an outpatient psychiatrist for medication
management once every 2-3 months. During the interview Beatrice seemed passionate
about her role as a peer counselor at the psychiatric hospital, was engaged and pleasant,
and provided elaborate responses to all questions. She spoke about the personal troubles
that led her to seek treatment, her treatment experiences, and family dynamics. She
described concealing her diagnosis to avoid stigma and to be “treated like everybody else,” and her family’s lack of support and understanding. Finally, she spoke about finding meaning and refuge in her religious faith and through helping others, as well as her optimism for the future and plans to advance her education in the helping professions.

For Beatrice, living with the diagnosis of schizophrenia entailed several dimensions. First, with respect to her self-image: (a) Beatrice accepted that she has a mental illness, but did not accept a negative prognosis and rejected the diagnostic label as defining who she is as a person. (b) An additional aspect that developed when Beatrice was diagnosed with schizophrenia was that of a spiritual life. Beatrice described her religious faith as the central source of courage, hope and strength in her personal life, and the source for meaning and altruism towards others. (c) A central struggle for Beatrice appeared to be that between her self-image as “defective” versus an efficacious helper of others, maintaining an attitude of empowerment and optimism about the future, and living “in-spite of” her illness. Second, in regards to attitudes and responses of others, being diagnosed with schizophrenia confronted Beatrice with others’ lack of support, which has led her to conceal or be less open about disclosing her experience. Beatrice spoke about concealing her diagnosis in order to be treated like everybody else and to avoid stigma. Finally, an important feature of Beatrice’s experience included negative and positive treatment experiences.

First, even though Beatrice seemed to have accepted that she has a mental illness, she talked about rejecting the diagnostic label as defining her identity. She spoke about being assigned various labels through the years, such as “disability,” “bipolar,” “depression,” and “schizophrenic,” in a descriptive and emotionally detached manner.
However, she made it clear that she did not want to be “confined in a box” by her diagnostic label, but rather by her actions and by who she is as a unique individual. In her own words:

…I just wanna be the best person I was meant to be before I was told you know; well this is what’s wrong with you or whatever. You know… I don’t even look at that, you know, whatever I am being told because I will be told something else tomorrow, you know… I always not wanted to be put in a little box and ‘you stay here”, you know… I just want to be myself. I wanna be self-assured and just be myself you know? I don’t want to be pacified. I don’t want to be talked down to I don’t want to be treated as though I have something they can catch, or you know I am not mentally retarded, you know and even if I was, I wouldn’t want to be stigmatized as though I couldn’t achieve anything or I’m in this little box and this is where you are and we are over here so you stay over there… You know, I just want to be… myself I want to be accepted for being who I am… like everybody else who doesn’t have the diagnosis … and what I can do or accomplish…

When describing her diagnosis, Beatrice mentioned that she received a negative prognosis from her physician who stressed that she should be on medication for the rest of her life if she wanted to avoid getting “worse and worse.” Beatrice did not take this prognosis to heart, but became more motivated to be a functioning member of society by holding a job and assisting others, and used her religious faith as a source of strength, hope and optimism about the future. Furthermore, she sought to advance her education by going back to college, and her active involvement with the recovery movement helped to empower her and develop a sense of self-efficacy.

As mentioned before, an additional aspect which strengthened when Beatrice was diagnosed with schizophrenia was that of a spiritual life. Beatrice described her religious faith as a source of encouragement and hope, meaningful contribution to others, and as supply of strength and protection. Themes relevant to the role of Beatrice’s religious faith and coping are presented in Table 3.
Table 3. The Role of Beatrice’s Religious Faith in Coping with her Illness

1. God as Source of Encouragement and Hope

No I don’t! (i.e., judge herself anymore) And I try not to… when things go wrong, I ask for forgiveness, I pick it up and keep on going, you know and … umm.

My faith. I think that’s what really helped me.

2. Religious Faith as Source of Altruism/Unselfish Giving Towards Others

Now I don’t think of so much of what I do is what I think… um, He has done for me, what God has done for me, and I want to do something back, you know? I want to do something back and I always felt, when I was in the hospital, that I wasn’t doing anything for God, and I wasn’t doing anything with my life – I was! I was raising children, but I wasn’t doing that even, satisfactory I didn’t feel you know…

No I wasn’t good enough for doing anything and I wasn’t helping anything with God or with His Kingdom or anything, but now I feel the little things that I’m doing now, I wanna feel …that it’s a help, but I still need to be able to open up more and let Him… not let it reflect on me but let it reflect on why I’m doing this, you know for Him you know, you know… that this is what He wants us to do, you know more so than what I wanna do to help, you know get glory for myself, you know… cause there is a verse in the Bible that if you get your payment down here, there is no reward for you, you know, in Heaven, you know.

I wanna give.

That’s what I feel, yeah! I am learning that and I am so glad that I signed up for Geneva cause that was the first, intro to human services and there was scriptures to go with it and that was exactly what was in the scriptures Matthew’s about doing it unselfishly, and do onto others as if you were doing it for Christ, because that’s what he said, when did you help Christ? “When did you give me something to eat and clothe me?” And everything He says when you did it on to the least of them.

3. Religious Faith as Protection

…That’s what I need to do now is to have constant prayer life so that I don’t have to in an emergency have a screaming pleading crying prayer, you know. I can have a steady constant relationship, like a good relationship and I can feel better about myself instead of the way I was feeling then helpless and hopeless. But I felt that
God was my only, and I still do that’s what my pastor preached about Sunday, that he is the only way when you say to him is the only help that you need, you know and he will bring people in your life… It’s not like you sit and wait for a cloud to open and God is going to come down (laughs).

Beatrice appeared to struggle with the conflict of seeing herself as “defective” versus an empowered and efficacious helper of others, maintaining an attitude of optimism about the future, and living “in-spite of” her illness. Growing up in foster care, being in an emotionally abusive relationship with her husband, living with an unsupportive family, and accumulating various mental illness labels throughout the years inevitably had an impact on Beatrice’s self-image and self-esteem. Focusing on meeting the needs of others through her role as a peer support counselor helped her to offer the assistance and understanding she never received by her family and others. She called helping others her “personal medicine.” Also, receiving meaning and hope through her religious faith had helped her maintain an optimistic attitude toward life and the future. However, even though she did not express it directly, using the term “schizo-defective” to describe one of the diagnoses she received in the past may indicate Beatrice’s experience of carrying that label: being considered defective or damaged.

Beatrice described concealing her diagnostic label from others in order to avoid stigma and not be treated as incompetent:

… Not many other people know that I have a mental illness…I know that there is a lot of negative stigma out there and um, I just don’t say anything in my church I join, I volunteer at the X ministry I sell the Message as it has been recorded we sell the tapes after the Sermon and stuff, and I know I was a little withdrawn and quiet, and they would always ask me what’s wrong are you okay and everything? And I wouldn’t say anything. I certainly wouldn’t say “I have a mental problem” or something you know? (Laughs)...Then I would be treated differently, I might be, not put down, just treated differently like they would say
I wouldn’t be able to handle this or that or something like this you know? They wanted me to run the cash register and everything and I just feel if they knew I had (a mental illness) I would be treated differently.

…Yeah… like everybody else who doesn’t have the diagnosis, right… and what I can do or accomplish. I know I probably have to divulge that to more people that I have mental illness and when I do I always say I had depression. I was diagnosed with depression. And sometimes I might say with psychosis. But I … I sure haven’t said schizo-defective…

In regards to attitudes and responses of others, Beatrice spoke about having to face others’ lack of support and denial of her diagnosis, which led her to be less open about her experience. Beatrice said that receiving a schizophrenia diagnosis changed her immediate family’s attitudes toward her. Particularly, Beatrice’s husband had been unsupportive, avoiding any conversation pertaining to Beatrice’s illness, blaming her for having a mental illness, and blaming their children’s misbehavior and failures on Beatrice’s “incompetence” as a mother due to being ill. In addition, Beatrice’s daughter “did not want to hear anything” about her mother’s illness or would joke about it (e.g., she once remarked “just take your medicine and leave us alone.”) Family members’ ignorance about schizophrenia and mental illness in general seemed to contribute to their attitude towards her.

Finally, an important feature of Beatrice’s experience included negative and positive treatment experiences. Beatrice spoke about diagnosis as a negative experience, as the psychiatrist delivered and emphasized a negative prognosis instead of encouraging her while still delivering the “bad news.” Beatrice talked about her diagnosis as an event in which she was marked out as mentally ill, but which led her to seek help, compared to “people on the outside” who have a mental illness but have never been formally diagnosed. In addition, Beatrice expressed that simply receiving medicine without being
listened to or allowed to be active in her recovery had been unhelpful. She also mentioned that not being taken seriously or treated respectfully by others, especially mental health professionals (e.g., a nurse “giving the cold shoulder” not acknowledging Beatrice was talking to her), led to a negative treatment experience. On the other hand, Beatrice outlined several positive treatment experiences, such as the usefulness of psycho-educational programs and other hands-on learning opportunities as well as her involvement in advocacy groups. She mentioned that participation in treatment groups had been the “best help” she “ever got.” She saw treatment as a source of “hope,” understanding, support and self-acceptance. Group therapeutic factors such as a sense of universality, imparting information, and modeling of effective interpersonal behaviors were crucial for Beatrice.

Jenny’s Experience of Living with the Diagnostic Label of Schizophrenia

Jenny is a 58-year-old, single, African American female coming from a low socio-economic status. She currently lives in an assisted living facility. In her 20’s and 30’s she worked as a nurse’s aide. Jenny was sexually abused from the ages of 9-12. Throughout the years, she received various formal diagnoses including major depressive disorder and schizophrenia. She has had numerous hospitalizations over the past 25 years, and received treatment in inpatient and intensive outpatient programs. She is currently seeing an outpatient psychiatrist once every two months for medication management. During the interview, she was talkative and appeared eager to inform me about her experiences. At times she was tangential, losing track of her thoughts. She did not respond directly to questions about the onset of her illness and the usefulness of medications. It seemed that once rapport was established, Jenny disclosed private
experiences such as child sexual abuse, and spiritual experiences mental health professionals might label “delusions.” Interestingly, she seemed to have some insight about other people’s reactions towards her and so perhaps avoided talking about her delusions to avoid stigma and discrimination. In addition, she seemed to understand the personal function of those delusions.

In some ways, Jenny did not identify as a mental patient and expressed anger towards people labeling her and discriminating against her based on knowing that she received treatment. She complained of being misdiagnosed in the past, and of being currently overmedicated. She did, however, describe herself as a “survivor of abuse and mental illness.” She also identified as an “advocate” for the rights of the mentally ill. Jenny saw participating in this research as an opportunity to share personal experiences, advocate, and educate and the public about mental illness survivors.

For Jenny, living with the diagnosis of schizophrenia entailed several dimensions. First, with respect to her self-image: (a) Jenny accepted that she has a mental illness but rejected the diagnostic label as defining and limiting who she was as a person. Instead, Jenny identified as an abuse/mental illness survivor and advocate of the rights of the mentally ill. (b) An additional aspect that developed when Jenny was diagnosed with schizophrenia was that of a spiritual life. Jenny stated that she now relies on her religious faith more for hope and strength. She admitted that her “delusions” (centered on her belief of the immortality of the soul and communication with deceased relatives,) though a source of discrimination and indicator of pathology in the context of the mental hospital, served as a source of hope and strength for her. Second, in regards to attitudes and responses of others, being diagnosed with schizophrenia confronted Jenny with
stigma and discrimination. This experience led her to conceal her diagnosis and experience of psychotic symptoms in order to avoid stigma. A related struggle for Jenny seemed to be that between trust and mistrust in her interpersonal relationships, which was also evidenced in the way she related to the researcher. Finally, other important features of Jenny’s experience included negative and positive treatment experiences as well as her being caught between living in two worlds: the world of delusions and past memories providing safety and optimism for the future, and the current world of abuse, mistrust, and stigma.

Jenny rejected the “mental patient” and “consumer” labels as part of her identity. Instead, she stated she was proud to call herself a “survivor” of mental illness and abuse and an advocate for the rights of the mentally ill. This view of herself empowered her. She added that she felt “angry” whenever someone assigned her a label (e.g., “crazy,” “mentally ill,” “a dummy”) and made it clear that she did not want to be defined by her diagnostic label, but by her actions and by who she is as a unique individual.

Furthermore, Jenny stated that since she was diagnosed with schizophrenia, her religious faith got stronger and served as a great source of support, hope and strength:

A: Since you were diagnosed…How has your life changed?
J: Well, I found that, with my … I depend on God very much so, you know, even though I don’t go to church too often …
A: So do you feel your faith is helping you through the illness?
J: Yeah. But, see they don’t know me that well. So some people judge it.

She spoke about an unconventional way her faith helped her: communicating with her deceased relatives. Taking into consideration the fact that she was deeply religious, and that in her religious faith souls are immortal and ever present, is critical in understanding Jenny’s experience. She seemed to be aware that the relatives she
mentioned are deceased, yet she stated that she communicated with them regularly. She also acknowledged that “sensing their presence” and talking to them offered hope, comfort and security in a world that has betrayed and “hurt” her. In the following interaction, she expressed that she communicated with her deceased relatives, but never revealed this to people other than her doctors and close friends.

J: Yeah … see, so I believe my grandparents.
A: So what do other people say when you say that you talk to them?
J: Um … they don’t … I mean, I just don’t talk about it. You know I don’t tell them (laughs).
A: Yeah, you don’t tell them because …
J: Cause, I think they come to me to let me know that I’m going to be alright.
A: Um-hmm. But other people from the outside, when you are talking about your experiences, do you feel like they don’t understand?
J: Yeah! Because … that’s why I don’t tell many people that I do this (laughs).
A: Do you think they will think negatively about you?
J: Aha! I’ve told somebody that, and they didn’t keep my confidence so I had to … shut up (laughs). I would tell my therapist that, I would tell my doctor that, but I would not talk about it to anybody else. Except for my girlfriends, that I’m friends with.

Second, Jenny spoke about the stigma and discrimination she had experienced throughout the years as a result of her diagnostic label. She was “angry” as she recounted the hurtful experiences that led her to conceal her diagnostic label from others as well as her experience of psychotic symptoms in order to avoid stigma.

Furthermore, a central struggle for Jenny seemed to be between trust and mistrust in her relationships, also evidenced in the way she related to the interviewer. On the one hand, Jenny seemed to attribute good will to others when she stated that they were willing to assist her with planning her wedding. On the other hand, negative experiences such as the experience of stigma, labeling and ridicule, based on her diagnostic label well as negative experiences at the hospital seem to have contributed to Jenny’s mistrust of
others. She noted that others (“doctors and nurses” included) seem to discriminate against mentally ill individuals due to ignorance (“they are not taught right.”)

At the beginning of the interview, Jenny seemed cautious towards me, but as the interview progressed and rapport was established, Jenny seemed to trust me more, revealing more about deeply personal experiences. Jenny’s initial cautiousness was reflected in a comment she made as she signed her consent form when she jokingly stated that she could “sue” me if her confidentiality was ever compromised. Given Jenny’s experiences with others, her struggle between trusting and being cautious of others is understandable.

Finally, Jenny spoke about the negative and positive treatment experiences she has had over the years. Negative treatment experiences included being overmedicated (she was currently on 13 different medications and dealing with unpleasant side effects) and being labeled and misdiagnosed. Positive experiences of treatment included being a member of an advocacy group, which served as a source of support and empowerment as well as a large part of her identity, and having an attentive therapist. Jenny seemed to have benefited from her active involvement in educational and advocacy groups and the impact on her self-esteem and sense of identity was apparent. At the same time, she seemed to have a good relationship with her treatment providers with whom she related in a trusting and disclosive manner. Jenny expressed the importance of feeling listened to and understood by others in her recovery.

On several occasions throughout the interview she spoke about past memories of her childhood, and revealed that she often escaped her current situation, finding refuge, consolation and safety in communicating with beloved deceased relatives. Furthermore, a
prominent “delusion” which Jenny introduced at the beginning of the interview and mentioned throughout, was her upcoming wedding (in 4 years) to a man, who, like her deceased father, loved, supported, and protected her. This delusion seemed to be a source of meaning and optimism for the future for Jenny. Consultation with her psychiatrist and therapist confirmed that Jenny lives in a facility with some other elderly females, and that she was not engaged, nor did she maintain a relationship with a man.

II. General Interpretative Summaries

In interpreting the themes across all participants, it became apparent that, even though the original objective of this project was to focus on the impact of diagnostic labeling (i.e., receiving the diagnostic label of schizophrenia) on participants’ lives, the majority of the themes that emerged addressed the experience of living with the mental illness of schizophrenia more broadly. As a result, this project evolved into a broader study than that originally proposed. If the discussion remained limited to the impact of diagnostic labeling on individuals’ lives, another large and important part of their experience could have been overlooked: that of living life with schizophrenia. To do justice to the complexity of participants’ experience, themes were grouped under two categories: one specific to the issue of schizophrenia as a disorder with which participants struggled, and the other pertaining to the diagnostic label of schizophrenia. These clusters together provide a more complete picture of participants’ experiences.

In investigating the experience of living with both the disorder of schizophrenia and the label of schizophrenia, data were analyzed focusing on the personal, interpersonal
and contextual dimensions of participants’ experiences. The 10 themes identified across the 7 participants’ narratives are detailed below.

I. Living with the Diagnostic Label of Schizophrenia

Four key themes integral to living with the diagnostic label of schizophrenia emerged. First, even though all participants were active in treatment in a schizophrenia program, thus recognizing that they suffered from a mental illness and required help for their struggles, they did not accept the diagnostic label of schizophrenia as defining their identity as individuals. Second, all participants spoke about concealing their diagnostic label in their interpersonal interactions for a variety of reasons. Third, participants spoke of facing others’ ignorance about what schizophrenia is. Finally, participants described the experience of stigma based on others’ knowledge of their diagnostic label.

1. Not Accepting the Schizophrenia Label as Defining One’s Identity

Participants can be classified into two subgroups: Subgroup 1, comprised of Devin, Shawn and Jack, rejected the schizophrenia label as part of their self-image; Subgroup 2, comprised of Barry, Daniel, Beatrice and Jenny, accepted the diagnostic label of schizophrenia as part of their self-image, but did not accept the label as defining their identity.

Devin, even though he no longer participated in outpatient treatment programs, infrequently saw a psychiatrist for medication management. While he recognized that he saw the psychiatrist because he has a mental illness, he avoided mentioning the term “schizophrenia” and re-stated that he would like to be “normal” during the interview. Furthermore, he refused to elaborate on his experience of the illness, even though he
responded to all questions. He denied ever experiencing symptoms typical of schizophrenia and mentioned that the only symptom he had was “racing thoughts.” He attributed “being sick” to antipsychotic medications ("I am doing fine! I mean before I was really sick…I don’t know if it is from the medicine…I am doing fine now.") He described being “sick” as an event of the past and stressed that he was feeling good and that he was “out of the loop” only “visiting every once in a while.” He no longer identified with the role of a mental patient, as he now assumed the role of a “visitor.”

In his own words:

It’s just I would rather not be sick you know. I’d rather be normal and not have racing thoughts and all the stuff that came with it. I just didn’t like it. That’s why I feel better now. I am glad it’s over. Hopefully it stays like that!

Barry, on the other hand, embraced and integrated the diagnostic label of schizophrenia as well as his role as a mental patient as part of his self-image. However, while he acknowledged the losses caused by the onset of his illness such as having to give up future career goals, he did not accept the schizophrenia label as defining his identity. Recognizing that living his life “as normally as possible” was not easy for him due to his tendency to be self-judgmental, his developing spirituality helped him accept himself and maintain an “optimistic life-attitude.”

Daniel also accepted that he suffered from schizophrenia and integrated the diagnostic label and role as a mental patient as part of his self-image. However, he did not accept the label as defining his identity. Daniel saw himself as different neurochemically (“I probably have more serotonin or chemicals in the brain that other people have less”) but not qualitatively from others who don’t carry the label. Daniel embraced his difference and brought examples of famous geniuses labeled schizophrenic to
demonstrate that receiving a diagnosis did not define an individual or limit who the individual may become. Even though he was “caught,” mandated to treatment and marked with a diagnostic label, Daniel stated that “there are a lot of people walking around with lots of illnesses that aren’t diagnosed,” underscoring that receiving a diagnosis need not define one’s identity.

Shawn, even though he acknowledged that he has a mental illness for which he was in treatment, avoided using the term schizophrenia. Instead, he described himself as “having symptoms,” “feeling really depressed,” “having weird thoughts,” “having strange racing thoughts,” “having fixations,” and “having a chemical imbalance in the brain.” He even asked me to define a psychotic episode (“Well, I will ask you this. What is a psychotic episode what does that mean?”), perhaps indicating that Shawn felt that he was more than a label, or that a label cannot capture his experience or define his identity. Avoiding the use of the term “schizophrenia” and using alternative terms like “feeling depressed” could also indicate Shawn’s attempt to normalize having a mental illness given that depression is a more prevalent mental disorder in society (carrying less stigma.)

Jack, like the rest of the participants, recognized having a mental illness for which he received treatment, but did not seem to accept schizophrenia as part of his identity. He used various other terms to describe the onset of his illness such as “depression,” “a condition,” “a mental disease,” “a chemical imbalance,” “such and such disease,” and “having an episode,” but avoided using the term schizophrenia. Moreover, Jack spoke about maintaining an optimistic attitude and having faith in recovery. In spite of having a serious mental illness, he did not allow it to define him or hold him back from realizing
his career goals. Jack proudly stated that he went ahead and earned his associate’s degree. In his own words: “…I wouldn’t say that it (i.e., receiving a schizophrenia diagnosis) affected my self-image or anything like that. I see myself still as having goals, you know, and stuff like that and reaching them, you know.”

Beatrice accepted that she is in treatment for having schizophrenia, but refused to accept the negative prognosis she was given when first diagnosed, and rejected the diagnostic label as defining who she is as a person. She decided to “live in spite of” having an illness. Beatrice saw the diagnostic label as implicitly indicating “defectiveness,” and as “confining” or potentially limiting who she can become. “I am not my diagnosis,” she affirmed. Similarly, she expressed the following:

…I don’t want to be pacified. I don’t want to be talked down to I don’t want to be treated as though I have something they can catch, or you know I am not mentally retarded, you know and even if I was, I wouldn’t want to be stigmatized as though I couldn’t achieve anything or I’m in this little box and this is where you are and we are over here so you stay over there… You know, I just want to be… myself I want to be accepted for being who I am… like everybody else who doesn’t have the diagnosis, right… and what I can do or accomplish.

Jenny, a self-identified abuse and mental illness “survivor,” rejected the diagnosis of schizophrenia as defining her. During the interview, she spoke about several experiences in which she experienced stigma and discrimination from others given her status as a mental patient. She made it clear that she did not allow those experiences to define or limit her. In her own words: “And I said I don’t want to be labeled…so they said ‘she is crazy.’ I was labeled so many times…I hated that. I hated it!”

2. Concealing the Diagnostic Label of Schizophrenia
All participants spoke about concealing their diagnostic label in their interpersonal interactions. To some degree, most actually attempted to conceal their diagnosis during their interviews by either not mentioning the term “schizophrenia” when talking about their illness, or using a different term to refer to their illness (e.g., “illness,” “depression,” “sickness,” “disease,” etc.) It could be that they identified “depression” as something more common or socially acceptable than “schizophrenia.” Also, perhaps personal experiences with stigma led them to be reluctant to reveal their diagnosis to others.

Devin did not say much about his experience with schizophrenia, and even denied experiencing symptoms in the past. He denied his role as a mental patent and perceived himself as a “visitor” at the hospital. Hence it seemed like Devin tried to conceal his experience of living with the diagnostic label of schizophrenia from me, but did not elaborate on his interpersonal interactions, other than to mention about the loss of his friendships since he was diagnosed.

Barry spoke about others’ denial or lack of acceptance of his diagnosis, which seemed to have discouraged him from talking about his illness with others. He spoke about concealing the details of his illness for fear he might “alienate” others if he revealed too much. Instead, he chose to isolate from others for the most part.

Daniel also spoke about concealing that he suffers from schizophrenia for various reasons: to avoid ridicule, to avoid feeling badly about himself, to avoid belittlement and invalidation from others, to avoid eliciting fear in others, to avoid differential treatment from others, and to avoid stigma. Even though he didn’t address his feelings directly,
Daniel described experiences of invalidation in his family which may have contributed to his decision to conceal his diagnostic label in romantic and interpersonal relationships.

Shawn gave examples of situations where he was discriminated against based on his diagnostic label. From those experiences he seemed to have learned to not reveal that he suffers from schizophrenia unless he trusted and knew the other person well. Shawn spoke about hiding his diagnosis to avoid stigma and rejection, and to be liked for who he was as a person.

Jack said that he generally concealed his diagnostic label from others, with the exception of close relatives who knew him personally (“…I just really don’t bring it up until I feel like 100% comfortable with that person that they know me well enough…but even then, it is kind of hard for me to bring it up.”) Jack stated that he concealed his diagnosis to avoid “being made fun of and taken advantage of,” to avoid making others uncomfortable, and to avoid “re-living bad memories.”

Beatrice embraced the fact that she has a mental illness even though she rejected the diagnostic label as defining who she was as a person or limiting her future opportunities. She spoke about experiences of invalidation in her family, which led her to not reveal much about her illness to others. She spoke about concealing her diagnostic label to avoid stigma, to avoid being treated differently, to avoid being perceived as “incompetent”, and “to be treated like everybody else” who does not have a label.

Jenny was “angry” as she recounted personal experiences of stigma and discrimination as a result of revealing her diagnostic label to others. What she learned from those “hurtful” experiences was to not reveal anything about her illness to individuals other than her therapists and close friends, to avoid being hurt again.
Additionally, she often withdrew into an alternative, “safe,” world in which she could communicate with trusted, beloved deceased relatives.

All participants typically concealed their diagnostic label in their interpersonal relationships. The only exception was in cases when they knew the person well so that they wouldn’t be misunderstood or judged solely based on their label. But sometimes they did not find acceptance and understanding even in their own families. Behind this concealment was the desire to be treated like everybody else not carrying a label. However, by being cautious and concealing such an important aspect of their identity, they may have limited their opportunities to establish deep, honest relationships with others, who could serve as sources of support and acceptance.

3. Facing Others’ Ignorance about Schizophrenia

Participants believed that there exists a great deal of ignorance or lack of education regarding what schizophrenia is. On the one hand, they experienced anger, hurt, and felt misunderstood. On the other hand, they attributed good will to others by attributing their negative attitudes to ignorance. At the same time, they felt unacceptable and invalidated.

Devin did not address this point directly, but through his emphasis on wanting to be “normal,” stressing that he was “fine” and denying symptoms, perhaps he wanted to evade stigma originating from ignorance about schizophrenia.

Barry was “angry” at his brother for not understanding his illness, but at the same time justified his brother’s denial of his diagnosis as a consequence of not knowing what
schizophrenia really is. For Barry, his brother’s lack of education about mental illness led him to mistake schizophrenia for “laziness” and “immaturity.”

Daniel elaborated extensively on the negative impact of the media in generating stigma, ignorance and fear. He saw the media as the “sole” (mis)educator of the public about schizophrenia. According to Daniel, the media did not offer a realistic portrayal of schizophrenics, depicting them as responsible for serious crimes, instead of showing how these individuals can also be gifted. Individuals learn to fear schizophrenics by attending to those negative and inaccurate portrayals. He also spoke about his family’s lack of education regarding schizophrenia (i.e., they equated it with mental “retardation”). In his words: “You know, I just have a mental illness. But you know, if you tell someone you are schizophrenic first thing they think is the way you say mental illness they think you are stupid.” “…It’s all about who is ignorant and who is not.”

Shawn, in addressing romantic relationships, gave an example of an interaction in which a woman, who had initially seemed interested, rejected him once she learned that Shawn was taking antipsychotic pills. He stated that he “hated” it when others judged him based on his diagnostic label rather than on who he was as an individual.

Jack, at the end of the interview, urged readers of this dissertation to educate themselves about schizophrenia and develop empathy, instead of discriminating against schizophrenics. In Jack’s words: “…For people who don’t understand it, you know, just do research about it so that they can better understand it! I mean it is a chemical imbalance. And I mean, try to put yourself in their shoes because it can happen to them!”

Beatrice spoke about her family’s avoidance of any conversation pertaining to her illness. Through participation in advocacy movements she sought to educate others about
mental illness. Through her function as a peer counselor, she sought to cater to the needs of other mental patients as she could empathize with their experience.

Jenny spoke at length about her experience with stigma and discrimination. According to her experience, people who discriminate against individuals with schizophrenia, “doctors and nurses” and students included, “are not taught right.” Jenny spoke about being a proud member of an advocacy group whose goal was to advocate for the rights of the mentally ill and educate the public about the illness.

4. Stigma

To some degree all participants experienced stigma and discrimination as a result of their diagnostic label. In response they felt hurt, misunderstood, invalidated and unaccepted as human beings.

Devin did not talk about his feelings regarding any mistreatment he might have experienced as a result of his diagnosis. However, he mentioned the loss of friendships following his hospitalization.

Barry spoke about feeling angry, hurt and “upset” in response to his brother’s reaction once he learned that Barry suffered from schizophrenia. He felt unaccepted and misunderstood instead of being accepted and supported, especially by people close to him.

Daniel said the following in response to a question about others’ reactions to his diagnosis: “Most of my family doesn’t believe schizophrenia exists. They don’t believe I’m sick…they don’t believe schizophrenia is real…they know I’m smart…when they hear mental illness they think retardation.”
Shawn gave examples of relationships and friendships that ended (they “got rid of me because they found out I have this illness”) once his illness was disclosed. Clearly, Shawn felt that he was not accepted because of his diagnosis. He gave examples of people who did not know that he has a mental illness who think that he is a likeable guy with a “great personality.” For example: “At this bar everyone likes me down here. I’m almost positive they don’t know about my illness. I’m wondering if they’d still like me if they found out.”

Jack spoke about concealing his diagnosis from others for various reasons. He stated that always at the back of his mind is the thought that somebody would “poke fun of” him or “feel uncomfortable” around him once they learned he had schizophrenia. Perhaps during the research interview he avoided mention of the term “schizophrenia” for the same reason.

Beatrice did not feel accepted by her family members who refused to discuss her illness. Apart from being invalidated, she was blamed by her husband who claimed that their children misbehaved because of Beatrice being ill. In addition, Beatrice stated that she did not want to be defined by her diagnostic label, but by her actions and who she was as a unique individual. In her words “…I just want to be…myself. I want to be accepted for being who I am…like everybody else who doesn’t have a diagnosis…” Because of stigma surrounding schizophrenia, Beatrice did not feel she could be accepted unless she concealed her diagnostic label.

Jenny spoke about negative experiences such as the experience of stigma, labeling, and ridicule based on her diagnostic label. She said that she “hated” being called “crazy” by others. Given those experiences, Jenny withdrew from the “real” world to a
“safer world” in which communication with her deceased relatives offered her acceptance and consolation.

II. Living with the Mental Illness of Schizophrenia

Several themes emerged regarding participants’ accounts of living with schizophrenia. First, the vast majority of participants (6 out of 7) spoke about the onset of the illness, which they described as frightening and overwhelming, leaving them confused and feeling that they lost control. Second, a subgroup spoke about an emerging spirituality as a key to self-acceptance, optimistic life outlook and coping with schizophrenia. Third, a key conflict present in all participants was between trusting and mistrusting others. Fourth, all of the participants experienced difficulties dealing with negative anti-psychotic medication side-effects. Fifth, participants spoke about their perceptions of unhelpful aspects of treatment. Finally, they all spoke about their perceptions of how they benefited from treatment.

5. A Frightening Onset

An important dimension emphasized in this research project was the personal dimension, situating the experience of living with schizophrenia in a historical context. Interviews began by asking participants to talk about their first experiences with the mental health system (e.g., first hospitalization). A key aspect addressed by the vast majority of the participants (6 out of 7) was the onset of schizophrenia.

Devin was not very expressive in his responses and refused to elaborate on his experience of his onset of schizophrenia. Instead, he focused on emphasizing his present
state of well-being. However, he appeared visibly anxious when he was asked to talk about his first hospitalization. Devin looked scared when he recounted that experience and stated that “being sick was bad,” that he was then “a lot sicker” and felt like he “couldn’t control” his “mind.” He added that his mind was “hazy” and that the whole experience was “rough,” but he “managed through it.” He did not say more, stating that he “couldn’t really explain” or put into words how he felt.

Barry stated that at the onset of his illness, it was hard to vocalize his experience to others. He “got lost trying to figure out” what was happening to him and expressed that the onset caused a lot of “confusion,” fear and distress. He tried to cope with the voices (hallucinations) and confusion by abusing alcohol in an attempt to “tone it down.” Barry tried to understand his onset of schizophrenia and seemed conflicted between attributing the development of symptoms to excessive drinking and portraying it as unrelated to his actions.

Daniel, visibly anxious, stated that when he first started “hearing voices” he felt “scared,” “thinking that something was wrong.” He started “isolating” and withdrawing and “became a recluse” trying to cope with symptoms on his own. Like the vast majority of participants, his behavior led him to be involuntarily hospitalized by his family. Even though he eventually learned how to cope with symptoms, mostly without the aid of medication, it has been a long and difficult process. When symptomatic, Daniel mentioned that “It is harder to do things like focus and concentrate and follow through with plans.”

Shawn spoke about trying to explain and understand the onset of his illness. He spoke about a “sudden” and unexpected onset of schizophrenia symptoms during which
he felt scared, helpless and that he “might have lost” his “mind.” He subsequently felt “really depressed” and guilty, initially blaming himself for triggering symptoms he was experiencing such as confusion, delusions, racing thoughts, and auditory hallucinations, by drinking alcohol the night before. He then sought an explanation from a psychiatrist who attributed that the development of Shawn’s illness to heredity. Shawn seemed confused as to which explanation to adopt, but like the rest of the participants, he experienced the onset of schizophrenia as frightening.

Jack saw his onset of schizophrenia as an “unexpected” event. He said that when he started experiencing visual hallucinations and delusions of reference he was “taken by surprise” as he “didn’t know what was going on.” Like Shawn and Barry, he tried to make sense of his experience and wondered whether psychotic episodes were triggered by illicit drug use or stress. Jack spoke about sometimes having regrets for possibly having contributed to triggering the onset of his illness: “What if I did things differently?” he wondered.

Beatrice stated that she was “very afraid” when she first started having “delusions” about others having the power to read her mind and her ability to read others’ mind. She thought that she was “out” of her “mind” and that her powers were contrary to her religious beliefs (“I was very afraid. It’s something to think that there is people out there that might have the power to read your mind…I didn’t want any power like that…It was against what God tells you…” ) Beatrice seems to have thought that succumbing to stressors such as distress at home and being unemployed contributed to the onset of her illness. Like the rest of the participants, fear was her first reaction.
Jenny was the only participant who did not respond directly to questions about the onset of her illness or the usefulness of medications. This could be because she was preoccupied with talking about her experience of abuse and stigma, encountering past memories of her father, and focusing on the delusion or her upcoming wedding. She mentioned that she was misdiagnosed several years ago and angrily stated that she “hated” being labeled.

6. Spirituality as Key to Self-Acceptance and Optimistic Life-Outcome

A subgroup comprised of Beatrice, Barry, and Jenny addressed the impact of spirituality in their lives, while Devin, Daniel, Jack and Shawn did not. Some interesting observations can be made regarding these two subgroups in relation to issues like self-acceptance and acceptance of diagnosis, future outlook, coping with schizophrenia and participation in treatment.

Beatrice described her religious faith as a source of encouragement and hope, and a supply of strength and protection. She described herself as previously self-judgmental, having low self-esteem, feeling worthless and “not good for anything.” Also, in the past, she saw God as punishment, had no sense of meaning in her life, and was actively suicidal. However, her religious faith grew stronger after receiving a schizophrenia diagnosis and this had important ramifications in the way she coped with the illness as well as her life outlook. Beatrice later saw God as a source of support, consolation and hope, and her religious faith as protection. In her own words:

…That’s what I need to do now is to have constant prayer in life so that I don’t have to in an emergency have a screaming pleading crying prayer, you know. I can have a steady constant relationship, like a good relationship and I can feel better about myself instead of the way I was feeling then helpless and hopeless.
But I felt that God was my only, and I still do that’s what my pastor preached about Sunday, that He is the only way when you say to Him is the only help that you need, you know and He will bring people in your life… It’s not like you sit and wait for a cloud to open and God is going to come down (laughs).

Beatrice no longer felt helpless and hopeless, but found meaning in life by reaching out to others. Service to others helped Beatrice feel like she is a contributing, productive, helpful member of society and at the same time helping with God’s Kingdom and contributing to the salvation of her soul. She accepted her diagnosis and role as a patient and rejected the negative prognosis given to her on the day of her diagnosis. Her life outlook became optimistic. In addition to being a peer counselor at the hospital assisting fellow patients, she became active in her recovery by participating in psycho-educational and consumer advocacy groups, and enrolled in college courses to earn a degree in the helping professions.

Jenny’s developing spirituality was also a great source of support. She stated that her life changed in that she “depended on God very much” now, and her faith helped her through her illness. Jenny, a child sexual abuse survivor and a chronic mental patient, did not always have an optimistic life outlook. However, her religious faith as well as active participation in psycho-education and advocacy groups helped her face life with optimism and courage. Even though Jenny recognized that the relatives she communicated with were deceased, communicating and “sensing their presence” offered hope, comfort and “safety” in a world in which she experienced “hurt” through abuse, discrimination, and stigma.

Barry spoke about his newfound spirituality as a source of “inconceivable strength,” a “solace” and a “gift.” Having faith in something greater than himself helped
Barry be less self-judgmental, accept himself and his new reality of living with serious mental illness, and therefore actively participate in treatment. In his words:

…The only thing that opened completely was a spiritual life. That didn’t exist prior… it’s been a solace and I think that was a gift… it gives me strength and stuff that’s almost inconceivable…I feel constant gratitude for that…For having that sort of belief or understanding or spiritual aspect that allowed me to understand where I am at or what happened… In a certain way or to be able to not to blame myself entirely… (pp.7-8)

For Beatrice, Barry and Jenny, developing spirituality led to a generally optimistic life outlook, greater self-acceptance, active treatment participation and faith in treatment, positive progress in their recovery, and a more meaningful existence.

7. Tension Between Trust and Mistrust

A key theme observed in all participants was the conflict between trusting and mistrusting others in their interpersonal relationships. This conflict also played out in participants’ interactions with me.

Devin volunteered to participate in the study but seemed to struggle between providing honest responses and at times telling me perhaps what he thought I expected to hear. Even though Devin was not very elaborate in his responses, he seemed to have provided some candid answers, for instance, that receiving a diagnosis had a negative impact on his life, that ECT and pharmacotherapy were ineffective and that “being sick was bad and being at the hospital made it worse.” However, he also appeared guarded, avoided eye contact and offered short responses. Interestingly, at the end of the interview he apologized for not offering more detailed responses (“I am sorry it wasn’t more information.”) Finally, Devin reported a loss of interpersonal relationships, and a reluctance to depend on others in his daily affairs.
Barry was candid with me about positive as well as negative hospitalization experiences. He mentioned how grateful he was for having people who cared and listened in treatment. Simultaneously, he was honest about the negative side effects of medication and his desire to occasionally go on medication “vacation.” He reportedly responded in the same trusting manner with his treatment team. Interestingly, his appearance contradicted the seemingly open manner in which he responded. Barry wore black sunglasses indoors and positioned himself turned away from me. In his interpersonal relationships, he noted the loss of friendships and his tendency to isolate and conceal things from others to avoid alienating them.

Daniel exhibited conflict between trusting and mistrusting in both his interactions with me and his interactions with others. On the one hand, Daniel described negative hospitalization experiences and tense interpersonal relationships, but on the other hand he perceived doctors as willing to help and justified stigma as caused by media’s misinformation. In addition, while attributing good will to his helpers, Daniel admitted that he contributed to the one-sidedness of his relationships by keeping to himself. While he recognized that sometimes others reached-out to him, he preferred to not be too trusting and emotionally involved in his relationships. During the interview he revealed many personal experiences, such as the onset of his illness, interpersonal struggles, not taking his medication as prescribed, and his familial relationships. He even asked me a personal question at the end of the interview. At the same time, he did not disclose much about his emotional reactions in response to questions about his self-image and discrimination or stigma. He characterized his interpersonal relationships as stressful and one-sided, mainly due to his tendency to conceal his emotions from others.
Shawn also struggled with the conflict between trusting and mistrusting others. He seemed to group others into two categories: those who “misunderstood” him and mandated him to treatment, rejected him or discriminated against him, and those who valued him as a unique individual beyond his diagnosis. Given Shawn’s experience with stigma and rejection, his cautious attitude, as well as his tendency to conceal his diagnostic label in romantic relationships and interpersonal interactions, make sense. This struggle also played out in Shawn’s relationship to me. Whereas at the beginning Shawn attempted to conceal his diagnostic label from me, using other labels like “depression” in referring to his illness, when rapport was established he began to trust me and disclosed more about his experiences.

Jack revealed that he refrained from disclosing his innermost feelings to others and preferred to spend time alone. Like Devin, Barry, Daniel, and Jenny, Jack described his withdrawal from interpersonal relationships and difficulty trusting others as resulting from his illness. In addition, Jack mentioned that he typically kept to himself in his interpersonal interactions, and concealed his diagnostic label to avoid stigma and discrimination. However, he trusted me enough to confide about his negative hospitalization experiences and not taking his medication as prescribed.

In describing the onset of her illness, Beatrice expressed that she became increasingly suspicious of others’ motives. She later recognized this as largely attributable to her illness. In addition, Bernice concealed her diagnosis and experience of symptoms in her interpersonal interactions to avoid stigma and to be “treated like everybody else.” During her interview she disclosed personal information such as negative and positive hospitalization experiences and marital difficulties. This trusting
attitude was reportedly also manifested in her relationship with her treatment providers. Seeing me as a graduate student working on a project, she offered elaborate answers to questions to help me complete the project. Perhaps seeking a more reciprocal relationship, Beatrice asked me a personal question at the end of the interview.

Jenny also exhibited a struggle between trust and mistrust in her interpersonal relationships as well as in her interactions with me. Her cautious attitude was reflected in her comment, made while signing the consent form, that she would “sue” if her confidentiality were ever compromised. However, once rapport was established, Jenny disclosed personal experiences, including past sexual abuse and discrimination. Also, Jenny trusted me enough to reveal her “delusions,” something she ordinarily concealed and shared only with her therapist and close friends.

The trust-mistrust dynamic seemed to be both a result of participants’ living with the illness of schizophrenia and their experience of stigma. Their experience of symptoms such as paranoid delusions, hallucinations and negative symptoms led them to be suspicious of others and isolate from them. In addition, having encountered discrimination based on their diagnostic label, all participants learned to be cautious in their dealings with others. Also, it could be that participants felt that their behavior seemed unintelligible to others. I maintained an unconditionally accepting, respectful attitude, employing empathic listening and following the lead of participants during the interview. It is possible that this attitude facilitated the establishment of trust which enabled a degree of honest self-disclosure for participants.

8. Medication Side Effects and Noncompliance
All participants have been through several medication trials throughout the years and had to be compliant in order to stay in treatment. In their interviews, most described their experience with taking medications and enduring or coping with serious medication side effects.

Devin seemed ambivalent about the usefulness of medications. When asked whether there were any downsides to taking medications, he stated “Not really…well, I mean it made me sleepy and a little bit drowsy all day, every day, but it was better than having racing thoughts.” However, earlier during the interview he attributed being “sick” to taking medications: “Yeah. I’m doing fine! I mean, before I was really sick…I don’t know if it is from the medicine but I am doing fine now.” Throughout the interview, Devin tried to downplay the severity of his symptoms by emphasizing that he is “fine” and would like to be normal.

Barry also spoke about dealing with serious medication side effects, and characterized them as being “sometimes worse than the actual illness.” When he first was diagnosed he was on “too high a dosage,” and doctors kept experimenting with different medications for two years. That period of time had been a “medication mess” for Barry. He spoke about medications “knocking” him “out,” making him feel “very sedated in the evening” and causing many “uncomfortable” side effects like: “salivating, dry mouth, difficulty swallowing, getting hungry, having to use the restroom, messed up motor-functions, and difficulty breathing.” Difficulty breathing was a very “scary” side effect. He confided that these numerous side effects often made him wonder whether following up with treatment was worthwhile: “The side-effects at times got me to the point where…all those medications, I was like, is it worth it? So I wish I’d rather just drink
from time to time.” At times he considered taking a “medication vacation,” something he believed that everybody on antipsychotic medication secretly did from time to time. However, Barry stated that one positive thing about the medication was that it took away his auditory hallucinations.

Daniel spoke about his view of medications and acknowledged not taking them consistently so as to avoid having side effects (“a long list of side effects…and who wants to live with all these side effects?”). He commented that the development of new and improved medications was the reason he resumed taking them, adding that there were “a lot of medications” he “did not like” previously. He said that the one positive about medication was that it was “one way to get back into the boundaries of reality.” He added, “if most of what you are dealing with is fictional then you can’t really deal with reality well.” Daniel mentioned that he spent 5 years without medications, learning to cope with symptoms on his own in order to avoid side effects like sexual dysfunction and weight gain. He learned to distinguish internal from external voices by paying attention to details and observing his surroundings. This tactic took “years of practice” to develop and had not been always effective. However, Daniel stressed that he avoided being overmedicated and learned how to “just deal” with symptoms like “internal voices” and “confusion” to avoid living with a lot of medication side effects.

Shawn seemed ambivalent about the usefulness of medication. He stated “Honestly, I take them and they work, but I don’t notice differences at all.” He added that medication was effective in taking away some of his delusions that used to be a “big issue,” but now he doesn’t “even think about these things anymore.” Shawn had a history of medication non-compliance.
Jack confided that at times he did not take his medications as prescribed. He complained of serious drowsiness as his main medication side effect, which interfered with his work performance: “…the side-effects pretty much had me drowsy to a point where I couldn’t really do anything.” He stated, “The side effects would hit me so hard that I’d just feel like pretty much someone hit me with a tranquilizer dart and it’s just like your body just start shutting down, like the only thing you wanna do is just like go lay down so it will wear it off.” Because of this, he stopped taking his medication in order to function at work. He also complained about “losing control” over his “body” and having to limit his daily activities because he was so tired, and “feeling slowed-down” such that he “couldn’t get anything done.”

Beatrice, even though she did talk about positive and negative treatment experiences, did not refer to any negative aspects of taking medications. She just emphasized that it was not enough for someone to take their medications to have a positive treatment experience. Instead, she emphasized the importance of discovering one’s “personal medicine” (i.e., what makes one feel productive, what gives their life meaning). Beatrice also found psycho-educational groups to be an effective and “hands on” component of treatment.

Jenny began her interview complaining of being overmedicated, and asked me for water. She stated that she was on 13 different medications that caused unpleasant side effects such as dry mouth, fatigue, attention difficulties and shaking hands. The two latter side effects were evident during the interview. Beatrice would occasionally lose her train of thought, and her hands shook so much that she tried to keep them on her legs or holding her walking stick.
9. **Unhelpful Aspects of Treatment**

Participants spoke about various difficult or unhelpful aspects of treatment.

Devin spoke about his negative treatment experiences in the hospital, but he was careful to counteract those complaints with something positive. For instance, he stated, “Being sick was bad and being at X Hospital made it worse. I mean it was better that I was getting help, but I didn’t want to be there.” He complained about the hospital having too many rules and regulations that were strictly enforced: “It’s just a lot of rules. You can’t do what you want to do. You are going to be doing what they want you to do.” These rules and restrictions of freedom made the hospital “not a nice place to be.”

Barry’s only expressed complaint about the hospital was being overmedicated: “…They weren’t very good with medication…I was completely not really there…I was completely out of it.” For the most part, however, he expressed his “faith” in treatment, and he said he felt “lucky” to have people to “care about” and “listen” to him. He attributed good will to doctors “even if (the medications) weren’t the right ones” because at the onset of his illness he felt “vulnerable.”

Daniel, like Devin, also complained about the loss of freedom and control over one’s own actions in the hospital. In his words, “I don’t like the hospital…They put you in a room, they give you pills and they force you to do what they want you to do. You don’t have real freedom in the hospital. You are under observation and you are forced to take medication. And you have to do what they say to do or they lock you in a room and tie you down.” He added, “If you want to sleep in you can’t do that…if you want to read when the group is going on you can’t do that, you have to abide by the rules of the program…not a lot of volunteer stuff there. Some hospitals are better than others…I’ve
been through a few.” This account offers information about the impact of mandated hospitalization on the patient.

Furthermore, Daniel commented on the “stressful and confusing” process of applying for social security benefits. While this does not represent an undesirable aspect of treatment per se, it is an important aspect of the process of pursuing treatment. Daniel understood that the system was selective about who legitimately should receive benefits, but his experience of multiple unsuccessful applications, and the frustration and confusion he had to endure had a negative impact on his health and well-being. This could be an experience common to many individuals in Daniel’s position.

Shawn spoke about certain aspects of the mental health system that made him perceive treatment as punishment. When he was involuntarily hospitalized (for the third time,) he was “frustrated” about the manner in which he was “forced” into treatment. This experience made him feel “horrible” and helpless, and made him “hate” the hospital because he was detained by police, handcuffed, and placed into a “paddy wagon” for an extended period of time. He felt misunderstood by his cousin and stated that she could have pursued a different route to get help instead of having him treated like a criminal. This experience left Shawn feeling singled out: “I never want anything like that again. I’ve seen people that are way, way, way, way worse than me and they are not in the hospital. People are sicker, you know, and they still didn’t have to go to the hospital.”

Furthermore, Shawn, like Devin and Daniel, spoke about the loss of freedom in the hospital as a negative experience. Even though he acknowledged that the “helpful” component of hospitalization is medication management, he stated that feeling trapped for an extended period was a “waste” of his “life.”
Apart from being overmedicated, Jack stated that being treated by uncaring staff members made him want to “get out of there” (i.e., the hospital) as soon as possible. He remarked that what bothered him most was several staff members’ “nasty attitude” at the hospital. Jack perceived the majority of staff as “not caring at all” about patients, especially those who “actually really needed help.”

Beatrice raised the same point as Jack when she spoke about mental health professionals’ attitudes in the hospital. She stated that being not taken seriously or treated respectfully accounted for her negative experience of the hospital. As an example she stated, “When I was on the inpatient schizophrenia floor, I went to ask the nurse something, but they just give you the cold shoulder. They wouldn’t even acknowledge that you were talking.” She contrasted that experience with one in which she felt listened to by staff who would acknowledge and talk to her, instead of talking down to her or ignoring her. The experience of receiving a negative prognosis was another negative experience, as she felt that in addition to that prognosis no support or encouragement was offered.

Jenny, in addition to her complaint about being overmedicated, stated that being misdiagnosed in the past accounted for a negative hospitalization experience. In addition, while talking about her experience of stigma and discrimination in her interpersonal relationships, she stated that in some situations she felt that doctors and nurses also label and discriminate against mentally ill individuals. However, she also spoke about feeling listened to and understood by her therapist as a positive experience of treatment.

10. Benefits of treatment
To some extent all participants spoke about the ways they benefitted from treatment.

**Devin** was ambivalent about medication and treatment. For him, one of the useful things about treatment was receiving a diagnosis: “I think it helped, I guess at least I know what was wrong or something.” Even though he did not elaborate on this view, it seems that receiving a diagnosis had been a somewhat relieving experience as it helped clarify “what was wrong.”

**Barry** spoke about faith in treatment as a source of hope, support and optimism at the onset of his illness, when he felt hopeless and vulnerable. “I don’t know if I’d even be the way I am now if I let myself do that much further without receiving treatment,” he stated. He spoke about the importance of having attentive and supportive doctors and family members in his recovery. In his own words: “…It is definitely great (to have people who care.) I have a great therapist and a great doctor…So I feel lucky to have people to listen to me and to also be able to be in the position to get help with medication…” Barry also felt grateful for the “unwavering support” of his parents. He was thankful for his mother’s support and acceptance and for his father’s true empathy, support and understanding by virtue of his own experience with mental illness.

**Daniel** saw one-on-one interactions with the doctor as a positive treatment experience when he compared the treatment he received in various hospitals. Furthermore, even though he spoke extensively about medication side effects and restriction of freedom in the hospital, he perceived doctors as willing to help. He identified education about schizophrenia as a helpful part of treatment, and mentioned a collaborative relationship with staff as helpful in preventing a possible relapse. In his
I am still able…I mean possibly able to have a relapse and start reclosing again…but you know, I try, I work on my therapy, my team of therapists and doctors…I work with them and try to do what’s right.”

Shawn, even though he emphasized negative hospitalization experiences, mentioned that his first experience with a doctor when he began to experience symptoms was a positive one. In this encounter Shawn felt understood by the doctor, who affirmed and encouraged that he would never be in a mental institution if he actively participated in therapy. Even though Shawn understood the usefulness of treatment in helping himself deal with his illness, he seems to have especially appreciated this clinician’s attitude towards him.

Jack focused on describing impact of the “nasty attitude” of “uncaring” staff members on his impression of treatment and the hospital. On the other hand, he contrasted that negative experience with a positive one, when he experienced the doctor as empathic, respectful, and attentive to his needs. In addition, he described a positive treatment experience in a group therapy setting. The therapeutic factors of universality and imparting information were helpful (Yalom, 1995). He felt relieved to learn that he was not alone in what he was experiencing: “…It made me see that I am not the only one that actually goes through this type of stuff and that there are other people out there who, like, have similar symptoms like mine and pretty much go through the same stuff I go through on a daily basis.” He added that it was “helpful” to receive “advice” and “helpful tips” from others on how to deal and cope with his illness more effectively.

Beatrice described negative treatment experiences such as receiving a negative prognosis and not being taken seriously or treated respectfully, indicating that an
attentive and empathic attitude on behalf of the staff could have been helpful. However, she also emphasized the benefits of taking an active role in her treatment and recovery. She spoke about the usefulness of a psycho-educational component of treatment. For instance, she found learning how to assert herself useful. She characterized her participation in therapy and educational groups as “the best help” she “ever got.” In her words: “…I was with people like myself and I was learning that I wasn’t the only one that had these kinds of thoughts and problems.” Participation in the recovery movement and advocacy movement was also a source of empowerment, and helped Beatrice live “in spite of” her diagnosis. Membership in those groups helped her accept her illness, integrate it as part of her identity, and strive to be actively involved in her treatment. Being employed by the hospital in a peer-counselor role also helped Beatrice feel that she is useful and helpful to others, which gave her meaning.

Jenny, like Beatrice, benefited from being actively involved in her own treatment and recovery. Being a member of an advocacy group clearly served as a source of support, empowerment and meaning for Jenny, and was also a large part of her identity. It had a positive impact on her self-esteem and outlook for the future. Jenny felt positively about being able to contribute to others’ recovery by educating them about stigma and by sharing her personal experiences. Regarding treatment, Jenny emphasized the importance of feeling listened to and understood by her therapist and others involved in her recovery.

Researcher Reflexivity

To analyze the data of this study, I used a hermeneutic-phenomenological method. Reflexivity and “bracketing” are two important characteristics of this method.
Given that research findings are to a great extent shaped by researcher presuppositions, making one’s approach as explicit as possible is crucial. As the study evolved, maintaining a progressive reflection journal was very important because it helped me (a) acknowledge implicit assumptions and presuppositions, (b) articulate my interest in the phenomenon under investigation, (c) reflect on personal and professional experiences which made me interested in the topic, and (d) explicate my approach.

My interest in the impact of diagnostic labeling and its effects on individuals began 8 years ago. As an undergraduate student, I first became interested in serious psychopathology, and schizophrenia more specifically, after taking a course in Abnormal Psychology. I was puzzled with the nature of the illness and the process which one goes through to become “mad.” I became curious about treatment options and how psychotherapy can be of help. I wanted to move beyond a theoretical or textbook understanding of schizophrenia, so I decided to take a practicum at a “Day Center” in my senior year as an undergraduate psychology student. The “Day Center” was a facility where chronic schizophrenics spent their day, located in Nicosia, Cyprus (my home country). The program included social skills and art workshops, occupational therapy, psycho-educational sessions, meetings with the psychiatrist and psychologist, and drama therapy. The goal of this setting was to prepare patients for re-entry into society and the world of work. Most patients, however, had not been employed for several years, and were placed in assisted living facilities and halfway houses by their families or the mental health system.

As an undergraduate student, my role was limited to observation and attending staff meetings. I had no input about patient treatment, but was free to interact with
patients as they attended programs. From the start the mental health professional and patient roles started to become more and more apparent. It became clear that there were two groups: the professional staff who were regarded as “experts” and examples of mental health, normality and rationality, and the residents, seen as “sick” patients having an “incurable disease.” In observing the interactions between staff and patients, it was not difficult to see that for the most part patients were treated in terms of their label instead of as fellow human beings in distress. Hope in the possibility of recovery seemed non-existent.

Patients were infantilized and constantly told what to do or not do and when, and were reprimanded or lost “privileges” (such as going to church, paying a visit to their family, or going to the movies or other “outings”) when they did not follow staff members’ instructions and demands. Oftentimes, patients were treated as if they were incompetent. If they opposed staff members’ commands, it was assumed that patients were “relapsing.” If clients were quiet, the staff often assumed that it was a symptom of their illness; clients were quiet because they were “depressed” or because they were “hearing voices.” In response many clients became passive and gave up any sense of autonomy, fulfilling staff members’ expectations.

The staff often acted as if they knew patients better than the patients knew themselves. In some situations, even clients came to view themselves in diagnostic terms. For instance, if a patient reacted to a staff member’s infantilizing comments, he would quickly apologize, “I am sorry. I am behaving the way I do because of my illness.” When I asked a psychiatric nurse whether recovery or improvement was possible, he responded,
“When a glass breaks, you can never put it back together.” I was dissatisfied and surprised with her response.

In terms of physical space, patients and staff occupied different areas. Patients were not allowed into staff members’ conference room or offices, and they took lunch as groups in different areas of the Center. Contact with staff was minimal, and patients rarely were truly listened to outside of scheduled, structured sessions. For the most part, staff meetings seemed like gossip sessions where oftentimes staff would mock and laugh at patients. I felt uneasy, conflicted and avoided participating in their interactions. In one instance, when I expressed empathy about a patient’s situation contrary to staff member’s perspective, the head psychiatrist gave me the following “advice”: “You shouldn’t be emotionally affected by the patients, if you will ever survive in this field. You are too ‘soft’ and should become ‘tougher.” I tried to persuade myself that the psychiatrist was right, and that in order to help individuals with mental disorders I had to suspend my own human reactions. Fortunately, I was not successful. This practicum was a disturbing experience for me but also an important learning experience.

Prior to coming into contact with individuals diagnosed as schizophrenic, I maintained several presuppositions based on “textbook” understandings of the illness. I expected them to be concrete, not articulate, extremely guarded and untrusting, non-reflective and lacking insight. Listening to stories of pessimistic prognoses, I had a hard time foreseeing the possibility of recovery and transformation. However, even though all participants in this study shared the same diagnosis, they were different in how they manifested symptoms, and operated at different levels of functioning. More importantly, beyond their bundle of symptoms they were complex human beings with unique
personalities, perspectives, histories, and struggles. Many were surprisingly trusting, genuine, articulate and self-reflective.

Becoming aware of the impact of my presuppositions and prior experiences was crucial for the purpose of this study. By recognizing that I emphasized the negatives of diagnostic labeling, I became more open to the positive aspects of diagnosis and treatment as well as the possibility of improvement and recovery over time. Aware of my original desire to “do justice” to participants’ experience by exposing the negatives of treatment, I also came to recognize that patients are not simply the victims of others who label and mistreat them; they are also suffering from a distressing illness which has a real impact on their lives and relationships. I learned that each individual is unique in his or her psychological experience of schizophrenia as an illness and as a diagnostic label.

Finally, as a result of the findings of this research, I came to recognize that instead of siding with one of the two extreme viewpoints regarding schizophrenia, it is important to acknowledge that the truth is more complex. Diagnostic labeling can be a source of suffering for individuals, but the diagnostic label of schizophrenia is not assigned to just anyone. It is often used to describe the psychological suffering and problems of living that have become devastating for the affected individual and their family, usually well before the diagnostic label is applied.

In addition to my professional experience at the Day Center, a personal experience with an individual very close to me who had a psychotic break sensitized me to the struggles of living with schizophrenia and provided me with an intimate understanding of various aspects of the disorder. This person suffered a psychotic episode after 7 months of studying overseas at age 27. Several difficulties in her history seem to
have precipitated a schizophrenic break from reality. She had a history of depression which seemed to have at least partly resulted from being bullied at school for being a bright student, being socially reserved and isolated, and having over-protective and demanding parents who discouraged romantic and social relationships that could distract from academic excellence. Furthermore, the stress of living away from parents, communicating in a foreign language, academic pressures, and lack of social supports probably triggered the psychotic break. Obsessive persecutory ideas filled her mind. She grew increasingly suspicious of others’ motives. The world became a fearful, dangerous place where people used her picture to telepathically enter her dreams, insert ideas into her mind, direct and torment her. The world was divided between good and evil and her soul was “black.” She felt like she “lost” her soul.

The impact on the individual’s family was devastating as well, as they were not knowledgeable of mental illness or prepared to deal with and help her. The family initially believed her paranoid story, but eventually realized that something was “wrong.” Trying to rationally dispute her delusional ideas was not effective. It was obvious that she needed help, but she did not want to see a psychiatrist.

The parents were in extreme distress and their mood, sleep, appetite, and concentration were disturbed. They were faced with important dilemmas: figuring out a way to get her help and protect her without alienating her by committing her into a mental hospital, planning an intervention while avoiding the stigma and gossip of others in their small society had they revealed that their loved one had “psychological problems,” and admitting to themselves that their loved one had a serious mental illness; she was no longer the person they knew.
My friend knew that she was “not well” but did not know what was happening to her. She was persuaded to consult a physician, who prescribed medication to help her feel better. However, she threatened to discontinue the treatment because of side effects like weight gain, trembling hands, dizziness, nausea, constipation, difficulty breathing, and because those medications were “for schizophrenics.” On the positive side, the medication helped her sleep, which she felt was good. She insisted on taking the smallest dosage possible to keep those side effects to the minimum and not feel like a “zombie.”

She did not like the psychiatrist. She felt that the psychiatrist “talked down to” her and often mocked her. For instance, he told her that she was “not articulate” and had “no social skills;” as she would not generate topics of discussion or talk much. She had no patience, showed no empathy, did “not listen and only gave pills,” and would “interrogate” her by asking close-ended questions. She did not find weekly sessions productive or helpful as they stayed on “the surface.” When the recommended treatment period was over, she resorted to a reclusive world and did not talk about what was on her mind.

My recollection of this story was painful, but I see putting it down into words as essential for many reasons. Eight years ago, my understanding of schizophrenia was theoretical and naive, whereas now it is much deeper and more nuanced. This personal experience helped me become more sensitive to the experience of living with schizophrenia. I developed an empathic and complex appreciation of the struggles of being diagnosed with schizophrenia as well as coping with the illness. It has given me motivation to further investigate and understand the nature and impact of this disorder, as well as the impact of diagnosis.
Discussion

As mentioned earlier, over the course of gathering and analyzing the research data, this project evolved into a broader study than the one originally proposed. The study’s central aim had been to investigate the experience of living with the diagnostic label of schizophrenia through the examination of participants’ accounts of the influence of carrying the label on their self-image, and on others’ attitudes and responses towards them. This aim has been met by the results of the study. However, to reflect the complexity of participants’ experiences, results were grouped into two clusters: one specific to the issue of living with the diagnostic label of schizophrenia and another specific to the issue of living with schizophrenia.

Prior to data collection, I approached the literature review with particular preconceptions and a specific interest in the issue of diagnostic labeling - especially concerning the negative impact of such labeling on individuals. The proposal for this dissertation emphasized how schizophrenia, or “madness,” was storied and understood throughout the years, as well as how the treatment of the mentally ill changed over time. The negative impact of psychiatric labeling was stressed and elucidated through citing the majority of the literature on the historical (mis) treatment of ‘schizophrenics.’ It is now clear that at first, at least to some degree, I implicitly sought to confirm those experiences of mistreatment through the voices of the participants. However, as I became mindful of those preconceptions, I was able to attend to the lived experiences of participants. As a result the study became about appreciating the experience of living with schizophrenia more broadly, including the impact of living with the schizophrenia label.
To recapitulate, in explicating the features of living with schizophrenia, themes were analyzed focusing on the personal, interpersonal, and contextual dimensions of participants’ experience.

For the personal area of emphasis, attention was drawn to situating the experience of living with schizophrenia in a historical context with particular focus on participants’ self-image. Second, the issue of living with schizophrenia and carrying the label was explored in relation to intimate and interpersonal relationships. The final area of focus concerned the consequences of living with schizophrenia in participants’ contexts, particularly positive and negative hospitalization experiences. Ten themes identified across the seven participants’ narratives were detailed and organized under two clusters: Living with the diagnostic label of schizophrenia and living with the mental illness of schizophrenia. What follows is a discussion of the research findings in terms to relevant prior scholarship, conclusions, and directions for future research.

Four key themes common to living with the diagnostic label of schizophrenia emerged from the data: (1) Not accepting the diagnostic label as defining one’s identity; (2) Concealing the diagnostic label of schizophrenia; (3) Facing others’ ignorance about schizophrenia and (4) Stigma.

First, even though all participants recognized that they suffered from a mental illness for which they were in treatment at a hospital’s schizophrenia program, they rejected the schizophrenia label as defining their identity. According to the content of participants’ conversations, those were divided into two subgroups: subgroup 1, comprised of Devin, Shawn and Jack, rejected the schizophrenia label as part of their self-image. Subgroup 2 comprised of Barry, Daniel, Beatrice and Jenny, accepted the
diagnostic label of schizophrenia as part of their self-image. Interestingly, in talking about the illness, participants either used several other terms instead of referring to their diagnosis as “schizophrenia,” or avoided using diagnostic terminology to describe their experiences. Some explicitly expressed the desire to be “normal” like everybody else who does not have a mental illness.

Research on testimonials of individuals recovering from severe mental illness indicates that they go through some common experiences in their journey of recovery. Common aspects include: redefining the self, accepting one’s illness, overcoming stigma, renewing hope and commitment, resuming control and responsibility, exercising citizenship, managing symptoms, being supported by others and being involved in meaningful activities and expanded social roles (Davidson, 2003, pp. 45- 48). The redefinition of one’s self as a person for whom mental illness is simply one part is the most overarching aspect of recovery. According to the recovery model, accepting one’s illness does not mean accepting the identity of a “mentally ill person.” Accepting one’s illness has to do instead with redefining how a person understands this particular one of life’s challenges (Davidson, 2003, p. 46).

Devin, Shawn and Jack rejected the schizophrenia label, whereas Barry, Daniel, Beatrice and Jenny embraced it. Both subgroups, however, did not accept the schizophrenia label as defining their identity. Participants expressed a desire to “fit in” with those deemed “normal” (i.e., not mentally ill) in society. They accepted that they had an illness, but did not allow it to define them.

Second, an important finding of this study is that participants unanimously spoke about concealing their diagnostic label in their interpersonal interactions for a variety of
reasons: the desire to be “normal,” to avoid “alienating” others, to avoid ridicule, to avoid self-pity, to avoid invalidation, to avoid belittlement, to avoid differential treatment, to avoid stigma, to avoid rejection, to avoid being taken advantage of, to avoid making others uncomfortable, to avoid re-living bad memories, to avoid being perceived as “incompetent,” and to avoid being hurt. This concealment was also evidenced during the interviews, as many participants either avoided mentioning the term “schizophrenia” when talking about their illness, or used a different term to refer to their illness (e.g., “illness,” “depression,” “sickness,” “disease,” etc.) Some stated that they were more likely to reveal their diagnostic label only if they fully trusted the other person. Behind this concealment was the desire to be treated for who they really were as individuals, beyond their diagnostic label. Also, several of the participants disclosed histories of humiliation and stigma as a result of their diagnosis. Given those experiences, the desire to conceal their label makes sense.

There is considerable evidence to confirm that mental illness is a stigmatized condition. In the introduction of this project, a section was dedicated to the history of the longstanding mistreatment and devaluing of those with mental illness. The most tragic example was Nazi Germany’s mass extermination of psychiatric patients as possessing “life not worthy of life” (Wahl, 1999, p.14). Numerous surveys of public attitudes toward mental illness also reveal strikingly negative views of psychiatric disorder and the people who suffer from it. Many of those surveys suggest dangerousness as a key element of public beliefs about mental illness, even though the vast majority of mentally ill individuals are not dangerous or violent (Wahl, pp.14-15). This long history of stigma and devaluation remains ingrained in public opinion even today. One of the reasons
participants concealed their diagnostic label in their interpersonal relationships was to avoid this stigma and rejection from others.

This present finding on concealment is consistent with previous research that has identified concealment as a common response to stigma. In his book *Telling is a Risky Business: Mental Health Consumers Confront Stigma*, Wahl (1999) identified concealment as a part of coping with mental illness and the stigma and discrimination that accompany it. According to consumer reports, they often denied being in treatment, and they avoided contact with others to avoid the risk of disclosure of mental illness (pp.143-144).

Wahl (1999) reported that over three quarters of 100 consumers he interviewed indicated that they concealed their disorders from others. He concluded that the widespread experiences of stigma and discrimination reveal clearly that “telling is a risky business” (p.159). Similarly, Link et al (1989) found that 89 percent of a group of 245 members of a consumer group admitted withholding information on their mental disorders in their social relationships in order to avoid stigma. Subsequent research by Link and his colleagues (1991) identified secrecy and withdrawal as two of the major coping strategies consumers used to protect themselves from stigma. Finally, Herman (1993) found that 80 percent of 146 recently discharged individuals from Canadian mental hospitals engaged in some form of information control to manage stigma. She identified three types of strategies consumers used: “Selective disclosure”, which entailed avoiding disclosure of mental illness status in situations in which the possibility of stigma and discrimination were judged high, “therapeutic disclosure” to a trusted few for support and catharsis, and “preventive disclosure” where consumers revealed their psychiatric
status early in a relationship. Participants in the present study engaged in selective and therapeutic types of disclosure. Also, like the consumers in Herman’s research, participants in the present study thought timing of disclosure of their psychiatric status was crucial. They selectively disclosed their status to individuals they knew well and trusted to avoid the possibility of rejection and ridicule.

Third, participants spoke about facing others’ ignorance about schizophrenia. They expressed feeling “angry,” “hurt,” and “misunderstood,” but attributed others’ negative attitudes to lack of education regarding schizophrenia. In addition to facing stigma and discrimination in their social relations, four of the participants spoke about their family members’ reactions, which included not accepting that their family member is ill (Daniel, Beatrice, Barry), believing that schizophrenia did not exist and is “not real” (Daniel), equating schizophrenia with “laziness” and “immaturity” (Barry), equating schizophrenia with “mental retardation” (Daniel, Beatrice), avoiding conversation about participants’ illness (Beatrice), and involuntarily hospitalizing them (Devin, Shawn, Daniel, Jack). Furthermore, Daniel saw the mass media as the main educator of the public about schizophrenia, and spoke extensively about the negative impact of these messages on public opinion in generating stigma, ignorance and fear through negative portrayals of schizophrenic individuals. Daniel and Jack urged readers to educate themselves about schizophrenia instead of being fearful about the mentally ill or discriminating against them. And Jenny and Beatrice, through their participation in the advocacy and recovery movements, sought to educate the public about mental illness. This last finding is consistent with that reported by Wahl (1999), who found that 70 out of 100 of the consumers he interviewed recommended education about mental illness as a way of
fighting ignorance and stigma. A number of consumers suggested that public education was needed on grand-scale efforts involving corporate commitment and generous funding (p. 154).

Fourth, participants spoke about generally not feeling accepted by others in their relationships. To various degrees, they all experienced stigma and discrimination from others based on knowledge of their diagnostic label. Consistent with this finding, published research on consumer surveys indicates that rather than receiving an outpouring of sympathy and support, individuals with mental illnesses are more likely to experience lack of acceptance, avoidance and rejection (Wahl, 1999). One of the most common experiences reported by mental health consumers was being shunned and rejected by others when it was revealed that they suffered from schizophrenia and were mental health consumers. Similarly, the majority of the participants in the present study described experiences of rejection and invalidation by others, family members included, once they revealed that they suffered from schizophrenia.

These findings underscore how much simple acceptance can mean to consumers. Wahl (1999) highlights consumers’ desire for others to be more caring, empathic and supportive towards them (p.162). Consumers felt that non-consumers often did not appreciate the sheer difficulty of living with mental illness, and called for empathic appreciation of their lives and struggles with both mental illness and its stigma. Furthermore, consumers urged empathy, and emphasized that mental illness is not a choice but can happen to anyone. Finally, consumers wanted the public to understand that not all people with mental illness are violent or out of control. As one consumer
remarked, “It is lonely because people are afraid of us. The vast majority of people with mental illness are not dangerous.” (pp. 162-165)

Six themes integral to the experience of living with the mental illness of schizophrenia emerged across participants: A frightening onset, spirituality as key to self-acceptance and optimistic life outlook, tension between trust and mistrust in interpersonal relationships, medication side-effects and non-compliance, perceptions of unhelpful aspects of treatment, and benefits of treatment.

The vast majority of participants spoke about the onset of schizophrenia, an onset which they described as frightening, sudden, and overwhelming. They felt confused, vulnerable, helpless, and out of control. They tried desperately to figure out what happened to them by either blaming themselves for triggering the illness or attributing onset to biological/genetic factors—a medical model explanation. From participants’ accounts it appears that the experience of fear and loss of control are integral aspects of living with schizophrenia.

The findings of this dissertation contradict many postulates of Social Labeling Theory, and confirm some aspects of the medical model—namely that schizophrenia is a real, frightening, and devastating illness. The findings of the present research showed that the participants experienced a profound and frightening shift of themselves in the world long before a name or label was given to it, counteracting therefore the denial of interiority and subjectivity that the Social Labeling Theory holds. Onset of symptoms like delusions and hallucinations was terrifying, sudden, and unexpected. Most participants felt like they had lost control over their selves and their lives. A description of this
suffering is evident in the Diagnostic and Statistical Manual of Mental Disorders (APA, 2000):

Clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (e.g., a painful symptom) or disability (i.e., impairment in one or more areas of functioning) or with a significantly increased risk of suffering…disability or pain. In addition, this syndrome or pattern must not be merely a culturally sanctioned response to a particular event…neither deviant behavior…nor conflicts that are primarily between the individual and society are mental disorders unless the deviance or conflict is a symptom of dysfunction in the individual (p. xxxi, italics added).

This definition describes schizophrenia as a debilitating condition causing considerable pain and suffering. In contrast, Social Labeling Theory challenges the psychiatric view that schizophrenia is a medical condition affecting individuals from within. This perspective views mental illness as a social role or “socially constructed category” created for individuals deviating norms for acceptable behavior in a particular society. While this is evidently part of the picture, this view ignores the devastating psychological impact of schizophrenia on the individual, as well as the fact that schizophrenia, beyond a socially ascribed role, is a real illness, with substantial empirical evidence pointing to genetic and neurochemical factors that underpin it.

According to Scheff (1984), the Social Labeling Theory of mental illness conceptualizes “symptoms of mental illness” as a certain kind of non-conformity (p.188). When a person is behaving in a disruptive and upsetting way and society cannot find a conventional label of deviance (e.g., crime, drunkenness, etc.) then the society may resort to a miscellaneous or residual category, which in Western culture is mental illness. Nonetheless, in his later work, Scheff acknowledged that some schizophrenia symptoms may have their origins in illness, and emphasized that the purpose of labeling theory is
not to replace psychiatric or psychological approaches, but to complement them by emphasizing that “mental illness may be at least as much a social fact as it is a physical fact.” (p.189)

Findings of this present study contradict Szasz’s claim that mental illness is a “myth” or an excuse which patients use to evade personal responsibility. All participants’ accounts demonstrated that schizophrenia, more than a myth, is a real, frightening, and devastating illness. To cite one of the participants’ reaction to an accusation that he used mental illness to justify “laziness” and “refusing to grow up:”

He told me that he thought that I was… being lazy! How about that! And that he thought that…stress was overwhelming me and I was afraid to grow up…I was very angry. I thought it was laughable also at the same time… but I told him at the same time, I don’t care if you understand. This is the way it is. This is … my life is not the same anymore as it was…. I told him, why would I want, why would anybody want something like this and then live on disability and social security from the age of 22… I mean… is that, like, you know, the secret getting ahead? And my brother… it was a very weird thing that he was throwing at me and I was really upset, but also at the same time I thought he’s obviously deluded himself so far… but he never say me whenever evidently, or talked to me whenever I was in the hospital all those number of times, even though my mom would update him and all this different stuff. But that was very hard because he is the closest person to me.

The most prevalent view in the nature-nurture debate of schizophrenia today is that of the “diathesis-stress hypothesis” which postulates that both genetic influences and environmental factors play a role in the development of the disorder. If schizophrenia were a disorder caused solely by genetic influences, then the concordance rate in identical twins should be close to 100% instead of the actual rate of 40 %. (Andreasen, 2001, p.199). Most experts agree that schizophrenia is clearly multi-factorial, involving multiple genes as well as many non-genetic or environmental influences (Andreasen, 2001, p.199). The findings of this dissertation demonstrate that for the participants in this
study the truth is multidimensional and complex, and lies somewhere in the middle between schizophrenia being a social (stigmatized) role and a profoundly disorienting subjective experience of dis-ease.

A subgroup of participants spoke about emerging spirituality as a key to self-acceptance, an optimistic life outlook, and coping with schizophrenia. These individuals used their spirituality as a source of encouragement, hope, self-acceptance, and optimistic future life outlook, with the consequences of active treatment participation, and positive treatment experiences. Interestingly, the subgroup that did not mention the role of spirituality in their lives had a history of medication or treatment noncompliance, expressed greater life dissatisfaction and focused conversation on negative treatment experiences. This finding is important to consider, as integrating spiritual practices in psychotherapy could help effect positive change.

Findings of the present study fit with prior research on spirituality and schizophrenia. Research indicates that spiritual matters can be an important part in the recovery process of patients with schizophrenia (Revheim, Greenberg, and Citrome, 2010). Revheim and his associates investigated characteristics of self-selected attendees of a spirituality therapeutic group compared to non-attendees. Findings indicated that spirituality status was significantly correlated with self-efficacy for both social functioning and negative symptoms. Furthermore, group attendees were significantly more hopeful than non-attendees and hopefulness was significantly associated with degree of spirituality status. These findings lend support for offering spirituality groups, in addition to traditional treatment modalities, to promote positive coping during recovery from psychiatric disabilities.
Another study conducted by Borras et. al (2007) investigated the relevance of religious beliefs in schizophrenia in terms of adherence to treatment. This study found that religion, including both spirituality and religiousness, was helpful for patients whose social life and personal identity were impaired by the course of the disease. The findings of this study were congruent with other research indicating that being religious increases patients’ satisfaction and adherence to treatment. The positive impact of spirituality on adherence to treatment was explained by an improved quality of life, a better social support, and more positive representation of the illness by believers (p.1239). Adherent patients had more group religious practices. Also, these patients stressed the importance of community support, compared to non-adherent patients who reported little or no contact with the community (p. 1244).

Finally, a study on spirituality and religious practices among one hundred outpatients with schizophrenia and their clinicians (Huguelet, Mohr, Borras, Gillieron, and Brandt, 2006) indicated that religious issues may be neglected by clinicians who are treating psychotic patients, even when religion contributed an important means of coping (p. 366). Religion (defined in the broad sense as including both spirituality and religiosity) was shown to be helpful as a coping mechanism for patients whose social life and identity have been severely damaged by the course of the disease (p. 366). The authors note that that religion as a coping mechanism has been the subject of growing interest, and expressed a concern for neglect of religious issues in psychiatric practice. They also listed several factors which may account for this neglect, such as an underrepresentation of religiously inclined professionals in psychiatry, a lack of religious education for mental health professionals, mental health professionals’ tendency to
pathologize the religious dimensions of life, and professionals’ unawareness of patients’ religious involvement (pp. 366-367). Like prior research, this dissertation suggests that religion can be an important factor in coping with the chronic and devastating condition of schizophrenia.

Another finding of the present study was that onset and diagnosis of schizophrenia had an impact of participants’ self-concept. Participants spoke about experiencing conflict between different aspects of themselves, especially between the pre-onset and post-onset selves. Schizophrenia onset brought about life-altering changes for participants. For instance, Devin experienced conflict between his “normal” and healthy past self, and the “sick,” dependent on others present self. For the majority of the participants (e.g., Shawn, Jack, Barry, Daniel, Devin) onset of the illness meant giving up many of their future goals and aspirations. However, the females of the group, Jenny and Beatrice, experienced themselves differently. Embracing their illness, seeking psychological help, holding on to their spiritual faith, and being active participants of the recovery and advocacy movements, Beatrice and Jenny no longer saw themselves as “weak.” They instead felt empowered and optimistic about what they can achieve and become in the future, and their self-confidence and self-esteem improved.

Davidson (2003), in his book *Living outside mental illness: qualitative studies of recovery in schizophrenia*, talked about research on the impact of institutionalization and the recovery movement on patients’ self-concept. He proposed that the presumptive loss of self and loss of touch with reality in schizophrenia is consistent with certain aspects of institutional life (p.12). Once diagnosed and hospitalized, individuals often lose the opportunity and ability to make decisions and to speak and act on their behalf. They have
to adhere to structured activities at the hospital with little freedom to plan their day. Also, given the (usually) negative prognosis offered by psychiatrists upon diagnosing schizophrenia, individuals often feel forced to lower or relinquish future goals, including those concerning career. Patricia Deegan’s (2001) autobiographical offered a testimonial of the impact of a pessimistic prognosis or the “prophecy of doom” as she calls it, and her decision to pursue her own recovery and goals.

Findings of the present study not only are consistent with existing research on experiences of loss suffered by those individuals labeled schizophrenic, but together seem to lend support to calls for grief counseling as an important part of the treatment approach. It is evident through the accounts of the participants of this study that they all suffered multiple significant losses as a result of being diagnosed with schizophrenia. Most participants now receive disability assistance and are unemployed, face financial difficulties, had to give up career goals and aspirations, lack romantic partners or close friends, and lack family support or their families do not understand the impact of schizophrenia on their lives. This suggests that grief counseling and psychotherapy can be a useful complement to currently used treatment approaches.

Worden (2009) in his book *Grief Counseling and Grief Therapy* asserted that, based on a preventative mental health model, early intervention can preclude a poor psychological and psychosomatic adaptation to loss (p.87). He cited research evidence supporting the efficacy and usefulness of grief counseling and therapy in meaning-reconstruction through helping individuals express thoughts and feelings about the loss and deal with emotional pain, assisting individuals on re-defining the self and re-learning ways to engage with or adjust to the world after the loss, and offering re-assurance and
education about normal grief reactions and behaviors like anger, helplessness, anxiety, confusion, disbelief and sadness (pp. 3-9; 84).

Being diagnosed with a serious mental illness like schizophrenia can be considered a “socially negated loss; that is a loss which society treats as a “non-loss” (Worden, 2009, p.3) therefore, hindering individuals from adequately grieving and receiving emotional support. Congruent with prior research, this study demonstrated that there is still a lot of stigma associated with the schizophrenia diagnosis, as well as lack of education about the nature and impact of serious mental illness. Therefore, all participants concealed their psychiatric diagnosis in most of their relationships. Normally, grief is a social process and is best dealt with in a social setting in which people can support each other in their reactions to a loss (p.132). However, most participants seem to have experienced a “socially negated loss” and the absence of social and familial support. By incorporating grief counseling in the treatment of individuals diagnosed with schizophrenia, individuals will be able to grieve and receive professional help with thoughts, feelings and behaviors with which they are finding it difficult to cope, find resilience, and learn how to develop a meaningful life.

Involvement of individuals in the mental health consumer/survivor movement allows patients to play an active and meaningful role in their recovery. Based on the personal narratives of many consumers, most definitions of recovery involve some component of acceptance of illness, having a sense of hope about the future, and finding a renewed sense of self (Davidson, 2003, p. 43). The participants of the present study, being in recovery, accepted the illness and incorporated it into a newly defined sense of self. At the same time, they had to deal with a major sense of loss of their “pre-illness”
self, goals and aspirations. Factors like spirituality, adherence to treatment, and involvement in the survivor movement facilitated a positive resolution of this conflict and a sense of empowerment for many of the participants.

Another key conflict experienced by all participants, also evident in their interactions with me, was that of trusting and mistrusting others. At times they seemed to struggle between providing honest responses and telling me perhaps what they thought I expected to hear (for instance, about the helpfulness of treatment). This struggle between trusting and mistrusting among individuals with schizophrenia is explicated in prior literature.

R.D. Laing researched and wrote extensively on the phenomenology of schizophrenia. He emphasized the value of understanding the ‘inner’ experience and communications those labeled schizophrenics. From an existential point of view, he viewed schizophrenia as a symptom of what he called “extreme ontological insecurity” (Laing, 1960). While “ontologically secure” individuals have a strong sense of personal identity and are capable of having gratifying relationships with others, ontologically insecure individuals perceive ordinary circumstances of everyday life as deadly threats. They have a low threshold of basic security in the world, and lack a firm sense of their own autonomous identity. Relatedness to others is not gratifying because ontologically insecure persons are preoccupied with preserving their identity to avoid losing themselves. Therefore, they often become isolated and withdrawn. According to Laing, ontologically insecure individuals encounter a form of anxiety called engulfment. In engulfment, individuals dread relatedness and continuously feel that being understood or loved is a risk. Therefore, they isolate themselves to escape engulfment and preserve their
identity (Burston, 1996). Bearing Laing’s description of the phenomenology of schizophrenia in mind, one can appreciate some of the challenges schizophrenic individuals face in relating to and trusting others.

As detailed in the introduction, Harry Stuck Sullivan characterized schizophrenia as a “peculiar disorder of social or non-social activity” (1962, p.223). He saw individuals suffering from schizophrenia as interpersonally shy, sensitive and defensive, and believed that unsuccessful past interpersonal relationships and un-fulfillment of their social needs led them to suffer severe loss of self-esteem, and feelings of inadequacy. Sullivan saw the function of treatment as providing a supportive environment to patients who were treated as humans beyond their clinical label. Frieda Fromm-Reichmann (1950) also spoke about the difficulty trusting others experienced by individuals suffering from schizophrenia. Like Sullivan, she described patients as extremely sensitive and fearing closeness, spoke about the necessity for an attitude of “respect” towards them, and expressed strong belief and optimism in the possibility of recovery, growth and independence (pp.13-14).

Karon and Vandenbos (1981) also identified as a key conflict faced by individuals with schizophrenia feeling lonely and moving towards people and moving away from them. Coping with a “terrible world” they develop symptoms which can be understood as defenses against terror (pp. 41-43). Sullivan, Fromm-Reichmann, Laing, and Karon and Vandenboss demonstrated that when treatment addresses this dynamic by establishing trusting alliances with patients, those with schizophrenia are able to improve, recover and grow.

I hope the honest responses shown by all of the participants reflect the trusting alliance I sought to establish during the interviews. Participants revealed to me intimate
information about personal experiences with the illness, relationships with others, negative hospitalization experiences, and experiences of abuse, stigma and discrimination. In addition, several of the participants reached out to me and asked a personal question at the end of the interview, perhaps seeking some kind of reciprocal relationship. For instance, right after I explained the consent form to Daniel at the beginning of the interview, Daniel, perhaps having paid attention to my accent, asked me where I was from. Subsequently, when I asked Daniel at the end of his interview whether there was something that he wanted to ask me or tell me, he responded “Do you miss Greece?” following up with his initial question. Beatrice also wondered about my background including where I was from and expressed that she was happy to meet somebody from Greece. Wondering who I was, Scott asked me about my marital status, age, and where I went to college.

Based on my preconceptions noted earlier, I thought that at least some of the participants would be too disorganized or mistrusting to respond to my questions. I also expected participants to be reluctant in disclosing negative treatment experiences. Unexpectedly, the majority of the interviewees made perfect sense, were not disorganized, were even eloquent in their responses, and even trusted me with deeply personal information about their past, their dealings with others, their impressions of treatment, and their coping with schizophrenia. This supports the findings of Laing, Sullivan, Fromm-Reichmann, and Karon and Vandenboss, as well as of Davidson and others; when individuals with schizophrenia are treated like persons rather than patients, they respond as persons rather than patients.
All participants also spoke about dealing with medication side effects. They described a conflict between taking the medication to better cope with schizophrenia symptoms, and a desire to not take medication to avoid the various side effects. For instance, even though Devin had to endure feeling drowsy daily throughout most of the day, not having to deal with schizophrenia symptoms seemed preferable. Barry described medication side effects being “sometimes worse than the actual illness,” and his wish for a “vacation” from medicine to have a break from dealing with serious side effects like sedation, difficulty breathing and swallowing, and disturbed motor functions. However, he continued to be compliant with his treatment to avoid experiencing auditory hallucinations. Daniel spoke about the dilemma between taking medication to “get back into the boundaries of reality” and learning how to cope with schizophrenia symptoms without medication to avoid dealing with side effects. Jack compared the strong sedating effect of those medications to “being hit with a tranquilizer dart.” He experienced those serious medication side effects as interfering with his job, and as causing loss of “control” over his body. Medication management is currently a key aspect in the treatment of schizophrenia. However, given the findings of this present research project, one wonders whether patients are being overmedicated, and if they are in fact being compliant, and whether alternative treatments, or at least alternative approaches to current treatment, should be considered.

The findings of this project fit with prior scholarship regarding medication side effects. Borras et al (2007) cited literature indicating that a significant proportion of patients do not take their medications, presenting an increased risk of relapse and hospitalization. Medication non-adherence, defined as the extent to which patients take
medication as prescribed by their health care providers, ranges between 50 and 60 percent (p. 1238). Andreasen (2001) also addressed the issue of medication noncompliance. In the author’s words:

Because the side-effects are so unpleasant, many people with schizophrenia do not want to take traditional antipsychotic medications. For them, the treatment is almost worse than the disease itself. Some would prefer to have psychotic symptoms if they have to pay the price of having side effects in order to get rid of them (p.213).

Medication is currently the most prevalent form of treatment for schizophrenia. For instance, most individuals diagnosed with psychosis are immediately placed on a neuroleptic with the goal of lifelong maintenance treatment (Penney & Stastny, 2008, p.186). The development of new and more effective medication for schizophrenia is one form of progress that has occurred in the treatment of mental illness over the past 50 years (Andreasen, 2001, p. 211).

With the birth of modern psychiatry in the 1950’s the focus turned to medical treatments like Electroconvulsive therapy (ECT) and pharmacotherapy. However, chlorpromazine and the “new generation” of atypical antipsychotic medications that followed targeting the dopamine system are not without side effects. Those include: rigidity of muscles, a frozen blank expression on the face, tremor, akathisia, anxiousness causing the person to pace and move around, and depression. “Atypical” anti-psychotic medication is less likely to produce “tardive diskinesia,” a potentially irreversible movement disorder that occurs in 20-30 percent of patients treated with traditional neuroleptics (Andreasen, 2001). However, the newest “a-typicals” have their own problems with side effects, including excessive weight gain and a relevant increased tendency to develop diabetes mellitus, and heart disease (p.214). In his 2002 book Mad in
America: bad science, bad medicine, and the enduring mistreatment of the mentally ill,
Whitaker (2002) offered an account of those devastating side effects through ex-patients’ testimonies.

Present study findings and prior published literature point to the need for serious discussion and dialogue about the use and misuse of psychiatric drugs as well as the importance of effective alternative treatments. Some encouraging evidence cited by Penney and Stastny (2008) indicated that, while patients’ life circumstances (e.g., trauma, foster care, isolation, mistreatment, and abuse) were deemed irrelevant or overlooked in the past, recently there has been a renewed emphasis on obtaining more in-depth histories and an increased awareness that psychotic symptoms can be traced back to traumatic experiences. They suggested that narrative accounts will become increasingly more important in the treatment of people at risk for psychiatric hospitalization (p. 186). As one of the participants of this study, Beatrice, mentioned, it is not enough for someone to take their medications in order have a positive treatment experience, but to focus on helping themselves through discovering their “personal medicine” (i.e., what makes one feel productive, what gives their lives meaning).

Another finding of this study was that all participants experienced some aspects of their treatment as negative, or even as mistreatment. Several participants spoke about experiencing strict adherence to rules as restrictive (“loss of freedom”) and making the hospital a fearful and “not nice place to be.” Moreover, overmedication and frequent medication experimentation made for a negative treatment experience. For instance, humiliating experiences like being “tied down” and isolated in a room, and being “handcuffed” by police and placed in a “paddy wagon” for an extended period of time led
Shawn to “fear” and “hate” the hospital. Not being “taken seriously or treated respectfully”, and not being listened to and understood, also accounted for negative hospital experiences.

These descriptions fit with existing literature on the various negative aspects of hospitalization and institutionalization. Davidson et al (1997) stated that, even though there exist many theories conceptualizing the loss of self as an intrinsic element of the schizophrenia disease process, recently there has been a growing body of first person accounts suggesting that loss of self is in part a consequence of hospitalization and social stigma. These authors identified three factors exacerbating individuals’ pre-existing feelings of powerlessness and helplessness over their condition. First, the stigma that continues to accrue to mental illness and schizophrenia in particular in popular culture is an external source of loss of self. A second factor is the “patronizing attitudes and practices that have been transferred from long-term state hospitals into community settings.” (p. 163) Third, models of treatment, such as the medical model, focusing on pathology and dysfunction to the exclusion or under-emphasis of processes of improvement, leave little room for the person to assume an active role in coping with the disorder. Taken together, these influences converge to promote a stereotype of a person with schizophrenia as “passive” and “inept,” or an “empty shell” of the person he or she used to be. (p. 163)

Burnim (2000) argued that being treated in mental hospitals for long periods of time segregates individuals from the rest of the society and greatly limits their autonomy. In addition, the poor care often found in institutions can cause “psychic damage” and “loss of social skills” and other capacities important for independent living due to lack of
opportunities to interact with non-mentally ill individuals other than hospital staff members. (p.77)

In Burnim’s words:

Institutionalized individuals suffer not only a dramatic loss of physical freedom…severely detailed control and invasive treatment, they also cannot enjoy those mundane, daily pleasures—working, shopping, enjoying the companionship of family and friends, or simply being left alone—the loss of which we on the outside world would find to be not only intolerable, but a threat to our very sanity. (p.76)

As mentioned before, several participants of the present study who experienced institutionalization complained about the loss of freedom as making the hospital a dreadful place to be. In the hospital, most participants disclosed being the victims of poor care. They had to endure the patronizing attitudes of some staff members who did not take them seriously or treat them respectfully. For instance, Beatrice mentioned that while in the hospital she was given “the cold shoulder” by staff that did not acknowledge her presence and did not respond to her when she asked them a question. Daniel said that he was tied down and placed in an empty “quiet room” and was left there in isolation because he did not follow a hospital regulation. Jack disclosed that he felt disrespected by some hospital staff members’ “nasty attitude.” Finally, Shawn described the instance of his involuntary commitment when he was handcuffed and treated as if he was a dangerous criminal.

In line with participants’ negative hospitalization experiences, there exists considerable literature documenting harmful and ineffective hospital practices. Some examples will be cited here. According to Burnim (2000), many patients reported that mental hospitals are not tranquil places where treatment and support is continuously provided by highly skilled practitioners. Locked units in particular are often confusing
and dehumanizing environments tended by line staff that does not include trained mental health professionals. Siebert (2000) described the sensory deprivation, isolation, neglect, dehumanization, indifference, and sense of helplessness experienced in mental hospitals run in a poor and dictatorial fashion by an ill-trained staff (pp. 156-157). Penney and Stastny (2008) cited a report by National Council on Disability (NCD) documenting the mistreatment of mentally ill individuals in hospital settings. The report indicated that people with psychiatric disabilities have been “beaten, shocked, isolated, incarcerated, restricted, raped, and physically and psychologically abused in institutions and their communities,” (p.187) and highlighted that people with psychiatric disabilities are frequently deprived of their rights and are treated as less than full citizens or human beings.

Davidson (2003), in his discussion of qualitative studies of recovery of schizophrenia, stated that consumers identified multiple ways in which mental health services impede their recovery. For example, early in the course of their illness, individuals report being told to relinquish their dreams, to expect chronic and recurrent course of illness and dysfunction, and to anticipate a lifetime of mental health treatment, medication, and disability (p.49). Patricia Deegan (2001) described the destructive, “spirit breaking” impact of early messages of hopelessness and despair she experienced when was first diagnosed with schizophrenia. She wrote about the negative prognosis or “prophecy of doom” she received from her diagnosing psychiatrist who stressed to her that she will never get well and that the best she could do is “cope” by taking medication for the rest of her life (p.5).
It is important to note that participants in this study also spoke about the various ways they benefited from treatment. Again, this is useful information for mental health providers. Receiving a diagnosis seemed for many to be a relieving experience that helped specify “what was wrong.” Attentive and supportive doctors and family members helped instill patients’ faith in treatment and active involvement in their recovery. A collaborative relationship in which patients felt respected, affirmed, listened to and understood seemed crucial. Furthermore, participation in psycho-educational and advocacy groups was beneficial for three of the participants (Beatrice, Jack, and Jenny,) as they served as sources of support, self-understanding, encouragement and empowerment. Active involvement by patients in their own treatment also seemed beneficial, as it strengthened faith in treatment as well as feelings of hope and self-efficacy.

Growing research evidence indicates the encouraging fact that recovery from schizophrenia is possible (Davidson, 2003). In contrast to the traditional view of schizophrenia as a pervasive and irremediably incapacitating condition, studies have demonstrated that a significant proportion of people with schizophrenia improve over time. These studies indicate that recovery involves reclaiming an effective sense of social agency out of the fragments of the disorder (Davidson, 1997, p.164). The Recovery Movement focuses on hope, education, peer support, advocacy, and personal responsibility, which promote empowerment: the belief in one’s ability to perform desired behaviors and experience life satisfaction (Revheim, Greenberg and Citrome, 2010).
Wahl (1999), in discussing the growing influence of the Recovery Model, urged mental health professionals to think about the strengths and resources of afflicted individuals rather than to focus exclusively on deficits and hardships, and to remember that individuals with schizophrenia can be active managers instead of passive victims of their illness (p.143). According to Davidson (2003), long term, longitudinal and short-term follow-up studies offer evidence that individuals can and do recover from schizophrenia (p.41). Sullivan (1962), Fromm-Reichmann (1950), and Karon and Vandenbos (1981) also provided compelling examples of the possibility of recovery from schizophrenia through psychotherapy.

Whereas the traditional perspective of clinical psychiatry defines recovery as alleviation of symptoms and distress, the consumer/survivor perspective on recovery does not require full remission of symptoms or other deficits brought about by the disorder. Instead, recovery involves some degree of acceptance of one’s illness as well as a sense of hopefulness about the future, one’s ability to rebuild a positive sense of self and social identity, and the pursuit of goals and meaning in life. While from the perspective of clinical psychiatry not everyone may be capable of recovery, from the consumer/survivor point of view, everyone is capable of recovery, although perhaps not to the same extent (Davidson, 2003, pp. 50-58)

Participation in various groups such as advocacy, therapy, and psycho-educational groups was a beneficial coping strategy for several of the participants. Jenny and Beatrice expressed that they felt “empowered” as a result of participating in advocacy groups. Engaging in advocacy and public education activities felt good to them, and being helpful to others greatly bolstered their self-image. Jack, Jenny, and Beatrice stated that they
valued therapy groups, where they felt that other participants understood what they were experiencing and were less judgmental and more supportive compared to non-patients. Participants experienced relief after learning that they are not alone in dealing with their types of problems. Furthermore, attendance in psycho-educational groups was helpful in various ways. For instance, Beatrice emphasized the usefulness of learning and applying assertiveness skills in her intimate relationships. Finally, most participants valued having attentive, supportive, affirming and empathic therapists who treated them with respect in a collaborative therapeutic alliance.

**Summary and Conclusions**

Based on review and discussion of the findings of this research, some important concluding points can be made. First, present study findings are congruent with prior literature indicating that spirituality can be an important source of hope, meaning, encouragement, support, self-efficacy, adherence to and satisfaction with treatment, and coping with schizophrenia. Second, findings of this research confirm aspects of the medical model and contradict many postulates of Social Labeling Theory—at least as an extensive interpretation of schizophrenia. Social Labeling theory, however, is still relevant as one part of a complex understanding of schizophrenia. Participant accounts demonstrated that schizophrenia is a real illness, with personal and interpersonal consequences beyond those that result from diagnostic labeling. However, acknowledging the medical aspects of schizophrenia does not require adoption of an exclusively medical prognosis and model of treatment. The Recovery Model offers a more optimistic and complex view of prognosis with respect to schizophrenia. For this
model, recovery is not an ideal or synonymous with cure or return to pre-morbid level of functioning. Instead, recovery means acceptance of illness, a sense of hope about the future, a renewed sense of self. As phrased by one participant, recovery means living “in spite of” one’s illness. It is crucial for clinicians to be hopeful and have faith in individuals’ recovery in order to help them have hope and faith in their own recovery and treatment.

Another finding concerns medication management, currently the chief treatment of schizophrenia. Participants of this study spoke candidly about their experiences with anti-psychotic medications and severe side effects, which led several to at least periodically stop taking the medications. These findings along with prior published research point to the need for serious dialogue about the use and misuse of psychiatric medications.

Findings of the present study not only are consistent with existing research on experiences of loss suffered by individuals labeled schizophrenic, but together seem to lend support to calls for grief counseling as an important part of the treatment approach. All participants of this study suffered multiple losses as a result of receiving a schizophrenia diagnosis (e.g., career, financial, relationship). Stigma and ignorance associated with the schizophrenia diagnosis often lead diagnosed individuals to conceal their diagnosis and consequently not receive emotional support from others. Research evidence suggests the potential efficacy and benefits of grief counseling and psychotherapy in adjusting and coping with loss, meaning-reconstruction, gaining emotional support and developing resilience.
Findings of this study on negative and positive hospitalization experiences also provide feedback on what is and what is not effective in participants’ treatment and recovery. This information is crucial for mental health professionals who want to improve the quality of care in order to facilitate patients’ growth and recovery. Positive experiences included (a) attentive, supportive, and empathic mental health professionals, (b) a collaborative relationship in which patients felt respected, listened to and understood, (c) participation in psychoeducational and advocacy or peer support groups served as sources of support, encouragement, empowerment, and hope, and (d) active, involvement of patients in their treatment.

Negative experiences pointed to shortcomings of antipsychotic medication (e.g., overmedication, medication experimentation, and side effects), institutionalization (e.g., loss of freedom, segregation, humiliation), as well as attitudes and actions of mental health staff (e.g., negative prognoses, patronizing attitudes and devaluation), and their consequences (e.g., not feeling respected as human beings).

Findings also highlight the need for education and research to combat ignorance and stigma regarding schizophrenia. Participants spoke about feeling “angry,” “hurt,” “abandoned,” and “misunderstood” as they faced others’ ignorance about their illness. As a result, all participants engaged in self-protective concealment of their mental patient status to avoid stigma and rejection. Consumer research indicates that education about mental illness is key in combating ignorance and stigma. Ideally, such education about mental illness should begin in childhood and adolescence, when individuals’ views are still in formative stages. Moreover, mental health professionals need to be educated about the perspectives of consumers.
As the researcher of this study I myself maintained certain stereotypes and presuppositions about schizophrenia, which were disconfirmed once I encountered these individuals in person. Surprisingly, participants were genuine, relatively trusting, and self-reflective, and eloquent; contrary to common portrayals of schizophrenics as “concrete,” lacking insight, guarded and mistrusting. I also originally saw consumers as powerless victims of unjust treatment and diagnostic labeling. Encountering empowered participants active in their own recovery allowed me to see the positives aspects of diagnosis and treatment, and learn more about recovery and advocacy as empowering options available to patients.

Finally, through their accounts, participants made us aware of their needs for acceptance, support, understanding, empathy and respect. They spoke about not feeling accepted by others in their relationships. Sometimes this lack of acceptance was evidenced even in family members. Harry Stack Sullivan’s adage that people with schizophrenia “are more simply human than otherwise” (Sullivan, 1962, p. 235) is a reminder that schizophrenia is only one part of the complex, unique individuals. Often, the presupposition behind stigma and fear about mental illness is that individuals with schizophrenia are no longer people like the rest of us. Once we as society become more educated about the nature of their illness we can empathize and appreciate the degree of suffering involved in schizophrenia, and therefore be more supportive of them.

**Contributions and Limitations/Directions for Future Research**

The method of this project has unique strengths in explicating the experience of living life with schizophrenia. In contrast to quantitative methodologies, qualitative phenomenological interviews elicit narratives rich in descriptive detail. The method is
collaborative and respectful, in that persons suffering from schizophrenia are included as full participants in the research endeavor, which depends on their expertise on a specific realm of their experience. According to Davidson (2003), participants in a phenomenological study assume the role of “autobiographical storytellers.” By bracketing, acknowledging, and reflecting critically on naturalistic and theoretical constructs, bias and preconceptions the researcher is able to better focus on, learn from, and deeply appreciate participants’ experiences and unique perceptions.

The findings of this dissertation have important implications for research, clinical practice, and public policy. In Western world, the medical model is the most prevalent treatment avenue for schizophrenia. This model places heavy emphasis on the biological and genetic bases of the disorder, and minimized concern for interpersonal interventions. This present study contributes to the literature that complements this perspective by demonstrating that schizophrenia can be understood psychologically through in-depth case studies. Furthermore, this study contributes to efforts to cultivate acceptance and understanding of serious mental illness and to reduce rejection, ignorance, and fear. It also familiarizes mental health professionals and the public with the emotional needs and struggles of persons with schizophrenia.

At the same time, this study has inherent limitations and opens up avenues for future research. The first limitation concerns the context or setting. Participants were interviewed at their site of treatment, and might have been more cooperative and compliant compared to individuals living in the community or not in treatment. Future research could focus on persons with schizophrenia outside of a formal (medical) treatment setting. A qualitative study comparing the experiences of those who accept
their diagnostic label and traditional treatment to that of those who reject the mental illness narrative would be interesting and potentially valuable. Furthermore, interviewing individuals in the community could allow for more in depth interviews given the absence of the external time limitations that exist in a structured hospital setting.

Mental illness is experienced, narrated, and treated differently in different cultures. Stigma also varies in different cultures. This project focused on first person accounts of lived experience of schizophrenia within the American culture. The difference in the experience of schizophrenia and diagnostic labeling in Eastern cultures should be investigated by future research. Furthermore, given that four out of the seven participants were African American, it would be interesting to study the experience of living with the diagnosis/illness of schizophrenia across different ethnic cultures such as Caucasian, Hispanic, African American, and Asian. In addition, the impact of spirituality as a coping mechanism was a surprising result that emerged in the present study. A qualitative study investigating the impact of spirituality in coping with schizophrenia, as well as spirituality and race in dealing with schizophrenia, could be enlightening.

The method utilized in this project was broadly phenomenological. A hermeneutic component was added to interpret the data. The general themes that emerged may be true for many individuals suffering from schizophrenia. However, given the complex nature of the experience as well as the small sample size and the particulars of these participants and their setting, I would not expect all persons with schizophrenia to show identical themes. I would hope instead that the findings of this study offer a glimpse into the rich and multidimensional experience of persons living life with schizophrenia.
References


Appendix A: Advertisement

What is it like to live with the diagnosis of Schizophrenia?

You are invited to participate in a study that will investigate the experience of living with the diagnosis of schizophrenia. Specifically, you will be asked to reflect on how the diagnosis has affected your self-image as well as how the diagnosis has influenced the attitudes and responses of others. In addition, you will be asked to allow me to interview you. The interviews will be audio-taped and then typed.

If you are interested, please contact the researcher:

Andri Yennari, M.A.
yennaria@duq.edu
412-xxx-xxxx
Appendix B: Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE: Living With Schizophrenia: A Phenomenological Investigation

INVESTIGATOR: Andri Yennari, M.A.
66 Philips Street, #1C9
Akron, Ohio 42303
(412) xxx-xxxx

ADVISOR: Russell Walsh, Ph.D.
Psychology Department
(412) xxx-xxxx

SOURCE OF SUPPORT: This study is being performed as partial fulfilment of the requirements for the doctoral degree in Clinical Psychology at Duquesne University.

PURPOSE: I am asking you to participate in a research project about living with the diagnosis of schizophrenia. Specifically, I will ask you to reflect on how the diagnosis has affected your self-image as well as how it has influenced the attitudes and responses of others. In addition, I will ask you to allow me to interview you. The interviews will be audio-taped and then typed. I may ask you to allow me to talk with you again about what you said in our first discussion, so that I am sure of what you meant.

These are the only requests that I will make.

RISKS AND BENEFITS: There is a slight risk you may experience some distress when you reflect on your experiences, and if you would like me to, I can arrange for you to talk to someone who will offer you support. Also, you will make a contribution to the knowledge of what it is like to have a diagnosis of schizophrenia, and you may also benefit from reflecting on your own experiences.

COMPENSATION: You will not be compensated, nor will participation entail any monetary cost to you.

CONFIDENTIALITY: Your name or other identifying information will NEVER appear in any printed material. If you mention another person’s name, I will change it to a
pseudonym. All written materials, and consent forms will be stored in a locked file in my office. I will destroy the audio-tapes after I have transcribed them. I will put a pseudonym on the typed version of our interview. I will have a list that shows the people’s real names and their pseudonyms, but I will be the only person who has access to this list which I will keep locked. This process is to keep anyone from knowing what you personally said. What you tell me will appear in my dissertation and maybe in articles, but no one will be able to identify you.

RIGHT TO WITHDRAW: You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time. Should you choose to withdraw, data obtained will not be included in the study.

SUMMARY OF RESULTS: A summary of the results of this research will be supplied to you, at no cost, if you ask me for it.

VOLUNTARY CONSENT: I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project.

I understand that should I have any further questions about my participation in this study, I may call Andri Yennari, the Principal Investigator (412-xxx-xxxx), Dr. Russell Walsh, the Advisor (412-396-xxxx), or Dr. Paul Richer, Chair of the Duquesne University Institutional Review Board (412-396-xxxx).

_________________________________________  _____________________
Participant's Signature                  Date

_________________________________________  _____________________
Researcher's Signature                  Date
Appendix C: Interview Transcripts

* A: Researcher (Andri)

Devin Transcript

A: Thank you for agreeing to participate in this study.
D: You are welcome!
A: For how long have you been receiving treatment?
D: 5-6 years may be 6; I could be wrong because I was in X hospital twice.
A: Oh ok I see! So you are talking about 5 years here or in general.
D: In general. Here about 2 years. But I was here a couple of years before that too for about a year.
A: Oh ok. So you were first diagnosed 5 years ago then.
D: Yeah.
A: Oh ok! So what was happening then? What were you experiencing?
D: I was a lot sicker then. I couldn’t control my mind or something it was a little bit hazy or something I really don’t know.
A: So hazy I guess you felt that you couldn’t control your thoughts is that close?
D: You felt that you were not in control.
A: Yeah! It was something like that yeah. I can’t really explain it I guess. I don’t know.
D: You are doing a good job!
A: Did you experience any symptoms like hearing voices etc?
D: No I never really heard voices. It was something in my mind that just wasn’t… I never really heard voices.
A: Ok! And then what happened? Did you seek treatment?
D: Yeah. The first time I went to a place called St Francis.
A: Ok
D: And then I can’t remember. It was 5 years ago then I went to X hospital, and then I came out then I went to a place in location, X hospital I think it was called.
A: Yeah
D: Then I went to X hospital again.
A: Ok, so you’ve been to various places and now you are here you said 2 years?
D: Yeah. I’m doing fine! I mean before I was really sick… I don’t know if it is from the medicine but I’m doing fine now.
A: So you are feeling fine now compared to the past.
D: Yeah!
A: Tell me a little bit about treatment, the treatment that you have been receiving over the past 5 years. How was it like for you?
D: It was fine! It was nice what else?
A: Basically I’m asking. Has it helped? What was that experience like? I know you said that you were feeling confused, hazy but then you were diagnosed so how was that like for you?
D: I don’t know (seems like he doesn’t understand what he is being asked).
A: Oh let me try to phrase it differently. So I guess you came in and sought treatment because you were experiencing those symptoms that you couldn’t control.
D: It was rough! But I managed through it. That’s about it.
A: Yeah… What was rough about it for you?
D: It’s just I would rather not be sick you know, I’d rather be normal and not have racing thoughts and all that stuff that came with it. I just didn’t like it. That’s why I feel better now, I am glad it’s over. Hopefully it stays like that! (Smiles)
A: Yeah! Have you been taking medications for it?
D: Yeah
A: Was it helpful to take the meds? Or did you feel that taking the meds also has some downsides?
D: Not really … well, I mean it made me sleepy and a little bit drowsy all day, every day, but it was better than having racing thoughts.
A: Yeah, yeah so balancing out the 2 I gather you think that taking the meds is a better option.
D: Yeah
A: Has your life changed? How did receiving a diagnosis impact your life in general?
D: It wasn’t good.
A: It wasn’t good
D: I feel right now I’m not really good at explaining.
A: You are doing a fine job yeah!
D: Thanks.
A: So it seems like it wasn’t good it was a negative experience.
D: Yeah. You know X hospital is not you know it’s not a nice place to be. You know what I mean?
A: Yeah. What is it like in X hospital?
D: It’s just a lot of rules, you know. You can’t do what you want to do. You are going to be doing what they want you to do.
A: Oh I see! So it’s as if like, a lot of other people making decisions for you without you having necessarily a say in it?
D: Yeah. So it’s not good in that way but it’s better than being sick though I guess. You know what I mean? At least you are getting help anyway.
A: Yeah, yeah. And I guess if you were to help me understand how was it like being sick when you were in X hospital?
D: Being sick was bad and being at X hospital made it worse. I mean, it was better that I was getting help, but I didn’t want to be there.
A: You didn’t want to be at X hospital?
D: Nope
A: Where did you want to be instead?
D: Just, you know, not be sick and living my life normally.
A: Yeah! What’s your idea of normal life?
D: Just working, and having money and living at my own apartment or something.
A: I see… whereas now …
D: Well I have my own apartment now. That’s someway I feel good. That’s about it.

A: Yeah, yeah… and I guess what I also wonder about and you will help me understand is how has the diagnosis influenced the attitudes and responses of other people that you know. Do you think you receiving treatment and you being diagnosed with schizophrenia do you think this has affected people’s attitudes toward you?

D: Not really, now that I’ve noticed but maybe behind my back I don’t know people I know, they don’t mind.

A: So I guess they treat you the way they used to before the diagnosis.

D: Yeah, yeah in my case yeah.

A: Yeah that’s your understanding sure! And how is your relationship with your family, friends…

D: It’s better than before. Better than ever I’d say.

A: Oh wow!

D: They come once a week; my mom helps me clean my apartment, my dad visits just to hang out. I never had that before.

A: Ok! Whereas before what was the relationship like?

D: I dunno I mean I would talk to them but we weren’t that close. So now we are close.

A: Do you think they are being supportive of you?

D: Yeah, definitely.

A: That’s a good thing! To feel that people are there for you.

D: They are my family anyway!

A: Yeah, yeah… and what about relationships with friends and other people that you don’t know? … As I understand you are close to the family.

D: Yeah, so before I had more friends though and now I really don’t go out as much and my friends they are doing their thing… so…

A: Is it that you decided that you like to not go out as much?

D: Yeah that’s all it is.

A: Yeah! So it’s not I guess as if your relationship changed because let’s say you weren’t around as much because you were receiving treatment or you weren’t feeling that well.

D: Yeah.

A: Ok um hmm. Has it helped to I guess, receive a diagnosis?

D: Well, I guess now, I mean it’s been 5 years so

A: Yeah it’s been a while yeah, yeah.

D: I think it helped I guess at least I know what was wrong or something.

A: Um hmm! Whereas before receiving the diagnosis, you didn’t have an understanding of what was happening?

D: Yeah. Probably that’s about right… I didn’t know what it was.

A: Aha and I guess, what have you learned? I guess I see that it has been helpful in figuring out you know, there is something wrong and this is called schizophrenia and we can put a finger on it rather than before. It was like very vague very ambiguous.

D: Um hmm.
A: Receiving the diagnosis of schizophrenia now was it helpful other than having the understanding that you have an illness. How has this understanding helped you?
D: I dunno.
A: But you feel it did or?
D: Yeah
A: Ok... The other question I had is about the future and how do you envision your future now?
D: Just, I had my license suspended for something and once I get a car maybe it will be a little bit easier on me.
A: To move around?
D: Yeah, I have people driving me everywhere. They don’t really want to be doing that so...
A: How did it get suspended?
D: I didn’t have insurance and I got pulled over.
A: But yeah, I don’t know when you think about the future what other things do you think about.
D: I don’t really know.
A: Ok... What would you like to teach me about your experience?
D: I really don’t know. I’m doing the best I can.
A: Yeah! That’s what matters yeah, yeah. So yeah, the purpose of this interview is to really, and I’m glad you’re feeling a lot better, is like for me to get an understanding of what is it like for you, you know, to receive treatment, to figure out that your symptoms make sense I guess and what is it like for you to live with schizophrenia. How does it affect the way you see yourself?
D: I feel fine really! I don’t know what to say.
A: Yeah, mean how do you see yourself? If somebody was to ask your self-concept, your self-image
D: I feel ok. It’s not that bad.
A: Aha! Alright. Are you anxious about talking about those things? I wanted to check in with you.
D: I don’t know. I just feel fine that’s all I know.
A: That’s good! That’s good! I’m glad to hear that yeah, yeah! I guess in terms of treatments what kind of treatments did you have? Did you have ECT?
D: Yeah. ECT is electric?
A: Yeah!
D: I had that. It didn’t do anything.
A: It wasn’t effective?
D: No. Not that I can recall.
A: So I guess people have it to decrease their symptoms but it didn’t help you?
D: Not really.
A: What other kinds of treatment do you receive here? Do you attend groups?
D: No I’m pretty much out of the loop now so I’m on my own so I come to visit every once in a while.
A: For meds?
D: Yeah.
A: So I guess compared to the past when you were receiving treatment how is your life different now?

D: I’m on my own, I do my own thing, I feel fine.

A: Yeah! Ok, ok. I guess if you don’t have anything else to say then, I can let you go.

D: Sorry I did the best I could.

A: Yeah! It’s not easy to talk about your experience.

D: So far everything is working out. I have no problems. That’s about it.

A: Yeah, alright! I want to thank you for taking the time to talk to me!

D: Ok! So that’s it then.

A: Yeah!

D: I’m sorry it wasn’t more information.

A: It’s ok. Thank you for talking with me.

D: Goodbye

A: Bye now. Take care now Devin!

D: You too.
Barry Transcript

A: So basically what it is about, what we are going to try to do is talk about the experience of living with the diagnosis of schizophrenia, how it affected your self-image, how it influenced the responses and attitudes of other people. And it may be helpful if you thought about specific examples if something comes to mind it will help me understand it better too.

B: Sure!

A: How long have you been receiving services?

B: Am… I guess I first started receiving services; the first time was really in 2003 so 6 years ago. I was 21 it was the first time.

A: What happened then?

B: That was the first time I was hospitalized. Prior to the hospitalization I was in alcohol rehab… Essentially what put me there was the, I guess, was the onset on this illness I guess. I didn’t really know what it was and certain things were changing or had changed and, I guess I didn’t really know how to vocalize or handle these things and was afraid to really talk to anybody friends or family you know. Even though I was living with a friend I was actually living in X where a lot of this heavy drinking was going on and I …

A: You were afraid to tell them.

B: Yeah. And the funny thing is whenever I had to go home because I lost my job and everything just, you know, I couldn’t do it anymore. I mean he (roommate) knew the whole time he and Ella, his girlfriend, knew, I sort of told them, you know what, you know the time I was you know, hearing voices and different things like that. But I don’t know just different, just I don’t even. To be honest with you, a lot of those early things I don’t know have been washed away.

A: Yeah… it’s been a few years.

B: Yeah, but, yeah, there was definitely a lot of that and then the drinking… I was telling the counselor there (rehab) you know, that I was still having those symptoms and they have been, you know, going on for months and months and being away, you know, in that rehab, you know, not drinking… and I was drinking every day I was really starting to not be well… you know?

A: Yeah…

B: So, as soon as I told the counselor, you know, what my situation was, he made a phone call and I was sent to X hospital and that was my first hospitalization.

A: So I guess, help me understand, you were experiencing voices for months and months you said, and it couldn’t stop in addition to the drinking problem…

B: Yeah I don’t know I guess that probably made it worse in a certain way I don’t know, but there is definitely that and there is a lot of confusion… I felt more confused over time. There is a period of time where I actually did not feel really good.

A: Um-hmm.

B: Like, with the lithium I was thinking clear, everything was sort of clear, and then slowly there was this confusion that started these different things. First it seemed like humming or something like that, and then it was more like static like voices that were unintelligible then I was more, it got more understandable. So it was
like this build-up at different times, you know, throughout a period of months. You know and I became, you know, very obsessed with trying to figure it out and I got lost within at least that aspect of things, and you know drinking a lot to try and tone it down.

A: Yeah, you tried to cope with it.
B: Yeah.
A: To make it stop.
B: And somehow it did. But you know, it certainly didn’t help with the amount that I was drinking and what I put people through because of it.
A: Yeah.
B: But yeah so I went to Law school first time then. So I guess I was 20 whenever all this stuff started and then I started receiving treatment.
A: Yeah, and I guess you said that didn’t like how you put certain people through something like a situation.
B: Yeah.
A: Would you like to say more about that?
B: Well, I mean, I really don’t know about, you know, certain specific odd behaviors due to the illness aspect, but I certainly know because of you know what became an alcoholism. You know I certainly was probably not the nicest person. I know my friend when I was living out there when I lost my job he lend me his credit card to use for certain living things, and I ended up putting hundreds and hundreds of dollars on different things like, mostly booze and all the different sorts of stuff like that which luckily I was happy I was able to repay him in that aspect.
A: Right.
B: But the money in the end wasn’t… you know!
A: At the time though…
B: Yeah it wasn’t good… but he had more insight. I mean he told me “You better pay me back” (laughs) and I knew that, but there was a lot more empathy I think, that I didn’t see coming from my friends, my close friends there.
A: Awww! So at the time you couldn’t see them trying to understand and empathize with you, but looking back, you realize…
B: Yeah, I mean I thought a lot of the times, you know, they were intruding on my day by being, you know, telling me about drinking and all this other stuff. You know we drank in high-school; we did all these sorts of stuff in high school.
A: Yeah.
B: He (roommate) went to college out there that’s when I was out there he was going to school X University and we went to high-school together. So we’ve been friends for a very long time so he has known me since we were little so.
A: Okay!
B: Which was an interesting thing because he saw this…
A: He saw the change in your behavior. He knew you for a while.
B: Um-hmm yeah for, at that point we have been friends, good friends for about 10-11 years.
A: Wow, yeah it’s a long time, yeah.
B: So, I mean, I feel lucky that of any of my friends; it was you know my friend John that was around.
A: Yeah.
B: So I probably got more than I think I did at the time from the benefit of having him around. But, yeah, (laughs) just to be all jokey about it, I guess you know, if there is one good place to have the onset of psychotic illness, you know, being in you know, beautiful high desert isn’t a bad place to be as opposed to Pittsburgh I guess.
A: B: Both laugh.
A: Yeah.
B: I don’t know, I went to Sedona a lot we would go down there almost every weekend and that’s old beautiful red-rocks and everything like that, I think it’s one of those beautiful places.
A: Wow! I have to visit!
B: Yeah, yeah.
A: So compared to the city of Pittsburgh we are just so crowded and
B: Yeah, I mean this is a whole different world. I mean it’s essentially high desert out there. I don’t know it’s a peaceful environment. But yeah I came back and I started receiving treatment.
A: Yeah, um-hmm!
B: My doctors immediately, at the hospital just based on how long I’ve been talking about what I have been experiencing, they put me on, my parents told me, like 6 medications. And I guess looking back; they weren’t very good with medications.
A: Yeah, what was your experience taking them?
B: Oh, I was completely not really there! I was on 3 or 4 different anti-psychotics and who knows what he dosage… I have been on Clozapin for 4 ½ years now. You know, only during that period of time when I was at that specific hospital and may be just a little bit beyond that before I started coming here. Yeah, I think it was way too much… I was completely out of it.
A: So you felt that taking the medications you were confused, you were out of it, but then did you notice any positive things about it?
B: No not… the way I noticed positives that I wasn’t, you know… things toned down in my head. Then I became a blank slate.
A: Blank slate?
B: Yeah, just like… the medication… It was better to have no thought that being inundated by everything outside. So I was just like… you know.
A: It’s almost more preferable to not think of things rather than just have all those overwhelming thoughts in your head.
B: Right, I mean it was just, yeah I mean it was just like having someone erase old scribbles from a chock board you know. So I mean I guess that part was good (laughs nervous).
A: Yeah… I never experienced the same symptoms but, you know, I can only imagine how difficult it must be to have this you said, humming and then voices that do not stop when you want them to stop.
B: Right.
A: They are there and existing you want them to go away but they are still there.
B: Right, right, yeah, I mean it was an odd thing for me to adjust to.
A: Yeah.
B: You know, I mean it was just in the same ways we are speaking the type of sound it wouldn’t be like… we can create any type of thing we want in our minds. And this is where I had some problems with my brother I was very close with, who I am very close with. I didn’t really talk to him for a couple of years the first time.
A: Oh wow!
B: Because he thought that it was all in my mind and I think he was probably, now that I look back on it, probably a little upset, probably a little in denial, different things like that. He lives in Houston also so he is a little bit removed.
A: Ok. So he didn’t want to accept the fact that you…
B: Yeah I think so. And I think also that his wife, his ex-wife now told him at the time: “We just saw Barry not too long ago and, I’ve read about what textbook schizophrenics are like… and that’s definitely not it” and that was enough to put it in my brother’s mind that… I don’t know… later on he told me that he thought that I was… being lazy! How about that!
A: Aw! Lazy!
B: That wasn’t the easiest thing for me to hear years down. And that he thought that there was me… stress was overwhelming me and I was afraid to grow up.
A: How did you feel about that?
B: Well, I told him to go f*** himself (laughs) sorry excuse me (laughs).
A: No, no, no, don’t worry about it! I can get the sense that you were angry!
B: Aw I was very. I thought it was laughable also at the same time… but I told him at the same time, I don’t care if you understand. This is the way it is. This is … my life is not the same anymore as it was. You know. I told him, why would I want, why would anybody want something like this and then live on disability and social security from the age of 22… I mean… is that, like, you know, the secret getting ahead? And my brother… it was a very weird thing that he was throwing at me and I was really upset, but also at the same time I thought he’s obviously deluded himself so far… but he never say me whenever evidently, or talked to me whenever I was in the hospital all those number of times, even though my mom would update him and all this different stuff. But that was very hard because he is the closest person to me.
A:Yeah, yeah, oh wow.
B: And the fact that, that was an area that could never be discussed because it bothered him. Not until about a year ago when I told him… He actually was telling me you don’t really need the medication. That was another thing. You know? And I was like well; I do need the medication because I noticed a difference when I am on it and when I am taking the medication.
A: Yeah.
B: And I have. And that’s real. So, but you know, luckily now that aspect is, you know, fine… but it was a difficult thing.
A: It was hard for him to accept!
B: Yeah, yeah… and that’s what I realize now. And you know, as my mom kept telling me about that but, I just always wondered why somebody so close like that would react like that. But I guess that’s a defense mechanism, you know and I
don’t question. But yeah, the medication thing he questioned that too and there are certain things that he wanted to ask me. I just told him that’s the way it is.

A: How did the rest of your family take it?
B: My… I have a younger sister… the first time she saw me after I… I guess she was a senior in high-school at the time just finishing up, I came back from Arizona and I was just completely, you know, loaded all the time and I think that kind of freaked her out.

A: Loaded?
B: I was drinking alcohol before I went into the hospital the first time, and then she was really upset whenever I went to the rehab and then she was really confused whenever I went away to the hospital.

A: Yeah!
B: And she didn’t see me again until my 21st birthday. But I don’t even really remember this too much because I just got my 6th treatment of ECT and I couldn’t even remember my family that day. But evidently she was there and she didn’t handle it very well. But yet she is unwavering support, and she’s always you know, would ask me how I was doing or things like that I definitely got that aspect from her that was different from my brother’s take on it. My mom was incredibly beyond supportive. My dad as well. My dad not in the same way but, he has bipolar disorder and, you know, he has been hospitalized you know, in his lifetime, so, and has gone through his own version of mental illness and I think he just kept it quiet sort of understanding about it.

A: You felt he was understanding?
B: Well yeah, he was the only one who really, if I said anything he would sort of know what I was talking about.

A: So he could really empathize having experienced.
B: Even though we’ve never really talked about things… in depth but we sort of know what one other is kind of talking about like with… electric shock stuff and sort of I don’t know what you would call it… the non-reality or something.

A: The non-reality?
B: Yeah… you know, whenever I guess he would get in the manic phases, you know I guess, that’s almost, sort of like whenever I would have the voices and different things like that they would you know go on, and I would get locked in those.

A: Yeah, yeah, so you never actually explicitly you never discussed about the actual illness but you sense he was able to implicitly understand being through an illness and having received services too.

B: Yeah, I mean I think he just sort of saw what he was going through in a different form… through his son, you know what he went through at the same age whenever he was growing up so I think he just saw it happen again. You know, it’s like now you go through something, you sort of live vicariously through your children in different ways and get to re-live things in that specific way he has a specific understanding of it… My mom was the person to ask a lot more questions and he would, you know still supportive but in a different way.

A: Um-hmm.
B: Yeah… I mean my friends were around from time to time. They went away for a while. I had 2 friends that would visit me in the hospital from time to time… Of
all the times that I’ve been hospitalized it’s very difficult for me to remember a lot of things just because the medications I was on… like the levels would be so high.

A: Yeah… and you said that ECT sometimes would impact your memory.
B: Yeah. I think I ended up having like 12 sessions of those and I think that wiped out a lot of my certain memory from that timeframe… Just like how… what I was telling you about my 21st birthday that’s what my mom was telling me it’s not what I remembered.

A: Yeah, I guess many people experience the different treatments in different ways.
B: Um-hum.
A: You mentioned how ECT in a way was helpful like medication in eliminating symptoms. But, I also wonder about how you feel having those memories removed or erased… is there any aspect of it that you don’t like?
B: About not having them?
A: Yeah, not having those memories and having the treatments.
B: Ummm… no I mean because at that point in time I was so vulnerable and I had faith and trust in my doctors, even if they weren’t the right ones you know? Like I have now. But I don’t know whatever they were looking for, for specific treatment avenues but I was certainly as open-minded as a patient could be.

A: Aha, aha, yeah. So overall you feel that you had faith in the doctors.
B: Yeah, the faith aspect was always there but it didn’t always lead to a positive result. It was just the constant attempt… which is good.
A: Yeah, yeah.
B: But it took a lot to get to anything successful, like a couple of years I think.
A: In terms of medications you mean?
B: Yeah, yeah… at least probably 2 years until I was on Clozapine you know and I have been on that since then. But for 2 years it was a medication mess.

A: Oh wow!
B: It was constantly changing the levels, changing different medications, you know. And I was probably on too high a dosage at the time… I was out of the hospital a lot of that time but right at the end of that period when all those medications were not working, I went into the hospital for the last time I was in the hospital which was in 2005 and I was placed on Clozapine and it’s been successful in a number of ways since so I’m grateful for that.

A: Yeah, yeah, so it’s finally working for you?
B: Yeah, I mean it still knocks me out and makes me very sedated in the evening. I mean there are a lot of difficulties after I take it. The side-effects at times basically almost got me to the point where… all those medications I was like is it worth it? I wish I’d rather just drink from time to time.

A: So sometimes you wonder is it really worth it having all these side effects.
B: Right… sometimes I thought they were worse than the actual illness! You know? Because sometimes I’d have difficulty breathing whenever I would… you know be dozing off… and then I’d be really salivating and all these different uncomfortable things. Or getting hungry, or have to use the restroom. And I’d be so sedated my motor functions were all messed-up. So I’d walk into walls and stuff (laugh anxiously)…

A: Oh wow!
B: I sort of laugh at it to a certain degree except for the breathing.
A: Un-hmm… yeah the breathing must have been scary.
B: Yeah, that always got me. Because I’d salivate at night and get like a dry mouth later on whenever you know I couldn’t swallow… it kind of freaked me out (anxious laughter).
A: I bet!
B: But you know, I’ve learned to, as best I can to handle with the diverse side-effects I guess, of the medication.
A: And, I guess, you tried to take your medications, I guess, balancing the negatives and the positives you prefer to take it?
B: Absolutely. To be honest, there would be times when I would like to not take it… like going out on a med vacation, and then return back like someone goes back to work.
A: Yeah. Have you tried that?
B: Yeah. I mean early on. I mean it actually is fine for a period of time but I mean it does twick things that I noticed… I don’t know… I’m not sure exactly how to describe those things but… I mean, it’s not something I would recommend doing, but I’m sure that it’s something that everybody who is on antipsychotic medication secretly does from time to time.
A: Yeah… because I guess the way you describe that mini-vacation it’s almost like wanting a break from all these side-effects.
B: M-hmm.
A: And at the same time you don’t want the voices I guess being there as if it’s almost like a switch that you cannot turn off… somebody else I knew used this metaphor from his experience, I don’t know if you experience something similar?
B: Yeah, I mean it’s definitely like that to a certain degree and my symptoms have changed over the past few years. You know, like I was saying. Like the voices and stuff like that are not something I get as often anymore.
A: Yeah.
B: I got that constant from 2002-2004 but since then it seems like the heavy medications sort of took over and now it seems like, I don’t know, there are a lot of other symptoms, but the voices is the one thing that is sort of not there anymore. But yeah, definitely even with anybody who works you know and going on vacation you know why you go on vacation to get away from all the stuff and then… yeah.
A: Yeah, you want to go on vacation.
B: Sometimes you get a paid vacation, sometimes you don’t. Sometimes you get away with it and sometimes you don’t (laughs). It’s like what I’m saying with symptoms hitting you or not.
A: Um-hmm yeah. And you know, I appreciate you sharing all these experiences it helps me understand what you are going through better… I know you mentioned when you received the initial reaction from your brother, you know you felt kind of angry.
B: Um-hmm.
A: Because that was real to you.
B: Um-hmm.
A: And being far away too he had an idea, you were close, but he still had that image of you being well.
B: Right! And also the fact that essentially, in his mind I was still the same. I hadn’t taken on a whole different person. Which made it even more difficult for him to assess I guess.
A: So I guess from your perspective, now do you see yourself… I think I mentioned something about self-image (pointing on the research ad) compared to before you experienced the symptoms were diagnosed and you received treatment, you know, versus now… now do you see yourself? Is it different? Do you see yourself differently, the same, both?
B: I don’t know… I certainly was more self-centered before. I think… I think the illness sort of shattered a lot of things in me. I dunno… I still feel like myself… I mean, there are certain times during these past few years, I guess there are sides to me that I don’t see that other people see… I’m trying to explain it…
A: Yeah.
B: Sorry I lost my thought.
A: It’s ok! So you were saying how with the onset on symptoms, receiving treatment and all that, you felt originally that you were self-centered but that image…
B: Yeah! Like I was just going about the regular steps I thought, should be at, you know… and then…
A: But then something shattered.
B: Yeah… I don’t know if my way of thinking changed… I’m not really… sometimes I have difficulty assessing before and after, but sometimes when I think about it is like looking at a photograph from childhood or something and I try to see it… Sometimes it’s there, sometimes it isn’t.
A: M-hmm.
B: So sometimes I don’t even really remember what my goals or aspirations or what my self-image knows. You know? I was probably pretty confident… you know I was a pretty confident person.
A: M-hmm, m-hmm yeah.
B: It’s not that I live with no confidence now… sometimes I just have, I just have difficulties, I guess.
A: M-hmm so you know, before you were confident in yourself, in your abilities.
B: M-hmm.
A: And now sometimes you experience some difficulties with the self-confidence. You don’t feel as confident.
B: Well yeah, it applies to that and to almost every facet of my life. The only thing that opened completely was a spiritual life. That didn’t exist prior.
A: Hmm! Um-hmm! Would you like to say a little bit about that? You feel more spiritual now than before?
B: Yeah… I mean it’s almost something that… certain things just made sense… or I might have been a questioning person prior, but for some reason, whatever happened and things were just completely understood to me now. At least in the way I see it. I don’t overly discuss it with people where it hasn’t become the focal point in my life like trying to proselytize something but it’s definitely, it’s been a solace and I think that was a gift.
A: Yeah! This solace I guess like an appreciation of what was there.
B: Yeah, I mean it gives me strength and stuff that’s almost inconceivable.
A: Wow! I’m glad to hear that!
B: So yeah, I feel very… constant gratitude for that.
A: Um-hmm! You are grateful for…
B: For having that sort of belief or understanding or spiritual aspect that allowed me to understand where am at or what happened.
A: Yeah! So it’s almost like accepting what happened?
B: Yeah… in a certain way or to be able to not to blame myself entirely. Because I don’t know if that’s something I can do! I never have. I mean, thoughts never crossed my mind.
A: Do you think in the past you were sort of blaming yourself?
B: Well, I don’t know if I might have exacerbated things by drinking so much… I mean I don’t know… it’s not like I went on and on for years and not addressing what was really… I mean, that was the one thing and another thing I feel very lucky about is the fact that I was able to address a lot of these symptoms to people who needed to know within a matter of, you know, 6 or 8 months of whenever they first started, as opposed to just going on for maybe a year or two.
A: Yeah!
B: I don’t even know if I’d be even the way I am now if I let myself go that much further. Because whenever I see people in the hospital I just know whenever they allow themselves to go un-medicated.
A: Yeah.
B: And who can’t get medication and I was one of the lucky ones.
A: Um-hmm. So I guess people who wait a little longer, maybe you know, the illness is more exacerbated?
B: I don’t think I would be… I mean I still would have to be here physically but I wouldn’t be here anymore I don’t think in a certain sense. I would just evaporate into booze or whatever. Something else, I mean if I lost what I had in a matter of 6 or 8 months by doubled or tripled that time or even else I wouldn’t even wanna know. Cause it seems like as it goes on more and more within the time passes at least I noticed it just intensified it never really ended. It just got more and more… you know.
A: Um-hmm so things could have been worse if you waited?
B: Oh yeah I believe, I believe. So I feel lucky to have people to listen to me and to also be able to be in the position to get help with medication especially.
A: Does it help you to have people who care? Like, you know your physician who wants to listen to you?
B: Yeah, definitely. I mean it’s definitely great I have a great therapist and great doctor.
A: Yeah!
B: It’s great to be able to have that.
A: Yeah! That’s important.
B: Yeah, it is it is very important cause I don’t like to delve into, you know, my objective experience of the world or subjective or whatever or what it is now just
to my friends too after or any people more than I have to because I think it just alienates them. I just feel like it’s too much information.

A: Ok!
B: At least for just for friends’ stuff you know.
A: You don’t want them to know every single detail.
B: Well no, and I think there is an understanding there I think that just know and whenever you know, my friends near whatever I say I’m not feeling well, they understand in a certain sense what I mean or if I’m not around for a while they understand, you know.
A: Yeah, yeah, yeah, so they respect your privacy, your subjective experiences but they know what’s going on.
B: Yeah. Most all of my friends and closer relatives are aware to some sense.
A: Have you ever had any experience with people who didn’t understand? Or may be they had their own conceptions – people can have many different ideas – especially when they don’t know about what is going on… You know your diagnosis.
B: Oh yeah, number one my brother. With other… I mean to be honest with you with outside people I probably wouldn’t care as much.
A: Hmm!
B: I mean I know that most people would if I was not well then I was out or something or just not feeling well I don’t know if people would notice or look or stare or something. I don’t know if you are talking about stigma with job.
A: Yeah!
B: I mean I had one job that I got fired from, you know, since I… I’ve been hospitalized. It was a job I thought I was good at. I worked at a record store, I love music.
A: Were you fired because you were hospitalized?
B: No I mean, I don’t know if that was one of the reasons, you know. I don’t really know. My thought was like I just didn’t fit into the social scheme of this smaller record store.

Secretary knocks: I am sorry to interrupt you, there is another person waiting for you.

A: Ok thanks we will be done in 5 minutes. Sorry about that. Ok yeah… Well sometimes there is some stigma associated especially when people don’t understand where you are coming from.
B: Yeah… But I think… I’m sure there are people who would probably delve into that area far better than I could… you know… I am certainly aware that it exists but… if it has been in my life around I probably ignored it if it was from the outside, you know.
A: Yeah. People that matter to you.
B: Yeah! If it was people who I thought could be the least understanding on a basic… or, that I needed their understanding, then I would get a little agitated. You know, upset.
A: Yeah, sure sure! And how do you see your future now or where you are right now compared to lets say in the past. How do you see yourself?
B: Well… in 2001 if I would have thought where I would be in 2009 I’d probably say I’d be successful, probably have certain job that I may have wanted or certain other aspirations that I dunno what they are but, I’m sure I would probably would have thought that.

A: Yeah, yeah. But right now?

B: I dunno I don’t… I don’t dwell on that too too much. I just try to be able to lead as normal life and… I dunno that’s something for me that’s difficult.

A: Yeah. I mean, you know, you talked about the spiritual aspect and this appreciation that you have right now.

B: Yeah.

A: And you don’t want to dwell on what could have been. What ifs…

B: Oh yeah, yeah. I can’t do that. I can’t think about the “what could have been,” but I know what the me from 8 to 9 years ago would have thought of where I would be now.

A: Um-hmm, yeah, yeah. Whereas now you just take each day as it comes and just go on with your life?

B: I, I guess… just that or I try to get out and do things from time to time but… I like to be or I need to be alone a lot you know and just too much noise doesn’t… I dunno… which sometimes is good for me and sometimes bad but… I dunno I try to stay or keep positive in some sense. You know not be too down on myself which is something that has existed in my personality since I was little you know.

A: Yeah! Well I wish we had more time I am so interested in what you are describing and your experiences.

B: Aw I appreciate the opportunity thanks a lot for your questions.
Daniel Transcript

A: Ok. Let’s get started. How long have you been receiving services?
D: Through here, since May or April.
A: Ok. Of this year?
D: Um-hmm.
A: Ok. So before here you used to go somewhere else?
D: Well. In the past I was hospitalized 3 times. But there was a gap of where I didn’t receive services for over like 2 years.
A: Ah ok. When was the first time?
D: It was at X hospital and believe I was around 18 or a little older.
A: Ok. and now you are
D: 32
A: 32 Ok. What was happening then? what was going on?
D: Umm I heard voices.
A: You heard voices and you haven’t experienced that before age 18?
D: No.
A: Take me there explain to me what was happening then? You started hearing voices.
D: Yeah, I did and… let’s see whatever happened… I’m a little foggy on the details.
A: Ok, whatever you remember.
D: I remember I was delusional and I believe my parents had me sent to a hospital.
A: Delusional you were told that you were delusional. What are some of the delusions that you were having?
D: Umm I believed I could hear people that were far away and I believed I could read people’s thoughts.
A: Oh ok… so you believed that you could hear people that were far away that other people wouldn’t hear.
D: Um-hmm.
A: And those people were talking and you believed that you could read peoples’ thoughts. So you expressed those beliefs and delusions and then your parents what did they do?
D: I believe I went to the hospital from there.
A: So what happened there?
D: They put me on meds and I guess observed me for a while.
A: What was your understanding of what was happening? Why do you think people were…
D: Hmmm I guess they were trying their best to hmm clarify… not clarify but make me understand that it was not real what I was experiencing.
A: When these things happened to you, when you were having the voices and the delusional thoughts
D: Um-hmm
A: What did you feel or what were you thinking? What was going through your mind when these things happened?
D: (Pause) I guess I was thinking that something was wrong.
A: Something was wrong
D: It was a long time ago… I guess I was a little scared.
A: Scared… you were scared about…
D: I don’t like the hospital.
A: What happened? what’s your experience of hospitals?
D: They put you in a room they give you pills and they force you to do what they want you to do. You don’t have real freedom in the hospital.
A: So they restrict your freedom you can no longer do whatever you want.
D: Um-hmm
A: You are there, you are under observation and you are forced to take medication.
D: Um-hmm. And you have to do what they say to do or they lock you in a room and tie you down.
A: Oh wow! Has it happened to you?
D: Oh yeah. When we first get mandated they always put you in the “quiet room.”
A: Oh I see.
D: That’s what they call it.
A: Quiet room. (Sigh) yeah. It must have been pretty hard to have that happen to you.
D: Um-hmm. You gotta to do you know like I said you have no control over what’s going in there.
A: Yeah. You have no control over Doctors’ and nurses’ actions?
D: Yeah. You don’t have control over what you get to do. If you want to sleep in, you can’t do that.
A: Um-hmm!
D: If you wanna read when the group is going on you can’t do that, you have to abide by the rules of the program.
A: So they have rules about certain activities that you are supposed to do.
D: Yeah. Not a lot of volunteer stuff there. Some hospitals are better than others. I’ve been through a few.
A: Aha
D: I liked X hospital more than I liked X hospital and X hospital.
A: Ah ok. What’s the difference there?
D: I guess the food was different.
A: Meaning better?
D: Yeah. And I guess the attitude of the people there. They are real structured but, some of them give one on one meetings with the Dr. more so than others.
A: Aha!… Did you get to experience that with the Doctors?
D: Um-hmm
A: So you, ok you experience those things, those voices and then next thing you know you are in a hospital.
D: Um-hmm
A: People are trying to treat you, they are trying to give you
D: Haldol
A: Yeah medications… Why do you think, you know from your experience, people have different perspectives but, why do you think people do that?
D: Do… what?
A: You have somebody who says well I hear voices, I have these beliefs that nobody else believes them the same way.
D: Hmm
A: And next thing you know you are in a hospital.
D: Well, it depends. Like, sometimes you don’t go to the hospital if you are not violent with yourself or others.
A: Aha…
D: And in most cases, if you are, like if you are in school and you are not disturbing the class, you know, stuff like that, you are less likely to go to the hospital.
A: Right, right…
D: But if you are like in a controlled environment and you are not, you know, adhering to the rules around, then you are more likely to go to the hospital.
A: Aha… Is that what happened with you? In your experience.
D: I avoided the hospital for a few years. I started… I became a recluse. Yeah, I didn’t leave the house much… when I was symptomatic. When I was having symptoms and all that.
A: Aha… ok, ok… Isolating yourself and trying to stay in your room, in your house how was that?
D: It didn’t help… It helped me not to go back in the hospital. But that’s about it.
A: Hmm
D: It was counterproductive symptom wise… like, I wasn’t getting no help but I wasn’t getting any better but… I wasn’t out there in the street.
A: Yeah, yeah… So then, what was your idea of getting better? Ideally what would you have liked to happen?
D: Just to be able to function more in society.
A: Yeah, yeah… Function…
D: Or responsibilities and stuff like that.
A: Ok… and that’s your idea of being able to function.
D: Um-hmm
A: Is being able to be in society and do things
D: Um-hmm
A: Ok… Before you were diagnosed before all this was happening, did you have plans? What were your plans for the future?
D: Yeah… I wanted to go to school for computers. I wanted to be in computers… I went 3 times and didn’t graduate.
A: You went to college?
D: No, I went to trade schools like Bradford, ICM and PTI.
A: I see! So that was your goal you liked computers you wanted to study and get a degree.
D: Um-hmm
A: And that was the plan… and then what happened?
D: Well once I was in school I got hospitalized and the other 2 times I went to jail for an offence that was not even the crime in this state.
A: Yean, what was that?
D: Fourth degree hindrance of arrest or prosecution. Here it will be equivalent to alluding (?) there it’s 4th degree hindrance of arrest or prosecution.
A: Huh! That’s different. It’s interesting how different States have different definitions.

D: Um-hmm. Yeah like different States are involved with doing different things. Like Jersey, I don’t think they are too happy with anybody. They are really just try to crack down on people and lock them up.

A: Oh wow!

D: Here they will lock you up. They are not as, you know, not as petty. Like, if you run from the police you get alluding instead of hindering arrest or prosecution. That’s why it was much more severe than alluding.

A: Oh Ok! So, were you running away from police?

D: Yeah, I was in that car… we went to Jersey for… the guy behind the wheel saw the police, panicked and drove away, I was asleep in the back seat. And when he pulled over, he ran and the other passenger ran and I ran. We found out the reason why he ran, was ‘cause he had probation and he wasn’t allowed to leave the State. So if I would have stayed in the car I would have had no charges. But since I ran, that’s why they gave me that charge.

A: Ok I see! Everybody ran and you just woke up and you ran too.

D: Yeah… um-hmm. But they didn’t look at it that way.

A: Seems unfortunate.

D: Well, they were just trying to get a charge to put on you. They had to think about my charge for a while.

A: Going back to, do you think things like that as well as the fact that you were hospitalized, the fact that you were diagnosed with mental illness played a role in, I guess of your plans for the future?

D: Yeah. Like it’s harder to do things. It’s harder to like… you know. Like if your mind is… especially if I’m sitting symptomatic it gets harder to like focus and concentrate and actually go through with that plan. You know every day might not be like that you know some days on those days when I’m symptomatic you don’t get real compassion from anyone else, but OK you are having a bad day and they are like well I’m having a bad day too.

A: So you feel that when you do tell people how you are feeling when you are symptomatic they don’t necessarily, they cannot get into your shoes? Is that what you mean?

D: Well, I couldn’t empirically say that, cause I never really tell people when I’m symptomatic. I’m not liking of that type. I will sit there and try to avoid conflict or change the subject or change the attention from me to something else. And if I can’t hack it I leave

A: Ok. So do you choose to remain quiet and not talk about what’s happening with you let’s say you know, you are hearing voices.

D: In most cases yeah. People look at you funny when you say you hear voices.

A: Aha! Hmm

D: A lot of people don’t even believe it’s a real illness.

A: Um-hmm. How does that make you feel to have people who either don’t believe you or laugh at you or something?

D: People are entitled to their opinions. I try to block it out. What doesn’t kill me makes me stronger (smiles).
A: That’s a nice attitude to have. I guess not allowing other people to affect you in a negative way.

D: It only brings me down more.

A: It only brings you down more yeah it doesn’t help. It must be tough. You know you want to express what you are feeling, you want to get people’s empathy and understanding, and you want to help them understand you.

D: Um-hmm

A: But then when you do…

D: Hmm… I found that if you go back that route they try to belittle you, they think that you are less intelligent and stuff like that and I’m not stupid.

A: No! of course not.

D: You know. I just have a mental illness. But you know if you tell someone you are schizophrenic first thing they think is the way you say mental illness they think that you are stupid.

A: Hmm!!

D: Um-hmm

A: That’s a lot of misconceptions!

D: Yeah there’s a lot of them. But you know, that there is a lot of famous people like great artists like Da Vinci was a schizophrenic.

A: Oh yeah! Yeah!

D: You know? It doesn’t mean that you are stupid. It just means that your mind works differently than others.

A: That helps me a lot too! To understand too! I don’t have those presuppositions and stereotypes.

D: Um-hmm

A: But at the same time, you know, coming from your perspective it helps me understand better how, it’s not helpful for someone to look down on you or

D: That would be condescending.

A: Yeah, that would be condescending yeah… it’s only making things worse.

D: Um-hmm

A: It’s not really helping you.

D: True, but you know it’s so hard to help a person that, you know, you can’t really see what’s going on inside your head and they only know what they tell you and a lot of people in those situations they don’t really come out ------ to get help dealing with their symptoms. They are usually, you know either they are recluse or they just don’t like being around people. And usually they don’t like talking much either. That’s at least my experience.

A: Yeah. So is that impacted, I guess, by people’s reactions? You know so if you have people who react they don’t know how you are dealing with things and so they have these stereotypes.

D: Um-hmm! That’s a factor too but most of the time it’s just you know you don’t feel like dealing with it…at least that you know, not taking you down the road to how I am here explaining it’s like a repetitive thing where you have to explain why to each one: ok this is what’s going on, I’m going through this and when you are going through this you really don’t have the mental state to actually convey it
to someone else... like, sometimes you are real delusional, you know, your perspective on reality is not clear.

A: According to other people’s standards or according to yours too?
D: According to... you know, it wouldn’t be a mental illness if you know, I wasn’t sick.
A: If it wasn’t in the way of you enjoying your life?
D: Um-hmm! So now I can’t put all the blame on others; you know a lot of the problems were unique. I am working on it.
A: Yeah, yeah! You working on it, and you sought help. How is that going for you?
D: In here they try to help you a lot, but the government does not help, social security not really help, it seems like they are designed to confuse and get you to quit before you even try to go through.
A: Oh wow!
D: They have you wait for... we’ll say 130 days and after that then they start sending you to doctors and this and that and there is real confusion and difficult process. And people that are applying for this are mentally challenged or disabled or this and this so the process should be, you know, somewhat I’m not saying easier, I’m saying it should be less stressful and less confusing. They should be right you know, well you know, you have a doctor you have been hospitalized ok well that’s it!
A: Yeah
D: There is designed to get people to quit trying.
A: So the fact that it takes forever to actually get in to see a doctor may have a negative impact on your actual health or you get discouraged.
D: You get stressed and stress adds to the anxiety, anxiety add to the illness. So this is like a chain of events. You get stressed and you... like, most people with my disorder can’t handle stress well.
A: Yeah stress inevitably affects... when you are having the symptoms stress is not helpful. But if things were more efficient, then people wouldn’t get confused or discouraged.
D: Yeah, but I think they wouldn’t like that there because there would be more people on it than there is now. So you know, I think that’s the underlying secret debate on why have it that way. So they want this designed to discourage people in the court.
A: I see. Did you have a personal experience with that? Did you get discouraged?
D: Yeah, I’m in the process now. The first time I applied it was so confusing and I went through all this stuff and finally just gave up. Then I reapplied. This is my 3rd reapply.
A: Um-hmm, wow, 3 times!
D: That’s common. They deny everybody the first time. Like I said that’s the design of the whole thing. They want you to go through the appeal process, and lawyers and all that.
A: Is it frustrating for you?
D: It is frustrating. But what can you do?
A: Yeah, yeah. It seems like there is a system in place there and it’s hard to influence it the way you want to.
D: Um-hmm. It doesn’t make much sense to me. People who don’t get help they go and do something stupid and then they give them like the death penalty or put them on death row. But instead of avoiding it if you will, I wish it was like “This guy is sick let’s try to help him before he does something stupid.” But that’s not the way the system is designed.

A: Right… So a lot of things could have been prevented…

D: Yeah… if they had a like asylum and structure ? a big step they didn’t have that years ago.

A: Aha

D: And they changed like a lot of stuff. A lot of stuff has changed. They didn’t have different medicines… like, I probably wouldn’t even have come back if a lot of stuff didn’t change and like then the medicine in fact they changed because there was a lot of medicines I didn’t like.

A: Yeah

D: And I was like ok this stops my voices, but it gives me this long of a list of side-effects. And who wants to live with all these side-effects.

A: Can you tell me some of those side-effects?

D: Oh it was like sexual side effects, there was some weight gain… there was a lot of side-effects. Depending on the medicine.

A: Yeah, yeah… Do you feel that you found something now that it’s better than other meds that you tried?

D: Yeah. I like, I forget the name of it… it’s the new they were advertising it on TV for depression right now… I can’t remember it right now.

A: It’s a new one that’s why I guess. So you tried this new medication and it’s helping you.

D: Yeah

A: Ok. Yeah I think it takes a while like you said each medication is different and it takes a while to find something that works for you without the side-effects.

D: Um-hmm

A: Do you think that there is something positive too about medications? I know you listed some side-effects.

D: Well, with a lot of them, that’s the one way to get you back into the boundaries of reality.

A: Yeah, yeah

D: You know, if most of what you are dealing with is fictional then you can’t really deal with reality well.

A: Yeah, yeah. So reality as the majority of people around you perceive it.

D: Yeah

A: So I guess the medicines helps you get tuned back into the reality versus the other reality.

D: Um-hmm. True, but with me… I’m not trying to have a medicine take away my symptoms totally because I don’t want to have a lot of side effects so I just deal with it. Like I dealt with it for 5 years without medicine. So, you know, it is a lot easier with medicine. But, you know I don’t need… I can deal with something that ain’t real as long as I am conscious enough to realize it “Ok that’s not real, you are going through this.”
A: Aha!
D: Like you have to take like more steps in mind, like you have to remind yourself of details, like bright lights are supposed to set you off, loud noises, crowds, stuff like that. You learn details and you learn how to tell you are having a bad day.
A: So you recognize these things that happen and you know that could be a side-effect of medications and you deal with them.
D: Um-hmm. Well side-effects of medication I don’t really like them, but the medicine I’m on now hasn’t really had any side effects.
A: Yeah. Compared to other meds.
D: Yeah. Like I used to take haldol, lithium, Risperdal? I think I was on Risperdal briefly. But, yeah. I didn’t like any of them.
A: But right now it’s better compared to other meds and you are able to function better.
D: Um-hmm
A: Participate in this reality. At the same time, you mentioned at some point that people don’t understand that… you know, it’s an illness but at the same time your mind works differently.
D: Yeah
A: It doesn’t make you an inferior person. Your mind works differently.
D: Yeah, um-hmm.
A: The chemistry of the brain is different, your mind works differently.
D: Yeah, I probably have some serotonin or something. Like other chemicals in the brain than other people who might have less. That’s what’s going on.
A: Is that what you meant when you said that my mind works differently?
D: Yeah. That and I had to deal with stuff other people don’t have to deal with. Other people don’t have to deal with internal voices, confusion, like, wondering if this is real or this is ok like, I hear somebody, like somebody call my name I gotta think ok… is that me in my head or is that somebody out in the living?
A: Awww… so do you look around to be able to distinguish is this internal or not?
D: Um-hmm, well, I learned, like, a lot of tricks. First of I observe all my surroundings and I pay attention to details, and the more information I have, it seems like, the easier it is to cope.
A: Um-hmm
D: So, you know I try to get as much information as I can and use this to my benefit.
A: Yeah… that’s great you are able to do that!
D: Well… that’s when I am able to do it. It took a lot of years of practice. I can’t say that I just, one day woke up and said I’ve figured it all out.
A: Um-hmm. It takes some time.
D: Time and practice. And nobody ever gets it perfect.
A: Um-hmm
D: I am still able… I mean, possibly able, to have a relapse and start reclusing again.
A: That’s a possibility.
D: Yeah… but you know, I try, I work on my therapy, my team of therapists and doctors… I don’t remember the word they say for what that was.
A: Treatment team?
D: Yeah, that’s it. I work with them and try to do what’s right.
A: Yeah, yeah. Hmm a question that I had is how is your relationship with other people like, family, friends, staff here… Do you feel that receiving a diagnosis has influenced those attitudes and responses of others in some way?

D: Well, they look at you differently but… a lot of them… you know ignorance is one thing, but once they are explained it is different. But when you don’t know, they you react like “I don’t know, I don’t understand”… Mental health isn’t a field where they really expand on it and teach everybody what’s going on with them. So it’s not easy for people to learn how to deal with people with mental disorders. So you know… to answer that, yeah, there’s been hit or miss I would say. Some people, you know, are understanding some people aren’t understanding and some people are confused by it, and some people have had somebody that went through it so they know the gist of it. So you know… it’s all about who is ignorant and who is not.

A: So different people have different perceptions and understandings…

D: Oh yes! They do. If you have never dealt with voices or hear voices or things like that you can’t comprehend how somebody else can hear voices when nobody is there and what they are doing with them and what does that mean. Does it mean that you will understand me right now, does it mean that you are going to start chewing on the floor, they don’t know.

A: Hmm! So ignorance then makes them… does it make them fear for the worse?

D: Yeah usually they go to the extreme. When you are afraid they usually go to the extreme. Like, I don’t know what’s going to happen, I don’t know if you are going to hurt me or whatever but you know so am I go on the extreme side rather than me be not so cautious and get hurt.

A: Yeah… that’s what ignorance does. I mean it’s hard for somebody who doesn’t experience symptoms to understand exactly what you are saying, but at the same time, I just wanted to throw an idea there – the media…

D: Oh they… the media don’t really tell you anything you want to know about mental illness. This person is schizophrenic. They don’t go into details; I didn’t know what schizophrenia or schizophrenic was at all.

A: So how do you think the media influences the layperson’s opinion about what mental illness and what schizophrenia is?

D: I don’t think they really do. Because usually the media would tell the worst case scenario. The guy got shot at McDonald’s or the guys that do something out the box they expect them to be schizophrenic or crazy or that’s what they portray. Everybody who has a mental illness is either a criminal or a psycho-killer or something like that. It can’t be a normal ------ There is Doctors, lawyers and all kind of people that have mental illness.

A: Yeah… so by showing the worst case scenario and portraying people who are violent as having a serious mental illness and it doesn’t do justice to other people who are gifted.

D: True. But that’s the media. The media don’t shine the light on, you know, all the good and all the bad. It just shines the light on what’s going to sell the most papers or get the most viewers. So… media is notorious for that they never portray a true perspective on anything and so it’s always one side… it’s their side.
It’s supposed to be neutral but it is never neutral, it’s always, this guy did this – the news at 11:00.

A: What sells… violence sells, shocking stories sell…

D: Yep! Violence, sex and money.

A: Yeah it’s really unfortunate… And I can see how, like, you are talking about people who don’t really understand and really fear for the worse and that’s why I thought… well, where do they learn those fears from?

D: Yep. They learn them from the media.

A: From the media… It could be, yeah!

D: You know that’s the only one educating them at all about it. There is nowhere else… If you are not a schizophrenic how do you learn about a schizophrenic? You look it up on the internet… but if you haven’t been around any, you are not going to look it up until you encounter one, or if you see something about one that intrigues you.

A: And, even the internet you know, if you want to read about schizophrenia, you read about all these symptoms that people have but you don’t get the idea of a person, is that what you mean? It’s just like a list of symptoms.

D: You got a point; it is a list of symptoms. There is no other media that tells you… Ok these are doctors and lawyers and these famous people in the past that have… Joan of Arc heard voices.

A: Yeah… a lot of famous classical musicians/geniuses had to deal with serious mental illness.

D: But a lot of people don’t know stuff like that… they just know that this person who shot up the whole McDonalds he was a schizophrenic.

A: That’s unfortunate.

D: But that’s how society is… like I said, it’s hard to catch people that are schizophrenic… there are a lot of people walking around with lots of illnesses that aren’t diagnosed.

A: Yeah

D: That are dysfunctional and they are dealing with it day by day. And there are a lot of people that are diagnosed that they are so severe that they can’t function in society and they are shutting down facilities that serve as their houses. What’s better there to do? The jails are already overcrowded so you can’t keep sticking them over there. So they are spread around the street. And… bad media – good media.

A: So would you say that diagnosis is both a blessing and a curse at the same time? Like you said, there are a lot of people undiagnosed…

D: You see, I don’t see the downside to being diagnosed. The only downside is that you lose some rights… you can’t enlist in the army or stuff like that… but other than that

A: Do you think people respond to you differently once they learn you were diagnosed? We mentioned that before.

D: Yeah but… just because you were diagnosed, other people that know is the ones that you tell. The doctor can’t tell anybody. So just because you are diagnosed, nobody else is going to know unless you tell them.

A: Um-hmm… How do you deal with that yourself? Do you tell people or
D: I tell people because I feel more secure. And I don’t care if people don’t understand too much. But I will take the time and if somebody asks me questions I will answer them to the best of my knowledge.

A: Um-hmm yeah. And another thing I wanted to ask is: Do you feel that receiving treatment/a diagnosis has affected the way you see yourself? You know, compared to before you were diagnosed?

D: Hmm… I don’t think so.

A: Do you see yourself the same way?

D: Well, my goals have changed, but that’s about it.

A: Your goals have changed?

D: So I guess, technically I don’t see myself exactly the same. But for the most part I think that I am the same. My goals have changed. Yeah… school and now its economic factors and that add to everything. I am so far in debt that I don’t think about school anymore. And it is hard to focus a lot of times on the distant future. You gotta take it one day at a time.

A: Yeah, yeah. So if somebody were to ask you how do you envision your future then you would say, just doing what I can right now and taking it one step at a time.

D: Um-hmm. I don’t (i.e. envision the future). Just wait till it gets there. No one knows what is going to happen in the future.

A: Yeah. So live in the “Now”. I know I’m asking you a lot of questions how is it going for you so far?

D: Alright!

A: I really appreciate your answers and all your effort. The last thing I wanted to focus on relationships. So let’s take the area of family, so your relationship with family members. How do you see that? And also romantic relationships with another individual. So how do you see those things?

D: They are stressful you know, well they are always stressful in my case they are a little bit more stressful.

A: More stressful? So let’s take the relationship with family.

D: Well… my family, I would say that we are semi-close. So we don’t really deal with stuff like that. Most of my family doesn’t believe that schizophrenia exists. They don’t believe I’m sick!

A: Oh wow. Is that your immediate family or extended family?

D: Most of it. It’s a little bit of both: some of my immediate, some of my extended.

A: So they don’t believe schizophrenia exists.

D: Yeah. They don’t believe schizophrenia is real.

A: Have you tried to educate them about it?

D: Well… (hesitant). I have a lot of stuff related to my family. Basically if they believe in something then nothing is going to change their opinion except for them dealing with it themselves. So I don’t try to educate them on it anymore. Some of them have mental illness themselves and did not get no treatment or nothing. They just survived so they expect me to do the same.

A: But are they the ones who took you to the hospital to receive help?

D: Yeah, well, I only got hospitalized once from my family and that’s when I was very young and that was my immediate family; like my mom and my aunt,
brother and sister. That was one thing. They know I’m smart. They know like the other sides of it so they are thinking well, you are so smart and all this and all that so how can you be sick?

A: Huh! So mental illness for them is
D: I think it’s like retarded for them. When they hear mental illness they think retardation.
A: The thing about retardation and intelligence is mental capacities is something different. What is your reaction to that? How do you feel about it?
D: I don’t really deal with most of my feelings. I usually dive into other peoples’ feelings and deal with their problems and leave mine to the side.
A: So you’d rather not mention anything about it?
D: Eh, I just don’t put too much thought behind it. But if I was forced to say something I’d say people are entitled to their own opinions.
A: So they can believe what they want but it is not going to affect you and the way you feel about yourself.
D: Yeah. It is not going to change anything.
A: You still feel the same way about yourself?
D: Um-
A: How do you feel about yourself?
D: In what regard?
A: It’s a vague and open-ended question.
D: I haven’t really thought about that… I will get back to you.
A: I know you said that you don’t like to talk about your feelings, and here I am asking you to tell me about them. I hope that’s ok? Please let me know if it gets uncomfortable.
D: It’s ok. That’s what I’m here for! (smiles)
A: Well, last thing I wanted to ask, still about relationships with other people, but romantic relationships. How is this for you?
D: Hmm, I usually don’t tell them about it, they usually figure things out when they do. But in most cases, most of my romantic relationships they don’t really care about what I’m thinking. Because I cater to their needs, and I am more involved with their stuff. But for the ones that really like me though it’s a problem because I don’t care enough about myself and my own problems and I’m more concerned with theirs, so that’s a problem between us. But the ones that don’t care they love me.
A: The ones that don’t care about…
D: Me. They care more about what is happening for them, then they like me more.
A: I see…
D: Basically self-absorbed ones.
A: So in your relationships it seems like you like to give and focus on the other person.
D: Rather than being self-absorbed.
A: Has this always been that way?
D: Pretty much yeah, I’m a giver.
A: Do you enjoy giving?
D: More than receiving. Well that’s not too good. You should be balanced and all that but you know, I’m working on it.

A: Ok… and lastly… if you were to tell someone who would really listen and would try to understand, how would you like to be treated by other people around you? If it was within your control to influence the way people see you, treat you, interact with you, what would you tell them?

D: Hmm! I don’t know. I don’t think I should be treated special. I’d like to be treated like everybody else.

A: Which is like?

D: I guess that’s bad (laughs).

A: That’s bad?

D: Yeah… people don’t treat each other good. Nobody wants to help everybody. But, I don’t think I should be treated special. You know… I have a mental disorder you know, that’s what I have to deal with.

A: Aha, yeah.

D: And me personally I treat each person on an individual basis. You know… I would spend the time to get to know somebody and then figure out what category of friend or acquaintance I should put them in.

A: Yeah. So you don’t want to put people in categories, you just want to experience a relationship with them and treat them individually.

D: Yeah! Um-hmm

A: They have different personalities and so treat them accordingly. And this is how you want to be treated. Versus as somebody who belongs to a category like mental illness. So don’t treat them based on membership to a category.

D: Yeah. They are people.

A: Well, I know I asked you a lot of questions. But is there something that you wanted to tell me or ask me?

D: Do you miss Greece?

A: I miss it. Yeah. Been away 9 years now.

D: Nine years! For School!

A: Yeah. School. But family will always be there. And home is where family is. The actual location… from climate to food to, everything is different.

D: So you don’t like the cold (smiles)

A: (Laughs) I don’t like the snow because I’m not used to it. 9 years now I should be used to it I am more used to it than when I first came, but it’s not the same as people who grew up with snow. I’m more used to heat.

D: Yeah so you can take the heat better than the cold.

A: Yes! I don’t mind the heat. It may be 110 degrees and people might be like oh my God and I would be like; it’s ok what happened it’s alright!

D: Laughs

A: So yeah! So here I am, I am so glad I got to meet with you today and I got to talk to you.

D: My pleasure. Thank you! No problem.
Shawn Transcript

A: Okay Shawn, so I want you to tell me a little bit about when did you first start receiving services, and what was happening then.
S: 1992 is when I started coming here.
A: Okay, and what was going on then?
S: Hmm, in 1992 it was summertime and I was having a good time and all of a sudden, like some symptoms came up and like I never had a symptom before!
A: Aw!
S: But some symptoms came up and I started feeling depressed, and basically I got depressed for a while, then I started feeling better after a while and was really on top of the world, and then my dad had me 302-ed.
A: Yeah, so he had you 302-ed because… what was happening?
S: He claims… well my dad passed away but when he was alive he said that I attacked my brother and he said that I drove his car fast. Now, how would he know if I’m driving his car fast if he is not in the car? Next thing I know you have the cops and they came to my room in my house so we got to take you to Western Psych.
A: So you didn’t attack your brother did he misunderstand?
S: Well, look we both, we wrestled around a little bit, you know, I didn’t attack him!
A: Yeah, your intent was not to harm him.
S: Right! What I’m saying is that my dad said all this stuff because… see I wasn’t on medication yet, you know, I hadn’t started taking medication, I hadn’t seen anyone yet. Except for, I did see one doctor, private doctor when I first started having problems, when I first started noticing symptoms, and he said to me “You will never be in a mental hospital! You are in good shape! And I liked that doctor I really did! I really liked that doctor but I could never see him again because my insurance did not cover services.
A: Oh I see.
S: Yeah, I really liked that doctor; he was a good doctor so basically all these months went by and I had my ups and downs and my dad 302-ed me and this was in 1992.
A: Okay.
S: Was here for 30 days or something and then I got out, and they diagnosed when I was in there my illness. Yeah, they were like “You have an illness”. So basically I got out, out of there in 30 days and then, I just did the normal thing, you know what I mean?
A: Yeah, yeah. So what was it like for you to experience those symptoms that you mentioned?
S: Well, I will ask you this. What is a psychotic episode what does that mean?
A: How do you understand it? Typically people experience voices, beliefs that are false…
S: Delusions
A: Are these some of the symptoms you were experiencing?
S: Yeah back then yeah.
A: How did you feel, experiencing those symptoms?
S: I was really depressed when this first started; see I almost thought that from drinking one night caused me to start having these symptoms. Here is what happened. I was doing my normal thing I was doing great, it was the summer of 1992 I mean my friends and I would go out to bars like 7 nights a week before I ever knew about my illness. We went out to bars a lot, like almost every night of the week, you know, having fun, it’s the summer, you know… and then just like, one day I was out the night before and I got pretty drunk, you know, I woke up and I was kind of hang over, and the weirdest thing happened. Like I had some strange, racing type of thoughts started happening. I was like what the hell is that, you know?

A: Hum! Do you remember what they (thoughts) were about?

S: No, so basically I mean I was like what the hell was going on! I called my friend and he said did you have a good time? I was like, um I’m not feeling so hot right now but when this happened I was like I felt like I might have lost my mind or something.

A: Yeah you felt like you were losing your mind

S: Because what I’m saying is I was having these weird type of thoughts.

A: That you never had before.

S: Right, right exactly! So eventually you know, it seems like when something like that happens it’s kind of chronic. Like it may stop for like 2 months, and it may come back. So finally I went and saw that doctor, the one I like, and I said to him, I don’t know what’s going on. I was out drinking the night before and I started having those symptoms and I think I ruined my brain; I messed up my brain by drinking. And he is like I’m going to tell you something, and you are going to feel better when I tell you this, you didn’t.

A: Yeah you didn’t mess up your brain. He is like, it’s hereditary. My mom has been sick for ever.

S: And my brother and I are both, we both got this, are sick we got illnesses from her.

A: Yeah

S: So I thought it was cause I drank that night, but you know what that doctor did say, that when I didn’t know what was wrong? He goes, you shouldn’t have drunk that night that you drunk because this would have never happened. But I don’t know if he was right or if he was just fooling around? You know what I mean? Because how can drinking a beer make you go crazy? (Laughs)

A: Yeah, if it’s hereditary.

S: Yeah, yeah, exactly! So the next meeting we had with him, that doctor, he wanted my dad to come visit. He wanted to ask my dad about my mother who doesn’t live with us who was always sick. So I guess bottom line was he trying to tell me that the drinking had nothing to do with you having symptoms, your mother had this illness and it was inherited.

A: Yeah, yeah. So I guess the illness expressed itself in 1992 and then, how has your life changed since the diagnosis, you know since you were diagnosed and treated, did your life change?
S: Not a lot, not really. See… I liked that first doctor because he’s telling me I will never have to be in a mental hospital and stuff like that. And here it is I’ve been in the mental hospital 3 times.
A: What was that experience like for you?
S: I hated it.
A: You hated it?
S: I hate the mental hospital. I hate it. I don’t want to be in the hospital ever again in my life right now.
A: Yeah, what do you hate about the actual hospital?
S: I hate just… It’s like you are wasting your life, you know, if you are stuck in the hospital, you know, you can’t get out and do things.
A: So there are many other things you could be doing, but instead you are locked in a hospital.
S: Yeah, I never want to go to the hospital again in my life.
A: Were there aspects of the hospital that first of all you didn’t like, or were helpful? I want to look at both sides.
S: The only helpful I would say is that they get you back on your medication. You know, they monitor you ok? But unhelpful, you are wasting your life, you are in there you can’t leave; I can’t stand being stuck on one floor forever.
A: So I guess you don’t have the autonomy to go and do whatever you want.
S: Right.
A: Yeah, so somehow would you say that you are restricted?
S: Yeah, definitely.
A: So the only positive thing is like you said getting you on the right medications.
S: Um-hmm
A: What’s your experience with the medications overall?
S: Honestly, I take them and they work but I don’t notice differences at all.
A: Hum. So I guess how do you know they work? Is it from what people tell you?
S: Well, it seems like when I am taking my medication all the time, I don’t have these fixations. You are thinking about something, and then you forget about it. That’s when you are on the meds.
A: Okay.
S: But you see sometimes when you are not on the meds you may be fixated or something or you might… what do you call that? What’s the word for it?
A: Seems like it’s almost like an obsession?
S: Yeah.
A: So you don’t have that anymore. Is that a good thing?
S: Yes, yes.
A: How do you see yourself, how compared to before you started experiencing those symptoms?
S: I’d honestly say that I’ve been doing great for like 6 years.
A: The past 6 years?
S: Um-hum.
A: Give me some examples to help me understand. You know, you feel like you are doing great, you know
S: See, there used to be some things that I’d be paranoid about, like with my eyes, when I was around a lot of people, I used to think people can look in my eyes and they would know my thoughts, and they would know that I might look that I’m depressed, you know. And now I don’t even think about that stuff anymore. And it used to be a big issue! I didn’t want to go amongst some other people because I thought that everyone was looking at me.

A: Um-hmm. But now you don’t have those thoughts.

S: Right.

A: How do others relate to you now, people who know that you are treated for an illness?

S: My friends you mean?

A: Yeah, friends, strangers, family. If you want to give me an idea about your interpersonal relationships, starting with family and friends?

S: Well, I don’t have much family left now. My brother, my cousin, her son and my oldest cousins. I used to have like 9 aunts, they all passed away.

A: Sorry to hear that. So how do they treat you, knowing that, you know you are going through an illness?

S: Well, my cousin really… she is a lawyer, I really don’t like the way she deals with me because like, she had me 302-ed.

A: Oh!

S: Twice.

A: What happened?

S: I wasn’t on my meds. See. What happened was, I was coming here, and there was a new doctor and I didn’t like this doctor, so I said I’m going to go see that private doctor I was telling you about, I wanted to go and see him instead, but I never was able to get an appointment, I didn’t take meds because I didn’t have any prescriptions, and I started getting sicker, sicker and sicker. And then she had me 302-ed.

A: Are you angry at her?

S: Yeah! She didn’t need to do that! I was trying to get a doctor.

A: Yeah.

S: It wasn’t like I wasn’t trying.

A: So you recognize the need to receive treatment, but the way she did that

S: Exactly! I didn’t like that. Not at all.

A: How did you feel then?

S: Oh, I was the worse because it was like forever that I was in those places.

A: Yeah.

S: And like I said, what that one doctor said “You will never be in a mental hospital”

A: And here you are.

S: I’ve been here 3 times. Never again do I want to be in a hospital. I felt horrible when she did that because there was nothing I could do but… I mean the copsuffed me and took me into a Paddy wagon. And I didn’t know what was going on.

A: And they cuffed you!

S: Well, all I have to say is my brother came into the house with a bunch of cops and my cousin, and the policeman says to me “You need to see a doctor”. And I had
the doctor’s number memorized, the other one, and on my cell-phone and I was like you think I need to see a doctor? I was like “I will call a doctor right now”, I start dialing and he cuffs me. And they took me down to the deck.

A: How did you feel when they cuffed you?
S: I was like, now I’m going to be in the hospital for a while here, this is the worst.
A: Yeah.
S: And then they took me to the deck and they sat there for hours and they talked, you know.
A: Was it frustrating for you?
S: Yeah! I never want anything like that again. I’ve seen people that are way, way, way, way worse than me. And they are not in the hospital. People are sicker, you know, and they still didn’t have to go to the hospital. And there is some people that are in here that seek treatment that were never in the hospital.
A: What does it mean to you being in the hospital?
S: Oh it’s the worst! I just hate it. It’s like, you could be out doing so much other stuff but you are stuck in like a floor, you know one floor of a place.
A: Yeah, yeah. What are some of the things that you wanted to do, if you weren’t stuck?
S: Buy a car, go on dates, go dancing, and do stuff like that.
A: Yeah, fun stuff that you couldn’t do when you were in the hospital.
S: You are married right?
A: Not yet. But what made you ask that?
S: I was just wondering. You can’t ask a woman her age so I can’t figure out what your age would be though.
A: I’m 29. I don’t mind you asking me.
S: Ah so is way younger than me actually.
A: So you said something about you cannot go on dates. I wonder why can’t you go on dates.
S: Because I was in the hospital.
A: Once you are out?
S: Once you are out yeah you can once you are out. But I need a car. You see I always had a car in the past but for a few years I haven’t had one now.
A: You haven’t had it because of financial reasons?
S: Yeah, well no at the moment, me and my brother owned our house that our dad used to own but he passed away in 2000.
A: Okay.
S: So, me and my brother were living in that house together after our dad passed on. Well, we just recently, a couple of years ago sold the house and we split the money each, in trust funds. So me and my brother each have some money, you know, that’s how ---- a car with that money.
A: I see. You said something about romantic relationships in general, what I wanted to ask is since you have been diagnosed have your romantic relationships been affected?
S: Well, honestly, I usually won’t tell them, unless I need to.
A: So you chose to hide it.
S: I mean, I tell them, listen I’m taking medication for a chemical imbalance in the brain.
A: So, I guess giving them the whole what’s going on then what would that do?
S: In my own mind?
A: Yeah, what’s holding you back from just saying, well, listen I have psychosis.
S: You gotta make sure that they are into you, what I’m saying is, you meet a girl right now and you tell her oh, I have psychosis you know, she might go the other way. But what I’m saying, you have to know these people, and then tell them, down the road.
A: Um-hmm. So I guess you are afraid that if you say it right away then they might discriminate against you based on your diagnosis, is that it?
S: Yeah, yeah, something like that.
A: Okay. Not see you for who you really are.
S: Right. Like, I’ve been told that I have a great personality.
A: I bet it’s true!
S: And like, I go to this bar every once in a while, and everyone in this bar loves me in there (laughs). It’s like Cheers. I’m like Norm.
A: Oh wow! So you feel accepted in that environment.
S: Yeah, like everyone thinks that I’m a nice guy, you know! Everyone knows about me.
A: Yeah! Have you had the experience where people with the knowledge that you have been in a mental hospital, you have a diagnosis treated you in a negative way? Have you had that happen to you?
S: Yes. May be once or twice. I mean, see this is a messed-up situation like … I got this friend, and he knows that I was in the hospital a couple of times. Basically when I met this girl, this girl is like really likes me and when I left the room for like a couple of minutes I hear him tell her. He takes antipsychotic pills.
A: Aw!
S: Yeah! He tried to ruin it for me.
A: So by saying that what is he doing?
S: He thought I didn’t hear because I was in the other room and he’s like “Shawn takes antipsychotic pills” and the girl is like “What is antipsychotic pills?” And he is like some medication for psychotic you know whatever and I walk in and I was like I confronted him but then I was like dude don’t tell people what I’m taking, and he’s like “It’s not a big deal:” But to me it is!
A: Sure!
S: This girl liked me until he said…
A: Yeah, and then her opinion was influenced by whatever preconceptions or stigma exist about the illness.
S: Right!... You said you are 29?
A: Yeah.
S: You know how old I am? Take a wild guess.
A: 38?
S: How did you know?
A: I didn’t know! (laughs)
S: That was good! You are psychic (laughs)
No I’m not psychic, but you look pretty young! To me.

Thank you!

So going back to what we were talking about, people seem to have this negative impression associated with the illness without knowing who you are. So once they hear that do you get the sense that they see you differently?

Very possibly. It’s almost like, say you are dating someone but you never told them you had an illness, and when they found out they might actually, you know, leave you!

Wow that must be hurtful.

This is another thing, I don’t understand this, but, I got this best friend from high-school, and we started hanging out when my illness started happening, like he was around me at that point, he’s like, what’s going on with you, he’s like, your clothes look different, you are not dressed up like you usually are. Basically, so finally I never told him that I was diagnosed with an illness, but we ended up not talking for a while. It’s almost like, he got rid of me because he found out I had this illness.

Wow.

But I run into him downtown a couple of times and we exchanged numbers. We haven’t been able to meet up yet, but the last thing I heard from … this kind of made me feel good though. My birthday was August 3rd, his birthday was August 4th. We were best friends, but not anymore, but when we were best friends, well he left me a message on my cell-phone “happy birthday” on my birthday.

That was nice!

Yeah! So that means that he is still thinking about me. But I thought he totally forgot about me, you know. But if he sent me a birthday thing …

Yeah, he thought about you.

Well, he is married too, that’s the thing. So that’s probably why he can’t go out anymore. We were tight. We were tight in high-school and after high-school.

And you also thought that maybe finding out about your illness maybe that was a factor that contributed to his decision to not talk to you.

Right, right, right exactly.

How does it feel to have people who don’t understand and label you?

Not good.

Not good.

Oh, I hate that … you know, like, if you meet me, you know, you don’t know me and meet me, not knowing that I have any type of illness, you know what I mean … what was your question again?

I guess when people don’t know about what’s going one and they might attach a stigma or you know prejudice against you based on the illness rather than who you are as a person, you know.

Here is the thing, you know I said this bar everyone likes me down there, I’m almost positive they don’t know about my illness. I’m wondering if they’d still like me if they found out.

Hmm yeah.
S: I’m sure they would, I’d like to think they would but that would just shock them a little bit. You know what I mean.
A: Yeah, yeah. Do you see yourself any different now that …
S: From what? From when I first started dealing with the illness in 1992?
A: Yeah. How do you see yourself?
S: You know, this is messed up, but when that happened, that 1992 thing, I was going to Pitt. But if I would have went back and re-did that … you know I said that I went to IUP, you know why I left? Because the whole time I was there in Indianapolis they were telling me, yes, you can go to the main campus of Purdue or Indiana after one semester from here “So that’s what I wanted to do”. So I was in this woman’s office every day making sure I’m definitely going up there right after a semester. And she was like “Yes, yes, yes” finally I came home for the holiday for Christmas from Indianapolis commuting to Pittsburgh and there was a letter for me in the mail. So I open it up and it’s from IUP says “Sorry, you cannot go to the main campus here because you did not complete enough credits”. And I’m like, what should I do now, you know? I’m going to leave IUP. Now I was I should have stayed there, I might have gotten a great degree from Purdue or IU, but instead I was like I’m going to leave I’m going to Pitt. So I drove back to Pittsburgh, tried to sign up for Pitt for next semester, it had already started you could not … and I had this buddy of mine from high-school and I asked him where are you going to school? He was like I’m going to Penn State McKeesport. I was like did you start yet? He said no. And he said give them a call. So I give them a call saying I need to go back to school here, Pitt has already started. They are like “We can put you in here as a provisional student”. Ever hear of something like that?
A: Yeah, provisional I’ve heard of it.
S: Yeah, so I was like alright. So I ended up starting to go there taking a lot of credits like 15 credits, and I had a buddy who was there, basically I got like a 2.5 GPA, but I didn’t want to stay there Penn State McKeesport and then go to main Penn State, I wanted to go to Pitt immediately. So like I said I started at IUP, switched over to Penn State McKeesport, from Penn State switched over to Pitt. Then, like I said when I was in Pitt, I started having the symptoms.
A: I see. So I guess do you feel that switching places has contributed to your illness?
S: No, no that’s before the illness.
A: Aw, that’s before the illness! So I guess you had these, you know goals and aspirations to get a degree but then those goals were not met because you got the illness.
S: Right.
A: Okay, I see, now I understand.
S: And now, I don’t even want to go back to school right now. I get that money from the house. Me and my brother got a lot of money from the house so
A: Yeah. So how is your life now?
S: Good. I mean, I keep myself busy. I go online I look at cars … I’m trying to buy a car real soon here. I look at cars, I go online, I get something to eat, I go to the bank, chill out, you know.
A: Well that’s good! Well Shawn unfortunately our time is up, but thank you very much for talking with me today.
S: Sure!
Jack Transcript

A: Ok. So basically I have a few questions and feel free to elaborate as much as you want. The first question that I have for you is… I wanted to know for how long you have been receiving services.

J: Ah (sign) how long? Back in 2005 when I was first diagnosed. When first things started to happen.

A: How old were you then?

J: Let’s see… I am 28 now, so I’d say…

A: 23-24?

J: Yeah around that age.

A: What was happening then?

J: Well, like at the time I used to isolate myself. You know, didn’t really go out as much and then… you know… like for days I didn’t really go out as much, I was just pretty much stayed in watch TV or play videogames and… I still went to work and, at the time when I had a job, like back in 2005. I still went to work and everything like that, but after I got done with work I just pretty much went back to the same routine and I just isolated myself not really going out as much…

A: This way you stopped working or did you just started isolating after you stopped working?

J: Actually when I was working I was still isolating myself. Like I said I’m still working but after I got done with work, you know, I moved right back to isolating myself and stuff like that.

A: Um-hmm... And after a while, was doing that… um I kind of had a kind of episode where I pretty much was just out of it, you know.

A: Hmm!

J: And it kind of took me by surprise because I didn’t know what was going on, you know.

A: Yeah… you didn’t know what was happening to you.

J: Yeah. Yeah so, when all this was happening I was living down in Atlanta.

A: Oh ok. Living alone or with family?

J: I was staying with relatives at the time.

A: Ok.

J: So, when all of this was happening like I said, it took me by surprise I really didn’t know what was going on.

A: Yeah.

J: And… like, whatever it was happening it was like I was seeing, seeing things like seeing certain shadows moving in… like if I had the TV on, for example, it seemed like it was pretty much talking to me or…

A: Taking it personally.

J: Yeah… right. Like talking to me or saying things about me and stuff like that.

A: That was something new, you never had that before.

J: Oh yeah.

A: Yeah! I understand why you were surprised.
J: Yeah. And at the time… my mom at the time… she was pretty much, she was kind of worried because she had never seen me like that before.
A: Did you tell her what was happening to you?
J: I explained in a way but couldn’t really give them like the full details of it because I didn’t know what was going on myself.
A: Yeah.
J: But… she pretty much called the hospital to put me in a place called X hospital it’s almost like X hospital, so they can see what was going on like, you know, pretty much just to do a check up to see what was going on wrong with me. And I was in there for about; I’d say about 2 weeks I was in there and…
A: What was that experience like for you?
J: It wasn’t all that good (anxious laughter)
A: Um-hmm.
J: I mean, I don’t know, like to me, in my experience it seemed like the staff didn’t care about the people there, and, some staff members just had like a nasty attitude and, they really didn’t keep the place clean like didn’t keep the place cleaned up or anything like that… So I don’t know…it was something about that place. It was just… I don’t know.
A: So the attitude, they just didn’t seem to care.
J: Well, yeah to me it just seemed like they didn’t care at all so… like there was people who actually needed help and they just like they were like whatever with them, so…
A: Did you get the sense that they looked down on you?
J: Umm… not at the time you know. It didn’t really cross my mind you know but the whole experience there, like, I didn’t like it.
A: It was kind of negative because people didn’t seem to care.
J: And plus when I was up in there I didn’t really know when I was going to get out and how everything was going on in there. I didn’t like the place at all and it’s just I wanted to pretty much get out of there because, like I said if like the staff members are nasty to the patients it was just… not all of them, some of them. Some staff members were okay but the majority of them had like a nasty attitude.
A: Ok so you didn’t like the attitude of the staff and those 2 weeks it made your experience not be positive.
J: Yeah. I think… let’s see, yeah I think I have yeah I ended up in that place twice but then I had another episode…
A: Did they explain to you what was happening then? I know that you went in and you didn’t know what was happening.
J: Well they explained to me that I suffered from depression and schizophrenia. Even all the way back because at the time, before I moved to Atlanta my mom passed and I probably at the time when it happened, when she passed I was probably in the depressed mood then but I wasn’t really aware of it so I just, I went about the day and just doing whatever, not really being aware that I was depressed or anything like that so… like over time it pretty much just caught up with me so…
A: So you had some stressors then at the time, like mother passing
J: Yeah… so… I’m trying to see (thinking) and I went there twice. When I got out the first time there I’m trying to see how long it was, I don’t know if it was like a couple of months before I went back again or if it was like a couple of weeks… it’s kind of blurry so I can’t really give you like the exact, like the proper time when I went back the second time so…

A: Okay, yeah.

J: Like I said it could have been like a couple of weeks or a couple of months.

A: So then what happened, you had another break similar to the first one and then you had to go in again?

J: Yeah… yeah. The second time I went in was pretty much like the first time, like I said earlier… staff members really didn’t…they didn’t care or anything like this so

A: Yeah.

J: So that experience right there was just… I didn’t like it at all.

A: Yeah, yeah.

J: I didn’t like it one bit (looks angry). And, after I got out of there the second time I was, you know, I did pretty well, was taking medication, was pretty much taking that on a regular basis… And I’m trying to remember… I think it was Lexapro and Risperdal?

A: Yeah

J: And some other drug… I can’t really remember what it was.

A: What was your experience with, you know taking those medications?

J: Well, I was taking them at the time and I was still working, and when I was taking them I was taking them, I think, during the day and at night and the side effects was pretty much, was like… I can’t remember how many milligrams it was, but the side-effects pretty much had me drowsy to a point where I couldn’t really do anything.

A: Oh wow!

J: It was like once I take it, I’d be ok like for 20 or 40 minutes, but then once it kicks in it’s just like I had to lay down because the side effects would hit me so hard that I’d just feel like someone pretty much someone hit you with a tranquilizer dart and it’s just like your body just start shutting down, like the only thing you wanna do is just like go lay down so it will wear it off. And at the time I was taking it and I was working at the same time, but it would start to affect my work because like I said I couldn’t do anything.

A: Yeah you were so drowsy yeah!

J: Yeah, and so I stopped messing with it because I didn’t like the side effects and, you know, how it was making me feel pretty much during the day.

A: So did you stop taking it?

J: Yeah, I pretty much stopped taking it and… I had to because you know I had to go to work and, you know, do the job and everything.

A: Um-hum!

J: And with me being on the medication, that pretty much slowed me down because like I said I couldn’t really get anything done. It was taking an effect on my whole body and everything.

A: Yeah.
J: So I stopped taking that medication for a while. Even though they kept prescribing me it I still didn’t take it, I didn’t take it at all.

A: To avoid the side effects

J: Yeah, just to pretty much avoid the side effects. I really didn’t... You know, I really didn’t want to like lower the doses because it was my first time taking medication and I didn’t really want to go to the Doctor so he can lower the doses because I didn’t know if the same things were to happen again, you know. I lowered the doses so I pretty much stopped messing with the medication for a while.

A: Do you think despite the side effects and the drowsiness there was a purpose to taking it? Did you see it yourself, I mean you were told different things, did you see... was there anything positive about it? I know you mentioned some symptoms like the shadows and the hallucinations and things like that.

J: (Laughs) hmm… medication did stop (his phone rang) I’ll have them call me back. But hmm…

A: So yeah we are talking about the meds and you had this drowsiness and all this negative stuff.

J: Yeah

A: But was there a positive to it?

J: Yeah, well like I said, the medication did stop you know seeing things and hearing voices and stuff like that, and you know... just like the feeling of not having control over my body is just like... you want to get up and do certain things, but it stays in your system for so long. It’s like you are still having the after effects of it, and you know, with me it was just like I was just laying in bed all the time and I was just always drowsy because I was taking it during the day and also taking it at night so...

A: Okay. Yeah... so it was as if you didn’t have control over your body, so if your body wants to go to bed and you feel sleepy, you want to do something else, but it’s as if you can’t do it because you are feeling drowsy.

J: Yeah, ‘cause I was just feeling tired all the time, and I’m trying to go to work... but even if you just want to go out it’s like you don’t want to do that because the Doctors were telling me to take the meds in the morning and take them at night, and with the side-effects and everything you are just so tired and always just drowsy all the time. It’s just becoming too much. So I was like, I would just stop taking it.

A: You stopped taking it but then were you ok or did the voices come back?

J: You know I was just doing ok... you know... I was doing okay for a while. I was pretty much doing stuff to get myself occupied and pretty much find ways to distract myself.

A: Um-hmm

J: And so, ok and on top of that I forgot to mention

A: Yeah

J: That, you know, back then, I was also smoking marijuana back then and so that also kind of triggered with the depression and all that and having episodes and that kind of triggered it also, and you know... I don’t mess with it anymore because just for that purpose it can trigger something.
A: So smoking might have triggered some of the symptoms that you were trying to suppress by taking the meds.

J: Yeah, so…

A: I see.

J: You know, so altogether I stopped smoking marijuana so I don’t even touch the stuff anymore.

A: Um-hmm. Right now have you found something like the medication that doesn’t have those side effects?

J: Well, the medication that I am on now is not like… they lowered the doses and everything. So the medication I’m taking now is pretty much, it is a lot better than the medication I used to take back in the past when I used to live in Atlanta, so

A: Do you remember what you are taking?

J: It’s Risperdal and Trazodone.

A: Okay. Do those work better for you?

J: Well they do work better compared to what I used to take back in the past so, I can say that… and let’s see… When I lived in Atlanta, I decided to come back here to pretty much finish up school. And when I moved back up here, you know, I was staying with relatives because I was going back to school pretty much to finish up to get my Associates degree and pretty much staying with them and I kind of had, I had another episode but this time it didn’t involve any drugs or anything like that. And this one really kind of just took me by surprise because the other 2 times, back in the past when I was in Atlanta it was pretty much kind of dealt with, you know, like doing drugs at the time, so those 2 times there kind of triggered the episodes back then, and, this time when I moved back here (Pittsburgh) and I had the episode, I wasn’t taking anything, so I don’t know if I was… I could have been like really stressed out or something but didn’t really pinpoint what it was and I just…

A: So maybe stress could have triggered it.

J: Yeah, so it could have been stress that triggered it.

A: Um-hum yeah.

J: Which pretty much just landed me back to Western Psych… and I was up in there for a couple of weeks. And I couldn’t say the experience of X hospital was going to be better compared to X hospital. At least with the staff there was actually there to help, you know, they actually had a concern for the patients there so

A: Oh that’s interesting. So you felt like they cared, like they just wouldn’t ignore you like the people in Atlanta.

J: Yeah. Like to me I’ve seen a big difference so…

A: Yeah, you want to be taken seriously!

J: Yeah. So the experience there was different from compared to X hospital. And I was up in there for like I said for like 2 weeks and pretty much the medication they had me on, but after I got our they had me on pretty much the same that I’m on now except for I’m not taking any Effexor.

A: Yeah.
J: You know Effexor XR. I’m not taking any antidepressants, you know, this time around so…

A: The staff is treating you better, what’s the response of people, how did you perceive people’s attitudes towards you, especially people who know that you have been receiving treatment that there is something going on?

J: Hmm… well, at first you know, they didn’t like it because the depression thing, I really didn’t like talking about it because I didn’t know if I told certain people they would take advantage you know… take advantage of me for having a certain condition, or even to a point even trying to poke fun at me because I have like a mental disease so

A: Yeah

J: You know, so in the beginning they did kind of bother me to an extent.

A: Did you have people who were… who maybe who took it lightly or made fun of you or say things to you?

J: Well… I haven’t experienced anything like that but, it’s always at the back of my mind, you know, I really don’t want to tell this person that I have such and such disease, you know, because they may feel a certain way or they may feel uncomfortable, you know, to know that I have a mental disease or something like that so… knowing me I just really don’t bring it up until I feel like, 100% comfortable with that person that, you know, that they know me well enough and then I might bring it up. But, even then, it is kind of hard for me to bring it up so… I mean, as it goes for my family I mean, they pretty much, you know… have been supportive you know, I mean they see me with the condition and they pretty much just wanna know, you know, what it is that makes, what triggers the depression and everything so they can pretty much understand it better so, you know, so that they know what’s going on so

A: Yeah, so you feel like they are making an effort to understand?

J: Yeah! Yeah. Which is a good thing, I mean. To me I just… even though they do understand, I still don’t like talking about it sometimes, you know… bringing up my condition and stuff like that.

A: How do you feel when you do

J: Ah some days when, you know, when I do talk about it, I can talk about it for a minute and it doesn’t bother me but, the longer I talk about it I don’t want to talk about it anymore because, it just feels, I don’t know it just feels like I just break up all the bad memories and start re-living certain things you know how I started and everything like that, you know. When I had my first episode and I didn’t know what was going on and stuff like that so…

A: Yeah, it’s unpleasant, usually people you know they don’t want to remember bad things and re-live bad experiences.

J: You know, I started thinking about what would happen if; you know if this never happened will the scenario would have played out differently if I never… if you know, the episode never really happened to me, you know, so I never got taken to the X hospital twice and you know moving here and not having a third episode and ended up in X hospital, so… I mean I know stuff happens for a reason but… you know sometimes it just, to me it just feels like you know… I just wish this never… some days I just wish that it never happened… you know.
A: Do you sometimes wonder, I guess how your life would have been if it didn’t happen?
J: Yeah.
A: If you were to imagine retrospectively… I mean it’s harder to do, but looking back if it didn’t happen what would you be doing?
J: Yeah… looking back sometimes I just, if all this stuff didn’t happen, I just you always have it at the back of your mind just what if… just what if it never happened
A: Um-hmm.
J: You know when things turn out to be different… It went down a different path, you know.
A: In terms of looking at the future then, did you have plans then, and now you have different plans, or did it change your outlook on the future?
J: Hmm… well, I wouldn’t say it changed the outlook that much I mean, you know, I mean even though I still went back to school and finished and got my Associates degree. Even though I had a condition at the time so… I pushed myself to go back to school so I finished that so
A: Oh good!
J: Having a mental illness, I mean, you wanna do certain things, it just feels like… you push yourself and you wanna do certain things and you want to keep going and you wanna push yourself and… I don’t know well to me in my experience it feels like sometimes a mental disease it just feels like it’s just holding you back because… It feels like it’s holding you back and, like I said you want to do things, you know and you know pretty much live your life but it’s kind of hard because… you have his condition you are living with and you are trying to balance it out as best as you can and… I mean don’t get me wrong, some days are better than others.
A: Yeah
J: But, I’d rather have more better days than having low days, like, you know yeah I wanna do this… like, one minute you make plans, yeah I’m going to do this and do that but when the next day comes around, you don’t feel like doing it you keep trying to push yourself to go and go and go. But you know you just keep pulling back like ok I don’t wanna go.
A: Yeah. It gets in the way of your motivation?
J: Yeah, you do. You really do. And to an extent you just get, you know you just get tired of it. You just kind of want it to go away. But… I don’t know. It can be time consuming sometimes… it can be
A: Does it affect the way you see yourself? I know it affects your motivation, but if you were to compare the way you saw yourself before all this happened compared to how you see yourself, has this diagnosis or illness affected the way you see yourself? Your self-image?
J: Well… I wouldn’t say it affected my self-image or anything like that. I see myself still as having goals, you know, and stuff like that and reaching them, you know. What I push myself to do, but like I said, you know, what might happen is this illness is kind of hard sometimes because it feels like it’s getting in the way. Like, not being motivated, you know, do different things to expand
your horizon but, it sometimes just gets in the way. And I don’t know it’s just pushing yourself to do certain things and some things it’s just hard to sometimes.

A: Um-hum

J: And even though, you know, I try my best to get myself out of that mood, but it seems like at the end of the day it’s still there it’s still lingering, you know, you know, but I’m not giving up you know I can’t (anxious laughter). I don’t want to give up, I want to beat this. So… I mean over the years I have seen some improvements. Like, I’m a little bit more active. Like now, I be going out more; you know keeping myself occupied going to the gym or hanging out with family members.

A: So you are doing something different.

J: Yeah

A: Do you find this helpful?

J: It helps. You know just getting out. You know, just to get your mind off– of certain things, you know, try not to think about your illness as much and you know just trying to stay as positive as much as possible, try not to let all those negative thoughts get in. Because once that happens, it can become too overwhelming.

A: Yeah. Like what kind of negative thoughts do you have sometimes?

J: Hmm… I would say that living up to my expectations and not really seeing myself where I wanna be. Like, I mean I know the stage I am at right now could get a lot worse, but I feel like I should be, you know a little bit more further along than I am now and sometimes it goes back to like what if but you know. Just you know, did things a little bit differently, you know, or, what if I never really I never got this condition, maybe I would have been a little further along than I am now.

A: Further along in terms of…

J: Hmm… you know, I’d say career and even you know, living situations, I mean even though I stay, though I have an apartment now, you know, I am just at the stage you know at the stage where you know… It’s like I want more. Like the apartment I have now it’s ok but, you know, I could have been in a little bit better spot than I am now. If I was stuck with… like keeping a steady job but… having a condition like I have now kind of been getting in the way because, you know, there is a part of me that wants the job that wants to have a job but, like I said this condition kind of was holding me back because what if I have an episode during work and my schizophrenia or depression interfere with my work, you know

A: Yeah. So you are afraid that if you do have an episode it might interfere with work given that you cannot control when you have the episodes or not, sometimes it just happens.

J: Yeah, you know so…

A: I see. And you know in terms of the interpersonal and relational dimension I think you mentioned about your family being there for you for the most part. What about outsiders, you know either friends or people you encounter? How
do you perceive their attitudes towards you? Does that get in the way of feeling positively about yourself?

J: Well… let’s see. In a way I’d say I don’t know how people feel about me… It really doesn’t bother me that much. I pretty much just keep to myself, you know I try not to let what other people think about me get in the way, so

A: So when they don’t know you

J: Yeah, it’s just like I’m more concerned about people who do know me you know, I am more concerned about people who know me.

A: And feel like they care about you, their opinion matters more?

J: Yeah, if it’s somebody I don’t know it’s like why should I care I don’t know you at all like that so

A: So for the most part you don’t like to let that affect you and people’s opinions, negative opinions especially it doesn’t get in the way.

J: No.

A: In receiving treatment I’m sure you came in touch with other individuals who either have something similar or different, other patients, what was that experience like for you? I know you talked about the relationship with staff members but you came in touch with other people too what was that like for you?

J: Umm… other people may have similar symptoms like I have but really I haven’t really experienced anything bad with them. You know the roommate they used to have me with, they have no problem with you, they pretty much got along with you, you know. We talked a couple of times, but they pretty much went on about their own business. So I couldn’t say I had any bad experiences with them.

A: So how did it feel like encountering somebody who is going through a similar situation?

J: It kind of made me see like what they go through, you know, and it made me see that I’m not the only one that actually goes through this type of stuff and that there are other people out there who, like, have similar symptoms like mine and pretty much go through the same stuff I go through on a daily basis.

A: So you are not alone in what you are experiencing.

J: Yeah. It was helpful to learn and to see other people, like what they do, and how they cope with their illness and stuff like that.

A: I see! So you learned how others deal with the same illness.

J: Yeah. And to see if they have advice because they probably been dealing with the illness much longer than I have and they gave advice, you know, some helpful tips to pretty much cope with it, and deal with it better.

A: Yeah! Do you remember specifically what you were told?

J: Hmm, I can’t think of it right now (laughs).

A: Ok! I’m asking you to go back (laughs).

J: Yeah (laughs)

A: You did a fine job talking about your experience from when it happened until now so you are really helping understand what you went through. People give advice! What kind of advice if you were to give somebody advice who don’t
know, who have not experienced the same illness like you do. What kind of feedback would you give if you had the chance?

J: Hmm. The advice I would give someone would probably be to just hang in there and not give up! Just take it one day at a time, I mean, eventually over time it will get better.

A: Um-hum

J: Just stay positive as much as possible.

A: Um-hmm, yeah, and that comes from your experience and you were saying that even though you have been dealing with this illness, with negative medication side effects for a while now, you persevered, you were able to achieve some of your career goals, you got your Associate’s degree and you are moving on.

J: Yeah.

A: If you had to say something to people who never had that experience of having to deal with mental illness what would you say about treating people who do have it what would you say to them?

J: Hmm. What would I say… for people who don’t understand it, you know, just do research about it so that they can better understand it? I mean it is a chemical imbalance. And I mean, try to put yourself in their shoes because it can happen to them!

A: Yeah, nobody is immune to it

J: Yeah.

A: So because they judge they should try to empathize.

J: Yeah.

A: And imagine how it would be like if it happened to them? I know I asked you a lot of questions, I don’t know if you have any questions for me or any comments?

J: How long have you been doing this?

A: Oh this study?

J: Yeah the study.

A: I got started in July and I’m really interested in learning and understanding from your point of view what is happening, how have you dealt with it, how you look at yourself, how you understand how other people see you and unless you ask the individual who is dealing with this illness you can assume all you want, that’s my perspective. But yeah, I really appreciate you meeting with me today and sharing your experience.

J: Yeah! You are welcome!

A: You are really contributing to the knowledge of people who do want to understand. Like you said, do some research. Well some people are going to do research to get an understanding of your accounts and educate themselves better.

J: Yes.

A: So that’s my main goal and I am very grateful for having you talk to me today.

J: No problem!
Beatrice Transcript

A: Thank you so much for meeting with me today. Are you coming from your support group?
B: No, I am coming from work, and going back to work.
A: I see! Do you work downtown?
B: Well, out of this building we have an office on the 7th floor but they recently moved us over to the X building in X location where there is another outpatient clinic from X hospital. And my supervisor’s office is over there so we have a meeting every morning so that’s where I was coming from.
A: Oh I see! So are you going back there after this?
B: I am going to pick up a client, then take him to have a flu shot and then bring him back here to see Dr. C this afternoon.
A: Oh! Alright! Well, let’s see. I wanted to take you back.
B: Um-hmm
A: And I wanted to know what your experience as a patient was, when did you first started receiving treatment and what was happening then.
B: Well, that would have been in 1990. Before then I had a brief episode of Depression. In the 1980’s when I was around 17 or 18 I was away from home, I had joined the military and it was behind some guy that I thought I was infatuated with, you know but, turned out wrong, and I attempted suicide by taking some pills. So that was the first time that I was ever… something was wrong; but, the first time I was admitted was in 1990. I was depressed, I was suicidal, I was having a lot of distress at home. My husband and I… he was sort of, not communicating well and my children were little and I know I was depressed at work I was being harassed by some people there and everything. So I felt like I had nowhere to turn so I started writing a suicide note one day, you know… I walked off the job, and then I went to see a psychiatrist and didn’t feel like I was getting any help there. So she asked me do I want to take some medicines. I said ok and I took that, but I didn’t feel I was getting any help, I felt she was just waiting for my benefits, to run out, my short-term disability.
A: Huh!
B: I just felt like I wasn’t getting any help, and so I told my husband what I was going to do. You know, that I wanted to commit suicide and stuff so that’s when the first time I went to the hospital. I went to X hospital and I stayed, they evaluated me and everything and they said it was Major Depression and Psychosis because I was very religious, I didn’t have a good relationship with God I thought… the way I was seeing Him was more like He was punishing me because my husband was a minister and we weren’t getting along and I wasn’t getting along in church and everything and I just felt “out there”.
A: That God abandoned you.
B: And we went to a new church and he is very spiritual and he said he could hear from God and I wanted to hear from God and I felt like God was speaking to me while I was in the hospital.
A: Mm hmm!
B: It was coming from the light though (laughs). If I concentrated on the light I could hear what he was saying but it was more like an internal conversation like, “Don’t let this happen again” and “I am here with you” and things like that and, but they just said I was psychotic and so, I went for years going to outpatient, talking with the psychiatrist and the therapist and just going and talking, taking medicine, talking taking medicine, going to outpatient… and every other year I would have another break and I’d go back to the hospital. Because nothing was being done. I wasn’t given any kind of activities to do. It was like, I was going to just be this way it seemed like… I would ask whether I’d have to stay on medicine for the rest of my life and he was like, yes because if you don’t it’s going to just get worse and worse, you know.

A: Oh – wow!

B: And he didn’t give me any positive outlook about how things would turn out or anything. And I stayed with them for a long time. About, from 1990 until 2001 I think. And then my husband changed insurance so I went with another outpatient/private psychiatrist, and I went to the X Pastoral Institute for therapy, and I went there, and in the meantime I was still working like a full-time job and she (Dr.) asked me had I considered disability, and I said no, they probably wouldn’t give it to me. I don’t know why I thought they wouldn’t, I’ve been in the hospital just about every other year, you know.

A: Yeah.

B: But I’d always bounce right back and say I’m going right back to work after my 6 weeks or 2 weeks. Sometimes it was right after I’d get out of the hospital, a couple of weeks I’d go back to work and I was doing a stressful job like customer service.

A: Yeah. It sounds like a stressful environment!

B: Yeah, yeah. I left the other job where I was feeling harassed, I didn’t go back after my first hospitalization, but I went to work for an insurance company. At first it was nice, it was paying claims and it was ok and everything, and then, they got bought out by United Healthcare and it got really stressful. They put us on the funds and we had to be on the funds and pay claims at the same time and we had to do production and kept raising the standards for if you get a raise. It was really stressful.

A: Sounds like a lot of work.

B: Yeah, the work was very stressful. The people were nice but work was stressful. And at home was just getting worse… my daughter, my one daughter got pregnant when she was 16 and that didn’t work out well… Well it worked out well now, she kept the baby. But it was stressful. And then my other daughter decided she was homosexual and so, all this from a minister’s family was really not good.

A: Yeah, yeah.

B: But we survived it and, I came here, again my husband changed insurance from when I was going to the Pittsburgh Pastoral Institute I decided I was off from work, my job closed and then, when my unemployment run out and I needed to get work, I wasn’t looking forward to going on interviews, I was constantly depressed and everything and then I had another break, and that’s when Western
Psych got involved. My husband said take her to the nearest… we went to Western Psych and they didn’t cover my insurance. I went to X hospital and that was horrific over there that was horrible.

A: What was horrible there?
B: Well, the people, they treated me not very good. They always insinuated that I wasn’t getting help I was coming there like, and it seemed like that, I didn’t take vacation. It seemed like I was coming there as a vacation to get away from things and stuff. And I couldn’t remember a lot of people’s names. I guess they (the staff) thought that I was treating them like they were waiting on me or something… I dunno. I just couldn’t remember their names and I remember one time they switched their name tags and I would say, such and such, and they say oh no no that’s her. And you know just different things. They put me in this room with this person who was actively really psychotic and she would do things like throw my towels on the floor when I went to the bathroom, the room was really dirty.

A: This was another patient?
B: Yes, this was another patient that was my room-mate at X hospital. And… um… just different things, you know, that they would do. But I got home from there, and each time I never wanted to go back to the hospital, you know… but, I wasn’t doing anything, really, to prevent from going. And someone told me, well you should get an ICM (Intensive Case Manager) you know, and I said what’s that, you know and the next time I had to go to the hospital was in 2003.

A: Mm hmm, ok.
B: And my husband had switch insurance and I came to X hospital. And at first they put me on the inpatient floor with schizophrenics. It was very crazy, I just cried non-stop, you know. I was paranoid, too, at the time and I thought that everybody was going to kill me in there and I would just stay in my room. I wouldn’t eat, I wouldn’t take medicine, and I wouldn’t do anything. Then they changed me to this floor that they just opened called the TRU Unit which was on the 5th floor. And it was very nice, they had groups that you would go to, all floors had groups, but this one was much nicer. You know, they had Psych social groups and they had. It was like a little hotel almost (laughs). It was a brand new ward that they were opening and it was just great.

A: How was staff treating you?
B: Oh, they were very nice. They would talk to you, whereas when I was on the Inpatient Schizophrenia floor, I went to ask the nurse something, but they just give you the cold shoulder, they wouldn’t even acknowledge that you were talking.

A: Oh wow!
B: But this, they were very nice there. And I was still very sick and I still didn’t respond to therapy and when I finished there they sent me to IOP (Intensive Outpatient women’s training) and, I had to go there for, I think it was 8 weeks or so was during the day I got home at night and I learned DBT training. I learned a little bit about DBT.

A: Was that helpful?
B: Um, it was a little helpful. I liked the part about being able to assert yourself standing up for yourself, getting yourself I think it was Yes Sir was the acronym for it Yes man or something.

A: Yeah!

B: Yes! And you had to just say… when I was home I realized I was doing it with my husband. He is always accusing me you did this and you did that you are doing everything, and I says no? That’s not what happens and then I would re-assert myself. I would say it over again, and he would say “you have an answer for everything”! (Laugh) And I never thought I do like that.

A: Yes you do!

B: So… It was good though, but still I went back to the hospital after then… I got sick.

A: What happened?

B: I was going to, this is when I first started going to X hospital, and I decided I wanted to work full-time again. At first I was working part-time. I got a job at a hospital in Medical records, then I was working part-time and I decided I want to work full-time because my husband was always pressuring me about the money and everything like that so I decided that I wasn’t helping enough and I was going to work full-time. And I run out of my medicine I remember and I was trying to hold on until my next appointment which was in a few weeks but I started getting really paranoid I went downhill pretty fast, I lost like 20 pounds.

A: Oh wow!

B: I started feeling that people at the job were out to get me, and in fact they did sabotage, or I thought they did. I open a closet and all these files fell down on my head and, you know just different things. I thought I wrote something on the lay sheet and I came back and it wasn’t there, and I was hallucinating and all kinds of things.

A: Do you think those things were happening?

B: No… I think I was sick. I think some of them didn’t want me there that’s true because Kate asked me why didn’t I get hired in X location why didn’t I get a job there and that was closer and stuff and I said well I tried but they weren’t hiring and they were supposed to be training me for a certain job, but they were only showing me little things about the job, and I felt like the supervisor was leaving it up to the workers to handle things and I just… maybe a little bit of it was somewhat true, but the majority of it was always getting sicker and sicker ‘cos that’s when I… what’s the boy that’s into witchcraft? The little boy?

A: Harry Potter?

B: (laughs) Yeah that’s when that was out, and I was like this person is in witchcraft and everything was spiritual… I know when I am getting sick when I used to get sick because I used to concentrate on that all the time.

A: So looking back, now that you are feeling better, how do you see yourself then? Do you think that those were delusions?

B: Yeah, I had a lot of hallucinations and a lot of delusions when I was in the hospital that last time.

B: In ’04 I would see things that look like they were dead people walking when I was in the hospital, I thought people were reading my thoughts, you know, that they
could read my thoughts, and I could hear what they were saying about me and I thought they knew my medical record, they knew all about me you know, so I just decided to stay to myself, I clamed up I didn’t say anything and I started not letting things bother me as they used to, I just wanted to concentrate on what I knew was true in my faith and I prayed a lot when I was in the hospital, and I just sang to myself. Then I did a lot of bizarre things like, try to follow this one lady I thought she was a Christian and she was leading other people to Christ, and then be discharged I wanted to be like them and they were doing speed walking or something up and down the hall and I was doing that, and it was truly bizarre in the last time I was in there was Christmas and New Year of 04 and that was a bizarre visit and everything.

A: So looking back you realize that those behaviors didn’t make sense.
B: No, they didn’t.
A: At the time they did.
B: Yeah, at the time they felt real real and, the last time I thought I was dying, I thought I was going to hell, I thought that the people there were evil, and they wanted me to be… it was really bizarre and I got committed to… because I wouldn’t go and stopped taking my medicines and everything, and I got committed to an outpatient program here downstairs on the 3rd floor as a condition of my discharge that they had me go through an outpatient program.

A: How was that?
B: It was good. There were classes on depression, there were classes on I think it was self-esteem. There were a lot of different classes.
A: Educational stuff!
B: Mm hmm and I heard that it was even better upstairs on the 6th floor here they have a lot of psych rehab groups and everything. So when I finished the program downstairs I asked “can I go to the program upstairs?” and they said sure! Like that. So I came up there and went through the program to groups, you know, met some people and I think that was the best help I ever got. Because before, I would just go to the hospital, go back to work on the outside, and come back to the hospital, go back to work. But here, I was out of work but I was with people like myself and I was learning that I wasn’t the only one that had these kind of thoughts and problems.

A: Was that relieving for you?
B: Yes, yes it was. Yes! Just knowing that there were other people… When I first got committed to come here I didn’t want to come here because I had seen some people like on the 7th floor one of primary care and they looked really ill and I would always tell myself “you are not that ill” and everything like that. But when I came here I met some people and they were telling me bits and pieces about their story and their life and stuff and like some of them had to go through worse than what I went through, you know, and so and some of them were working the ones that were running the groups on the 6th floor all have mental health issues and everything and they have been there some of them 10-15 years and they are teaching groups and everything and um…

A: Do you feel understood by them?
B: Yeah, yeah I do. I felt you know, if they can go through have mental health problems in the past and look what they are doing now, you know, and stuff like that, you know, so I didn’t feel like well I can do something, I can do it, but what made me change was… I decided I started wanting things again. That was the thing I think I wanted a car and I wanted this and that and when I got my disability cause I got turned down for social security disability at first, they said I was too young, I was 49 I think and I had too much work experience, not to work and the other reason they gave me I forget… It was three things what they said why I did not qualify for disability no matter what the doctors said, you know. So I went and got a lawyer and I got this lawyer advertised on television (laughs) so I went to them and she looked at my record and said she would take my case. And when I came up for appeal… um I met with her once and told her my story and everything and then I was going to have her associate to go to court in front of the judge. And I didn’t meet him until the day of the hearing and he was late and he came in and shook my hand and we went in and the judge had somebody from occupational therapy there who worked for social security. And she was listing how many jobs can this person qualify for. And there were like thousands.

A: Oh wow!

B: You know, with my background experience cos I have an Associate’s degree and I worked for 7 years in medical records, I worked for 13 years in an insurance company, I did customers’ service, telemarketing… you know.

A: You have a lot of work experience.

B: Yeah, so I did all that and so there were thousands of jobs and my lawyer only said but she is only permitted to work part-time. Plus I had back surgery and I can’t do anything physical, you know, so what can she do to support herself part-time will she be able to have meaningful gainful employment or something like that. And she said nothing. So that was the end of it. I wouldn’t be able to do any of those jobs that she said I was qualified to work part-time. It wouldn’t be gainful employment to support yourself. Now I work part-time but I only make $10000 a year so that’s not what they consider a gainful employment so they had to say no she is disabled. There is nothing that she can do. And so the judge granted the disability. And went on disability. And I wasn’t planning on going to work. I was on disability I got it granted in 2006 and I decided I wanted a car. I claimed bankruptcy in 2004 when I got sick and I went to the seminar on how to repair your credit after bankruptcy. And one of the things they said was to buy something like, credit and build a credit history or something. And there was this car dealership that the people who did the seminar dealt with, and they said that they could get you a loan even after bankruptcy and it would be a good rate. So I didn’t go for it first and they kept sending me letters telling me to come out and see them and everything. So I decided to go look. I went out one Friday drove home in a car, and my doctor and my rehab everybody was no! no! Why did you do this? (Laughs) They tried to get me to return it and stuff… I do things on impulse sometimes I buy things and do things…

A: Do you think buying a car was an impulsive decision?

B: Yeah. Cause I go sometimes by my wants… I want it; I think I should have it. I go buy it, I go do it, you know. I didn’t have a job I just have my disability.
A: Oh, I see.
B: And so I really didn’t have the amount of money that I was supposed to in order to afford the car loan but they approved it anyway so I couldn’t return it cause they said what they do is they sell it at auction and then whatever they get for you, you are still responsible for the balance of the car loan. So I said I might as well keep it, so the only other thing to do was to go to work. And I had just gotten my disability in 2006 I bought the car in 2006 and then I was deciding to go to work in 2007. So I wasn’t looking forward to going to work. But then there were some peer jobs available here, like that, so that’s when I started to apply for the peer job that they had available here and then I got the job.

A: Yeah! What is your role here?
B: Um… they call it Community Aide on Peer Support. They call it peer support counselor with the mobile medication program. I go to people’s homes… we have 5 nurses and we have 2 peers. And I go to people’s homes and sometimes I sit with them and we talk. Sometimes I schedule their appointments and I take them to their appointments. Like, I help… one person she was in a personal care home and she was miserable and I went and got her application for housing. She wanted to live with her mother. Some of the things I do they say that’s for their case managers to do, but case managers are real busy and sometimes they don’t have the time. You know? So I did it and we did that and I followed her through and she did get out, the personal care home got shot down and her name came up on the list the same week and she did get out of there and was able to get where she wanted to be, like that.

A: So you were able to help!
B: Mm hmm! Mm hmm. And I helped this other person… I went down, he wanted his license real bad, you know, he was driving without a license he bought this car… I know how it is to want something (laughs) and you’ll get it illegally sometimes (laughs). He bought this car from some guy and had to plates on it no registration; he didn’t have his license or anything. So he did get caught driving it on a one-way street in the middle of the night and got pulled over and got a bunch of tickets and I helped him get the booklet, get a state id, went and got his birth certificate, he studied the book re-passed and got his driver’s permit.

A: Oh wow! So how do you feel about that? About helping people?
B: I feel like I am really doing something positive because before when I was sick I would just sit around saying oh poor me and crying and sad and all that. And now I really don’t have time for that. I am looking out for what other people’s needs are, you know, and if something is going wrong with me I am able to let it roll off my back and look forward to something else. I am going now to try to get my Bachelor’s degree. Me and my daughter are going to school at night for Human Services with Geneva College.

A: Aw that’s awesome!
B: Yeah so that would be good. And I might go into Social work if I can finish this program. And I used to not like social workers because I was raised in foster care and I always look at them as they were taking me to this home to that home, you know, and I really did not talk to them that much or anything. But I am going to look for a way to help people, you know, in a positive way and just be there.
A: And that give you meaning?
B: Mm hmm! It does it does.
A: Feeling like you contribute.
B: Yes, something to get out of myself and give to somebody else like that. I know what it is to want and have needs and have them unmet, and someone tell you you don’t need that. You know… but if there is a way that they can do it and it’s not harmful to them, you know, I will try to help.
A: To help out! Yeah!
B: M-hmm.
A: Going back to relationships with other people, and people telling you: that’s what you need, that’s what you don’t need… Do you feel that since you were diagnosed the diagnosis affected people’s attitudes and responses towards you?
B: Yeah… especially my family. Not many other people know that I have a mental illness. I am supposed to be, they want you while you are in recovery to divulge that information and share your story and stuff, but I know that people do just from their attitudes and what they say about other people. I know that there is a lot of negative stigma out there and um, I just don’t say anything in my church I join, I volunteer at the X ministry I sell the Message as it has been recorded we sell the tapes after the Sermon and stuff, and I know I was a little withdrawn and quiet, and they would always ask me what’s wrong are you okay and everything? And I wouldn’t say anything. I certainly wouldn’t say “I have a mental problem” or something you know? (Laughs).
A: Yeah. What was your fear? That if you were to say that to them?
B: Then I would be treated differently, I might be, not put down, just treated differently like they would say I wouldn’t be able to handle this or that or something like this you know? They wanted me to run the cash register and everything and I just feel if they knew I had (a mental illness) I would be treated differently.
A: Mm hmm.
B: And my daughter she sort of, my family… my husband he doesn’t anything about anything, you know, even when I was just diagnosed with depression, he did go one time to see a therapist with me, and she was attacking him why don’t you do this why don’t you do that and everything, so he never went back and he never wants to hear anything else about it. Cause he felt that all I do is sit and talk about him or blame him or something, which is what I was doing, but still he’s not supportive at all he doesn’t want to hear about it he says everybody’s got problems so I don’t even think he knows…
A: So in a way he is minimizing.
B: Mm hmm.
A: Everybody has problems.
B: Mm hmm.
A: And your problems are not more important than other people’s.
B: Mm hmm. I don’t think he knows what my diagnosis is besides depression. I don’t think he knows they were saying schizophrenia. My youngest daughter who had the granddaughter my granddaughter who is 14 her mother lives up by Mellon Arena not far from us, and she will joke, I guess that’s just her way of
handling, she sort of jokes about it but then he sorts of tells me that she is proud of me now because I came a long way, she saw me when I was sick and dragging myself around and going to the hospital all the time and not taking my medicine and now when I told her that Dr. X is weaning me off of my depression medicine she is like “what is his name who is he? I wanna talk to him” (laughs) you know, she is not thrilled about it you know, but, um, I said he is the Head of the service line I think he knows what someone needs and when they are capable of being off of a certain medicine.

A: Yeah!
B: Whatever, so she just have to deal with it, you know, that if I am getting better, if I am better and he says I don’t need a certain medicine anymore you know… whereas they were like “just take your medicine and leave us alone” you know, sort of like, they don’t wanna… She really doesn’t want to hear if I am talking about anything to do with my illness or anything.

A: Hum.
B: You know she really doesn’t want to hear about it. She is glad that I am doing better and everything and she is proud of that, but she doesn’t want to hear any of the details or anything like that.

A: Hum! How does that make you feel? How do you understand her reaction?
B: I know… I feel better about her than I do about my husband not wanting to hear. But I think she’s picked up some of his ways, you know, it’s a learned thing, you know… so if I am talking, she will have a conversation with him, cause he used to not talk to her or anybody early in the family, you know, now they have a better relationship. And she can call him like every morning and they talk and they gossip and everything like that. But if I go to ever say something to her she would go “what is it now?” You know. So I let alone I says, you know, well I don’t know what all that I put her through cause she was young and some people blamed her that it was her fault, and she was a good child she wasn’t trouble and neither was my other daughter or anything but…

A: It was your fault that.
B: Like, if she was doing something like misbehaving or something, or not doing what she was told, her father told her it was my fault I was sick, when really was more, if it wasn’t anybody’s fault but if it was anything, it was cause I wasn’t getting my needs met more with him than the children. They didn’t have anything to do with it, you know… They were like, in 1990 she was born in 78 so she was pretty young then, so it didn’t have anything to do with them they weren’t stressing me or anything. It was mostly him not being there. He was in church all the time day when he wasn’t at work he was in church he’d come home and I’d try to tell him something and he would go “I have a headache” and there was no talking to him, you know, or anything. It was just do my duties at home go to work earn the money bring the money home pay the bills never go out never take a vacation never do anything.

A: He didn’t want to hear about it.
B: No, he didn’t want to hear anything, you know… except for… nothing! You know. So I was just supposed to be happy with the way things were. And his

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family was very stressful they would always put him and us down, you know, like we were not on their list of family favorites or anything like that.

A: Mm hmm.
B: So when I would try to tell him something about his family or something he would be like “you are yelling at my family” you know he’s never let go of them even though he knew how they were treating me and treating him and my children got abused by his sister’s son when they were little you know, they got sexually molested, like, you know.
A: Oh-no!
B: And they had to live with that. And when I found that out, still… but…
A: So you didn’t get the support of the family.
B: M-m No.
A: Or the understanding, because I guess they refused to go there, to go into your shoes.
B: Yeah, mm hmm, mm hmm.
A: Were you able to get that from somewhere else?
B: Not until I came here, that was in ’04 or ’05 when I came here for outpatient rehab and everything and started getting therapy here and seeing the psychiatrist and going to groups here, and then I started making some connections with people that were having the same illness and everything.
A: Yeah!
B: Because people on the outside, even though some of them have illness, they are not being treated and everything, and then they take it out on you, or they however they behave, it’s different than people that are actually getting help and they realize they have something wrong with them and you know, it’s just different, you know, here. So that was from 1990 to 2005 I felt like I was on my own and all I was doing was sitting there talking and talking and talking… and whether they were listening or not I didn’t feel like I was getting anywhere… just spinning my wheels and then I came here and there is all kinds of thing to do and to advance.
A: Oh that’s great!
B: Yeah, now the recovery movement is out there and I am in a lot of different recovery groups) outside of here and everything… so it’s all good.
A: So in a way you are helping others get what you didn’t get.
B: Mm hmm, mm hmm.
A: Would you say that?
B: Mm hmm! I like to let people here know what’s going on out there in the recovery movement we have a group that were sort of administration up here in X hospital. And we have a local organization called Community Support Program (CSP) and it meets down by X hospital at Life works, and they sponsor… we go to conferences on recovery.
A: Oh-wow!
B: And you know, we went to Harrisburg for 4 days this year, and next year it is in Valley ------- and we have a movement called the Pennsylvania Mental Health Consumers Association, they call us consumers, people with mental health issues. So we have a conference every year, and they have meetings every month
and they talk about recovery issues, and they are trying to let everybody know what’s going on out there so (smiles).

A: Oh, that’s nice!
B: It’s really good!
A: So you have a role where you help out people.
B: Mm hmm.
A: And I wonder, you were diagnosed, you had some bad experiences with how people were treating you, but at the same time you found understanding.
B: Mm hmm.
A: So, compared to the beginning when you first got diagnosed when you didn’t see reason to live, even, how did treatment and receiving a diagnosis and services have affected your self-image? You know this new role that you find yourself in? In the past versus now.
B: It’s like I can’t even believe the difference in how I feel about myself. I felt very low, just not good at anything before, when I was sick and when I was first diagnosed, even though I think a lot had to do with may be the way I was raised, and being in foster care and not having anybody to turn to help with raising the kids, and everything like that. And the way things seem to be turning out with the kids and everything, and then I was blamed for that of course, my husband blamed me for my daughter getting pregnant and my other daughter feeling like she was gay and everything like this so… but now, I don’t… I try not to… put blame. Like they teach us in recovery not to judge and not to be judgmental I try not to judge, and in effect, I don’t feel that on myself anymore.
A: You used to judge yourself and now you don’t!
B: Now I don’t! And I try not to… when things go wrong, I ask for forgiveness, I pick it up and keep on going, you know and … umm.
A: Yeah! So your faith is helping you too.
B: My faith. I think that’s what really helped me.
A: Aha!
B: Like I lost all faith, you know, because I had the wrong image of what God was, I had the wrong image of myself and I had the wrong image of who God was. You know, I felt at first he was just up there looking down convicting me, I felt like under the wrap of God all the time
A: Yeah!
B: Like that because things weren’t working out in my family and myself, I was a people pleaser, I was always out to please other people, you know, but I wasn’t accomplishing anything, really.
A: Mm hmm.
B: Now I don’t think of so much of what I do is what I think… um, He has done for me, what God has done for me, and I want to do something back, you know? I want to do something back and I always felt, when I was in the hospital, that I wasn’t doing anything for God, and I wasn’t doing anything with my life – I was! I was raising children, but I wasn’t doing that even, satisfactory I didn’t feel you know, but … um …
A: So you feel like you weren’t good enough?
B: No I wasn’t good enough for doing anything and I wasn’t helping anything with God or with His Kingdom or anything, but now I feel the little things that I’m doing now, I wanna feel

A: That it’s a help, but I still need to be able to open up more and let Him... not let it reflect on me but let it reflect on why I’m doing this, you know for Him you know, you know, for Him like that, you know, that this is what He wants us to do, you know more so than what I wanna do to help, you know get glory for myself, you know... cause there is a verse in the Bible that if you get your payment down here, there is no reward for you, you know, in Heaven, you know.

A: Aw!

B: If you get all the glory for yourself and everything down here for what you do, then you had your payment, you know, but we are supposed to be storing up treasures for ourselves in Heaven.

A: Yeah! That’s very powerful!

B: Mm hmm, mm hmm!

A: That’s a powerful belief and your faith is guiding you and you feel more comfortable with yourself, you feel like you contribute to other people and

B: Mm hmm, mm hmm, mm hmm!

A: You are not doing that for selfish reasons

B: No...

A: You are really doing that because

B: I wanna give

A: You wanna help, you wanna give!

B: Mm hmm, mm hmm!

A: And God will provide for you down the line.

B: That’s what I feel, yeah! I am learning that and I am so glad that I signed up for Geneva cause that was the first, intro to human services and there was scriptures to go with it and that was exactly what was in the scriptures Matthew’s about doing it unselfishly, and do onto others as if you were doing it for Christ, because that’s what he said, when did you help Christ? “When did you give me something to eat and clothe me?” And everything He says when you did it on to the least of them

A: Yeah!

B: You’ve done it for me, like that, and that’s what it says.

A: That’s great!

B: Yeah things are looking good.

A: Yes! So I’m glad things are going well for you now. You reached different points in your life where you were very low and you had no hope.

B: Mm hmm, mm hmm

A: But now, you held on, and continued and were able to be where you are now!

B: Yeah, I really had no hope. It was one of the things that I remember when I first went to X hospital and they put me on the TRU unit when it was new, and they were saying that this outpatient women’s program is gonna be good.

A: Mm hmm!

B: And they said we have hope for you. And I said I really didn’t (laughs) had any, you know, and I didn’t get as much out of... I did get the one thing about having
more self-esteem maybe and have more, what’s the word when you are not aggressive but you are assertive? Self-assertiveness, I did learn that from the DBT but I learned more when I came here on the Rehab program.

A: Ok! Yeah… So overall would you say that receiving the diagnosis and treatment, overall, was it helpful to you, let’s say in terms of understanding your illness?

B: Mm hmm. And I still need to learn more, I need to study more about schizodefective and about having bipolar so that I get a better understanding, you know, about what it’s about. I thought I was more bipolar. No I didn’t have high manic phases I have a lot of impulsive things that I do like spending and things that I do wrong, even now I’m having problem with taking loans out excessively on the internet. I’m on there day and night and I spend my money and then I say “I can’t buy my medicine, I need a loan” you know. And I am in there trying to get loans and I had like 5 loans going at one point and I’m just now paying them off bit by bit you know.

A: Mm hmm. And also the way you understood what was happening to you then. You know, when you were hearing the voices and things like that versus, you know, looking back you do have some knowledge now about schizoaffective, different types of illness. What were you feeling then and what are you feeling now?

B: I was very afraid. It’s something to think that there is people out there that might have that power to read your mind, or to control… but I was determined that I had been told… you know. If you are out of your mind or you open your mind up to things like that you can, spiritual things can come in, that’s why… um, and I was very afraid and I didn’t want any power like that. Because I thought it was negative, it was against what God tells you. Cause he tells you about spiritual things in the Bible about witchcraft and about people that read signs and things like that. It tells you to steer away from that.

A: Yeah!

B: So I didn’t want that, you know. That’s what was happening to me, I didn’t want it and I just prayed all that I could. And that’s what I need to do now is to have constant prayer life so that I don’t have to in an emergency have a screaming pleading crying prayer, you know. I can have a steady constant relationship, like a good relationship and I can feel better about myself instead of the way I was feeling then helpless and hopeless. But I felt that God was my only, and I still do that’s what my pastor preached about Sunday, that he is the only way when you say to him is the only help that you need, you know and he will bring people in your life… It’s not like you sit and wait for a cloud to open and God is going to come down (laughs).

A: Right, you also have to do something to help yourself.

B: Yeah you have to do something, you have to reach out and other people will be there for you too that He sends to you, you know. I went to one church and the minister said you want to feel something with skin on it, you know, it’s good to say that God is going to help you, which He is, but He helps you through other people here that He puts and, it might be your doctor, it might be your therapist,
or it might be your friend or your peer or something, you know, or it might be just somebody in the hospital or it could be anywhere in the community, you know.

A: Mm hmm!

B: So you have to be there to accept that kind of help too, you know like that, cause like I said, it’s not going to be like Him speaking at the burning bush you know, maybe it will but not all the time is it going to be there for everybody you know, so you have to…

A: Reach out.

B: Right, you have to reach out. They tell you that in church too. You can’t just sit there waiting. You have to like, it says, there is something you have to do, you know!

A: Yeah!

B: It might be just honoring God or praising God or thinking God for what He’s done and stuff like that

A: Yeah, doing things like you do for other people too!

B: Mm hmm, mm hmm, mm hmm yeah!

A: I see! Well I had one last question.

B: Okay! (Laughs).

A: If you were to tell someone, you know I am learning about your experiences, somebody who didn’t have the experience of a mental illness, then what would you like to tell them in terms of, you know, how would you like to be treated by others who knew that you have mental illness?

B: Mm hmm. Well, I don’t want to be pacified. I don’t want to be talked down to I don’t want to be treated as though I have something they can catch, or you know I am not mentally retarded, you know and even if I was, I wouldn’t want to be stigmatized as though I couldn’t achieve anything or I’m in this little box and this is where you are and we are over here so you stay over there… You know, I just want to be… myself I want to be accepted for being who I am.

A: Yeah… like everybody else!

B: Yeah… like everybody else who doesn’t have the diagnosis, right… and what I can do or accomplish. I know I probably have to divulge that to more people that I have mental illness and when I do I always say I had depression. I was diagnosed with depression. And sometimes I might say with psychosis. But I haven’t even said bipolar and I sure haven’t said schizo-defective. You know… cause I told my best friend that that’s what I was diagnosed with. She was a nurse, she is retired and she was very understanding and she told me just to stay on my medicine and she told me about a pastor who was schizophrenic and he used to preach the best messages, you know, and stuff like that.

A: So did it make you deficient in anyway to have a mental illness?

B: No, no. If you learn how to live with it… learn how to live in spite of it, you know, you got to… Pat Deegan, have you heard of Pat Deegan?

A: Yes! Yes!

B: She’s made some real inspirational posters that I put upon the bulletin boards around here, and one of it is “I am not my diagnosis” and… what is the other one called… um, I can’t remember.

A: I am not my diagnosis
B: No, I am not my diagnosis. I should have I am gonna memorize this because it’s so good you know, what she is saying, you know. Like there’s more to it than… what we are going to have in the clinic now what she calls personal medicine?
A: Yeah.
B: Instead of just pill medicine, just taking your pills.
A: Mm hmm that’s only part of it.
B: Mm hmm that’s only part of it but she believes in having a personal, a power statement like, what is your personal medicine besides your pill medicine?
A: Aha!
B: What is it that you do that makes you feel better about yourself… makes you do better, makes you live? What is it about that that you… It could be like, your faith, it could be volunteering, it could be Math! One guy said that when he starts getting manic he does complicated math problems and it makes him feel better and everything like that, you know? And so some people like to sing, some people like to do this or that, you know and… so what is it besides taking pills that you do that helps you in your recovery, you know?
A: Mm hmm, mm hmm. You help yourself. There are things that you could do other than just taking meds.
B: Right, and sit there and just take your medicine… but mine is like to help. That’s mine, I like helping my family, you know and I like helping others, and I wanna work on my relationships. You know, working on my relationships is my personal medicine too you know.
A: Mm hmm!
B: And that’s with God and with man you know. So that’s one thing I wanna do you know? I just wanna be the best person I was meant to be before I was told you know; well this is what’s wrong with you or whatever. You know… I don’t even look at that, you know, whatever I am being told because I will be told something else tomorrow, you know. But I just “ok that’s what it is what am I supposed to do? What can I do to treat that” and then I just go from there, you know.
A: To create meaning for yourself and for your life.
B: Mm hmm, mm hmm, mm hmm.
A: Yeah, yeah… Go beyond that label that you were given.
B: Mm hmm! Because I always not wanted to be put in a little box and ‘you stay here”, you know. Even though I’ve always been an introverted type of person, you know, and I’m just now coming out to be… I don’t want to be a bit extroverted…
A: You don’t want to be confined into a little box.
B: Mm hmm, no I just want to be myself. I wanna be self-assured and just be myself you know?
A: That’s fantastic, that’s fantastic!
B: Yeah! Mm hmm
A: Well, I know I asked you a lot of questions today and I really appreciate your perspective.
B: Mm hmm!
A: And listening about your experience. Is there something that you wanted to tell me personally or in general, or a question that you want to ask about me?
A: I’m from, originally I’m from Cyprus. It’s a Greek island.
B: Ah Ok!
A: In the Mediterranean, you can tell by my accent actually.
B: Yeah (laughs) yeah aha!
A: (Laughs)
B: I was trying to listen and see… you are Greek! (Smiles)
A: Have you ever met somebody from Greece or Cyprus?
B: No I don’t know anybody that was Greek but that’s good that I got to meet one!! (Laughs). Are you going to go there or are you going to stay here when you finish?
A: Finish here and probably go back because this is where my entire family is.
B: Ah ok.
A: Yeah I’m here for school. It’s a lot different from the food to the weather to everything. But you know so far I’m enjoying it.
B: You’ve been here 5 years?
A: I will be here 7 years.
B: Oh ok! That’s great! (Laughs) I’ve been here; I am originally from N. Jersey so I’ve been here like 27 years.
A: Oh-wow!
B: I had a hard time adjusting at first, but now I like Pittsburgh.
A: Yeah, it’s always an adjustment, but we are doing what we can and that’s good. Thank you so much for meeting with me today!
B: Thank you! My pleasure!
Jenny Transcript

A: How are you doing today?
J: Alright.
A: Thank you for meeting with me. Would you like some water?
J: Yes please.
A: Here you are.
J: Thank you.
A: You are welcome!
J: Cause my pills … the doctor says I have 13 pills.
A: Aw that’s a lot of pills!
J: Some are psych and the other ones physical. So I got more pills … so you know, I told him I was having trouble with thinking.
A: With thinking?
J: With thinking. It was kind of, you know … like some days I get good days and then, some days I get depressed, so I got a lot of things going on cause I’m getting married in 4 years.
A: Wow! You are getting married in 4 years?
J: Aha! So my fiancé is trying to help with … I have some friends that are very good friends because I talk to them and tell them what I want! (laughs)
A: Aw good, good! It helps to have good friends.
J: Yeah! So we are thinking should we have people bring things, you know, because they can choose whether they wanna bring some fruit or something.
A: Yeah, ok.
J: We are asking because some people may be able to help out, you know, because we are not expecting some of my friends to pay … you know … they could bring in something and that will save us to get married and stuff, so people are being nice by, you know, amazingly that … ‘cause the staff wants to come too! So I got a lot of (laughs).
A: A lot of people to attend the wedding!
J: Yeah!
A: Well Jenny here, what we are going to do today, this is for you (Researcher hands out a flyer with research question) this is basically the idea of what we will be discussing today and I had a couple of forms. I will go over the study and what we will be discussing (describes study).
J: Well, first of all, I was diagnosed so many years ago, because they didn’t know how I was abused as a child, so they didn’t find out what my diagnosis was until I started coming here. I was abused as a child … my adoptive mother abused me a lot, and let her friends, male friends … you know where I’m headed.
A: Um-hum. It must have been a difficult experience.
J: Yeah … my dad was mad, cause they were divorced, so I didn’t get to see my dad like I should have. And I was close to my dad. When I came here, they labeled me depressed and then they spent a little more time talking to me and then they found out that I had psychosis.
A: When did you start coming here Jenny?
J: I’ve been here 10 years!
A: 10 years!
J: Aha … cause I was going up to X hospital and I was seeing a private doctor and therapist, and then, they were changing up there to a research … and I chose to … she said, Jenny you gotta choose, we wanna stay here or they changed it to a group-type session and I didn’t want it cause I had it before so … (whispering) it’s a pain in the butt (laughs).

A: The group?
J: Yeah!
A: You didn’t enjoy the group?
J: Aha …
A: What was it about the group that you didn’t enjoy?
J: Well … they said that I had major depression at the beginning and then they had me as schizophrenic.
A: So you didn’t enjoy the group because they didn’t diagnose you correctly at the beginning?
J: Um-hum. And I said I don’t want to be labeled. I mean I had a lot of abuse in my life, and I guess my dad was upset because he left me in that situation, and so he blamed himself a lot. And I had to keep telling my dad “I don’t blame you” I mean, “You didn’t know”. Some friends of his that they were friends of the family saw what was happening to me and called my dad and said “Look, get that girl out of there. She is abused, and you are letting other men abuse her”. And so, he got me out when I was 12 years old!
A: Wow 12 years old!
J: Um-hum. And my dad found a woman that he loved, but he explained to her: “She has been abused and I don’t want her to be abused … but she was a drinker.
A: And so I guess you were abused.
J: Yeah … so they said “She’s crazy” (laughs)
A: Who’s crazy?
J: Me!
A: Oh!
J: I was labeled so many times that …
A: Who labeled you?
J: You know people in the street and … I hated that! I hated it!
A: Sure!
J: But I didn’t want to get in jail for fighting. So … even though my dad was a policeman (laughs).
A: Oh wow! Yeah!
J: That was hard on him. Because he would protect me. Because he felt he had to do it, because he left me behind. And he had my brother for 5 years and I didn’t get to see him for 5 years.
A: You didn’t get to see your father for 5 years!
J: Um-hum. We … my dad told me “You are not stupid”, “You are not retarded”. That was one diagnosis so it took me a long time to trust people. The only one I did was my dad.
A: Yeah. It seems like your father believed in you and knew who you really were, compared to other people who didn’t know and called you names.
J: Um-hum. Because, see, that’s why I say I wanna do studies, so if I can help in any way to help even kids that are being abused now. I have an advocacy group that I’m running, and I’m trying to teach them how to stand up for themselves.

A: Yeah! Yeah!

J: Because I have gotten some consumers to come over and talk about their illness.

A: And do you talk about your illness too?

J: Yeah!

A: So you are trying to help them through talking about your experiences?

J: Aha! And they said “How could you stand all that”. They said “I know Jenny that you went through that”. Looking at me you wouldn’t.

A: No! You went through a lot!

J: Yeah. I was … my dad he’s been dead for … Lord let him live till I was 30. So, I prayed to God to let me have my dad for a long time. Cause my dad was seeing other doctors and trying to find out where he could go to make sure that … you know, he says “She is not stupid, she is not dummy, she is just slow”. He called me slow. But he was upset when people would hurt me like that.

A: Sure!

J: “She is not stupid!” (in loud voice). And he wouldn’t listen to researchers and doctors because, if you’re going to put that label on me … you know, he would be … so I miss my dad.

A: I bet! He was protective of you and caring for you. Sure! Of course you miss him.

J: Yeah.

A: What are your feelings? When you had people call you names your father was defending you, but how were you feeling at the time, when you had people say those things to you?

J: It made me angry. It, you know, I say I don’t want, you know, anything to let me down. Lord led me to have people in my life to be nice to me now, like they would help me in anything I want to do with this wedding. I told them years ago, we are going to think about taking some counseling. Marriage counseling.

A: Marriage counseling with your fiancé?

J: Aha. Cause somebody said it would help.

A: Are you having any difficulties?

J: No. We love each other, we tease each other and he wants to get married. So I say, don’t rush it! 4 years. So we first decided to go to Justice of The Peace. Then we decided that we should go to counseling. Cause we had our case workers helping us.

A: Is he supportive of you?

J: Aha. He comes over every once in a while.

A: He comes over to see you?

J: Um-hum

A: Where does he live?

J: He lives in another PSI.

A: Ah, ok! So you live in a PSI yourself?

J: Um-hum. That’s like a CRR.

A: Okay. So does he also have an illness too?
J: Yeah. Um-hum, I support him and he supports me. So, you know, he is always here when I need him. Cause sometimes I get down … and he knows that sometimes I have a bad day.

A: Um-hum, so he can understand given that he is also dealing with an illness.

J: Um-hum. He says “Honey, if you go to counseling with me, we can look at a marriage with two people who have mental illness”. We are making history; you might say (laughs).

A: (Laughs).

J: Cause not too many people … Here is your pen (lifts pen from ground where I dropped it at the beginning of the session – loses train of thought).

A: Thanks. So not too many people get married who have mental illness.

J: Um-hum! Yeah. So we are making history. I’m having some girlfriends be in my wedding and they are all fighting for a position (laugh). I say “I can’t do that”. I said my sister has to be the bridesmaid. Cause she is married. So I might try to get my brother to come I haven’t seen him for a good while. I will tell my mom to come on and give me away (laughs).

A: That would be a nice time.

J: Yeah.

A: In your life. Something positive to look forward to in 4 years. You are going to marry somebody who understands you and is supportive of you.

J: Um-hum. And he says that he doesn’t care if anybody doesn’t approve. His sister tried to talk him out of getting married to me, but he told his sister “You need to worry about your business” cause she is in relationship that isn’t good one. And I told him, we are going to get married no matter who says … you know, that’s between him and me.

A: Yeah, yeah! So no matter what other people say, it’s your decision, and you are going to get married, since you love each other and that’s what matters.

J: Aha … he says, my mom doesn’t hear what anybody else in the family says. He is going to marry me whether … he said the only one he wants to prove is his grandma … and I talk to them. And I talked to her the last time. I thanked her for sticking up for her son. I say I would not do anything to hurt your son. I give you that promise.

A: Yeah, sure!

J: You know, grandma already talked to me on the phone, and she says “I can’t wait to see you”. She said “I have to get my grandson to bring me over.

A: Yeah, so she is looking forward to your wedding too!

J: Aha.

A: Nice! And seeing you happy.

J: Yeah, cause I said … everybody wants to … I’m going to have to cut some (laughs).

A: You can’t have everybody!

J: Right! Too many people.

A: Well, Jenny, I wanted to go back to a point you made earlier about medication, you are receiving some medication right now, and my question is about treatment in general. Since you were diagnosed, how is that experience for you? How has your life changed?
Well, I found that, with my … I depend on God very much so, you know, even though I don’t go to church too often …

Um-hum.

I am looking for church so we can go to church. I’m sorry I need to get some water (reaches out for water bottle).

Yeah, take your time! So I guess faith is an important part of your life.

Um-hum!

And you are finally getting treatment here.

Um-hum.

But, yeah, where does Faith come in? Does it help you to have faith when you are ill?

Um-hum! Right now we are just looking for Church, but as you know, there is stigma.

Yeah.

And I fight for that. I advocate for it. See, I went out of this building one day, and the students … when I get better I hope that I can advocate … go to these schools for the kids, learn and teach the nurses and doctors that discriminate against us. Even the schools, you know, discriminate against us “Oh look! This is a dummy!” And I get riled-up.

I bet! Yeah!

Do I look like I’m crazy?” And one girl says “Yeah you look crazy”. I said “No I’m not! You just saw me come out the building”.

I see! Which building, this building?

Aha, so I can’t …

So they are assuming you are crazy because you receive treatment?

Yeah, aha!

Not because of who you are.

Um-hum. So I say a little bit more casual, I say “I’m not crazy. Do I look crazy?” What do crazy people do or look like? I mean, why don’t you go up there and see what they do! They said “No I ain’t going in there, they are crazy people”. See, they are not being taught right.

Because they are young.

And kids.

Yeah, children and older people, they don’t know. Is that what you are saying? They are ignorant or they were not taught about mental illness.

Um-hum. Yeah! That’s why I advocate, go back to advocacy. We advocate for our rights, we fight for … I’m in the advocacy group that’s being taught out in this building. So that’s why I get so frustrated, because I know what I am!

Aha, aha!

A survivor. I’ve survived! I survived child abuse, I survived. See I don’t call myself like some of them, consumers. And you are going to hear different names.

What do they call them?

Some call themselves patients. Because that’s what they see in them, which is good. To a point. Because, I was lucky to have my father for 30 years. And my dad gave me support.

Yeah, yeah!
J: And then I had to go in and see him every day, sleeping on a bed. My mom was upset because they put straps to the bed. Because he kept trying to get out of bed.
A: Was he in the hospital?
J: Yeah. He had cancer. And he died.
A: Oh I see. I’m sorry to hear that.
J: But, I had to tell my mom. And it hurt me that they had to do that to him. I said “Mom, there have to be other places” and the nurses said that he was starting to go. And the doctor was mad because he wanted to tell the family. Cause the doctor knew what he was going to do, and he said “I have to do it for his health”. I had to talk to mom, and that was the hardest thing to do.
A: Talking to your mom
J: Talking to my mom and explaining why he had restraints. Cause if he got hurt, the family would sue the hospital.
A: Sure.
J: And the doctor explained to us. I already knew cause I was a nurse’s aid. So I tried to tell my mom, to explain it to her. She didn’t want to hear it. It was hard for her. So we the kids had to be strong for her, because she loved my dad and she didn’t want to have her husband die.
A: Of course it was hard.
J: Then a friend of hers came down to stay for her as long as she could. See, so I’ve been in pain. I lost a dad.
A: You lost a support.
J: Yeah.
A: He was a good dad.
J: Yeah, he was good to me.
A: When many people were not treating you well, your father was there for 30 years supporting you and treating you with respect.
J: Aha, he was. He said no when they said that I was a dummy, he got mad and told the nuns off! Because I was, I went to a Catholic Church. And then, my dad got mad at him because I went to a private school and on his car somebody marked “Nigger go back to Africa”.
A: Oh wow!
J: And my father said, “I’m not going anywhere. This is where I live. I am not African”.
A: He also got discriminated against
J: Aha!
A: Like you did difficult experiences. But yeah, you mentioned that, your father is gone, right now he is with the Lord. And you have people who don’t understand because of stigma and ignorance. Do you have some people who do? Do you feel like there is also those people?
J: Um-hum. I have a friend that has a brother that’s helping her get help for her brother. Cause her mother is older and her dad just died. And so she is worrying about her son where is he going to go.
A: So you are trying to help her get help for her son?
J: Um-hum. So I feel sorry for her, you know, I say “Okay, I can’t force you to go but I still suggest that you go to family NAMI. You know what NAMI is?
A: Yeah! National Alliance for Mental Illness.
J: So they are relatives who can go to fight for our rights, and sometimes … So I got her started on this, so I was glad to hear that. And she says she would help me with my wedding (laughs). So, she’s a planner so she said I wanted to do something for you.
A: Yeah! So she wants to reciprocate.
J: Um-hum. She’s gonna … I says keep in touch with NAMI, cause they can help you. It’s the organization for help people … See they can do just as much for us as if you fight …
A: As you can advocate for yourself
J: Aha!
A: So they can also advocate for you
J: Yeah, so, you know, I told her about NAMI and I gave her some information you know how she, you know how you can help people with all different illnesses you know NAMI … is the one I like better.
A: Yeah, it seems like they are doing a fine job helping people advocate for themselves and their loved ones.
J: Aha, so I say to my friend, just get in touch … because we have one here … a NAMI.
A: Yeah. So you feel supported by those people?
J: Aha! I showed a friend of mine. She had a daughter who has schizoaffective. We don’t hear too much about schizoaffective that much, because I looked into books. Very little research.
A: Very little research on schizoaffective disorder compared to schizophrenia you mean!
J: Aha. I have schizophrenia plus major depression.
A: Has the diagnosis affected the way you see yourself? Compared to before you were diagnosed?
J: Hum. I guess because I believed that, you know, something was wrong. Something different, you know. And being on all these different medications and stuff, I wanna try to get off of some of them. That’s why the doctor said I’m going to do something for you, you know, if you still feel you need medication change …
A: Do you feel that some of the medications are helping? I know you said at the beginning you kind of knew what was going on but you weren’t sure until you sought treatment. So what was going on then?
J: I was hearing voices. Medications can help. And like I said, I was support for him, and he was support for me.
A: That’s your …
J: Fiance. Cause that’s how we met. We were in a group home together. And we just started talking to each other, then we started dating and (laughs) and now we are getting married.
A: Yeah. You are getting there. So the relationship is something that’s going very well for you, and he can understand you and know where you are coming from, and you support each other. But going back to, you described that at the
beginning when voices appeared, what were you feeling at the time when you would hear the voices? What were you thinking?

J: Um … well, when before we started going together, we were just friends. And that is how that started (laughs).

*Door knock – secretary “I just wanted to give you the time check”, Andri “Ok thank you”*

A: Sorry about that, she was checking up on us to see what we are doing.

J: Aha!

A: Ok. So you were talking about your relationship.

J: I mean he had some rough stuff. His father was a military man. So you know they are tough in the Marines.

A: Oh! He went to the Marines.

J: Aha! So he was army bad (laughs) so I call him my little army man.

A: So the way you see yourself now compared to before you received a diagnosis and treatment has it been the same or different? How do you see yourself?

J: How I see myself now is I get excited … before I was down and depressed and I went up to X hospital for a little while, and I came down here on my own! They said there is a program … cause they were changing the program up at X hospital and she knew, my therapist knew … I was getting a little anxious (loses train of thought).

A: You were anxious?

J: Aha! When people were talking about me, I had to get the strength back that I had, you know, so, cause she felt that I didn’t need the group. She gave me a choice. And I said “I don’t want to go to 2 places”. So I’ve been with this program for almost 10 years.

A: Wow! Do you like this program?

J: Aha! I fight for my rights so I’m proud of myself.

A: Yeah, you should be!

J: Well, my dad, I talk to him sometimes. And, there is no specific time he comes to see me. But they are all positive because he tells me that he is proud of me. I see my granddad and my grandma.

A: You see them?

J: Yeah … and talk to them.

A: You talk to them even though they passed?

J: Aha! You know, it’s like, some people think that when people see dead people that … you know, your mind … but they are not frightening me, they are just … how proud they are of me and it’s going to be alright and the wedding is going to be alright.

A: Yeah!

J: Yeah … see, so I believe my grandparents.

A: So what do other people say when you say that you talk to them?

J: Um … they don’t … I mean, I just don’t talk about it. You know I don’t tell them (laughs).

A: Yeah, you don’t tell them because …
J: Cause, I think they come to me to let me know that I’m going to be alright.
A: Um-hum. But other people from the outside, when you are talking about your experiences, do you feel like they don’t understand?
J: Yeah! Because … that’s why I don’t tell many people that I do this (laughs).
A: Do you think they will think negatively about you?
J: Aha! I’ve told somebody that, and they didn’t keep my confidence so I had to … shut up (laughs). I would tell my therapist that, I would tell my doctor that, but I would not talk about it to anybody else. Except for my girlfriends, that I’m friends with.
A: So people, who know you, know who you are and understand where you are coming from.
J: Aha, yeah!
A: Versus people who are on the outside and don’t know you and they might assume something negative about you.
J: Um-hum!
A: You mentioned a while ago that some people may call you crazy.
J: Um-hum. So it’s safe to talk to my father and grandparents, they give me encouragement. My dad still with me! (Laughs)
A: Yeah, even though he’s gone.
J: Aha
A: He is still with you. He is still looking down and caring for you.
J: Cause I feel his presence and, he is trying to say “It’s gonna be ok”.
A: So do you feel your faith is helping you through the illness?
J: Yeah. But, see they don’t know me that well. So some people judge it.
A: Yeah!
J: And I hate when they say “This person had a history of mental illness”.
A: Because what does that do, to you or other patients? What does it do when they say that?
J: It makes me angry. You know, you know that my family, my grandfather, my grandmother, they all love me, so I wouldn’t be scared of them. I will talk to them sometimes … you know? And he says “Daddy understands” and then my grandmother who died when I was young, she says, I forgive you, and then my grandfather says he is sorry for leaving me downtown (laughs). He was 6’2.
A: Tall guy!
J: My grandmother was short, but she sure came ---------. He said “Hello chickie hello chickie” (laughs). He was glad that the policeman brought me home. Cause my grandmother was fussing at him “Get the hell off this ----- and go find this child”. Cause he was 6”2 and I was a little kid. He didn’t even look back, he left me downtown! He got on the bus and he thought I went on the bus. My grandmother said, “Don’t you hit that child” (laughs). See I have memories.
A: Sure! Of course.
J: You know, I was mad at my grandmother for dying. She had cancer, lung cancer. My grandfather died in his sleep and they had to ask my aunt for the keys. Cause she had a set of keys and my dad had a set of keys. But he was out on his honeymoon. So we had a hard time getting him to … you know. If I could wish for somebody to come back would be my dad.
A: Sure, sure, yeah! He was so kind and so supportive.
J: See, other people would help me, but I’m a survivor!
A: Yeah!
J: I’m a survivor! And I’m a survivor of mental illness. I say I’m a survivor of mental illness and abuse.
A: Yeah, I can see you’re proud when saying that.
J: Aha, cause I say, the best way to teach is to show.
A: What do you want other people to know, drawing on your experience? What do you want to tell them?
J: That they can stand up for themselves.
A: Yeah!
J: I mean it’s not as bad as you thought. I’m in a group called “Let’s act” that’s an advocacy group. And we write letters to the senators and stuff who we don’t to get a hold of the bill ----- and that empowers me.
A: Yeah!
J: You know, cause Bush, Obama, they are cutting all the services and he doesn’t. They are not giving him (Obama) a chance because …
A: Services are needed.
J: Yeah, services are needed. Because I feel sorry for the kids. Services are supposed to be for the people. Not cut. Guess what, Bush is living it up now. He doesn’t have to worry about that. He made all this himself, before the President Obama got into it. So he said, “I don’t have to worry about it, let the next President worry about it”.
A: Hum, that’s what Bush said?
J: Aha!
A: So you feel that services are needed and feel that the services have helped you and they empowered you?
J: Um-hum
A: And I know you mentioned at the beginning that you are taking a lot of medications, but from your experience, do you see any positives or negatives of taking medications?
J: Positive because he told me that he can switch some of my meds that I need, you know so …
A: Yeah, how do they help you some of the medications?
J: My psych’s doing very good. My psych medications.
A: So it’s helping
J: It’s helping a little bit. Like I don’t do well with letting people go. Cause I’ve always had somebody … to …
A: To care for you?
J: Aha! You know, my mom worries about me, and my sister worries about me.
A: So they help you to let those things go?
J: Aha!
A: Do they help with voices and other symptoms too?
J: Aha! So, the doctor wants me to see how …’cause the doctors don’t want to give more pills unless it’s necessary.
A: Do you have any negative symptoms related to medication?
J: Yeah sometimes, some medicines.
A: Ok. Well I had a final question and I’m going to let you rest, I know we’ve been talking a while now. How do you see the present and the future compared to the past before you received treatment and diagnosis? It is different than before?
J: Yeah! Cause when I was first diagnosed I was major depression, then I got sick and went into the hospital and the doctor that I had then was upset because the hospital changed my medication without consulting me or him and he was mad cause he was a good doctor and he put me on the right pills and stuff. He was like “What did they do to you?” So he put me back in the hospital to flush out my condition because one medicine was getting me crazy (laughs).
A: Getting you crazy?
J: They weren’t working well. And my doctor said “You had no right to take those pills off of her”. So he went upstairs, got his stuff and told them “Don’t you touch her, don’t give no medication” because she has a right to sue you. So he was looking out for me. He said “I don’t want nobody coming near this girl”. And he was a good doctor.
A: Yeah, you felt like he was advocating for your best interests.
J: Yeah, and he talked to my sister, and she came over to see what was going on. She said “You better not put any more medicine on my sister” cause the doctor said “They messed her up” with the medicine giving her what they thought she needed. And he was mad.
A: I bet
J: Cause he said “I don’t like to see her in this condition”. They didn’t’ call him because they knew he was one of the best doctors in the hospital.
A: How did you feel when you realized you were given the wrong meds?
J: I was angry. And I say, “Look, my family can sue you. All I have to do is sign a piece of paper”.
A: Aha, sure you were angry! How do you see the future now though?
J: I see the future is going to be … I am going to have some supports. I have friends that support me. I ask people for food and stuff, you know. I said “You have a choice, you can bring a present”.
A: For the wedding
J: For the wedding (laughs). I prefer the wedding, them helping out in the wedding.
A: Yeah. Good! I am glad to hear that you feel supported! Is there any question or anything that you wanted to ask me? I appreciated you talking about your experience. Is there anything you would like to say to close off? About the process or about what we talked about today?
J: You know I get to see my therapist every 2 weeks and she is helping me real good. I mean she listens to me and that’s the first time somebody listened to me was my therapist that I got here.
A: She listens to all you have to say?
J: Yeah. And then I got some other doctors and they didn’t stay. But I am used to it, but sometimes it’s hard.
A: It helps to have somebody to listen to what you have to say and be there.
J: But sometimes you can’t, you know jobs. Well it was nice meeting you.
A: It was so nice meeting with you and talking to you and I appreciate the insight that you gave me and helping me understand where you are coming from.