

UNIVERSITY OF CALGARY

Meanings in "Madness:"

A Phenomenological Study of Mental Illness and Spirituality

by

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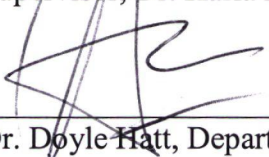
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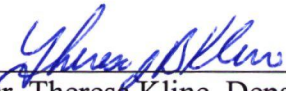
The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled “Meanings in ‘Madness:’ A Phenomenological Study of Mental Illness and Spirituality” submitted by Nadine Jeannette Quehl in partial fulfillment of the requirements for the degree of Master of Arts.



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ABSTRACT

This thesis addresses the relationship between religious/spiritual beliefs and understandings of mental illness in a western Canadian city. Research subjects were members of two support groups, one for individuals with bipolar affective disorders and one for those with schizophrenia. A phenomenological approach is used to explore the realm of meaning as it is experienced in the “life-world” of consumers, and the methodology includes participant observation, life history interviews, semi-structured interviews and group interviews. Issues of identity, normalcy, and loss as a result of illness are examined, as is the notion that mental illness is a “gift.” Criticisms of the current treatment and thoughts on ideal treatment are highlighted, and the ambiguous nature of religious/spiritual beliefs in coping and understanding one’s illness is explored. Because of the link between spiritual beliefs and models of mental illness, it is proposed that such beliefs should be taken into account in treatment options.

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I would like to thank all of the consumers who gave of their time and energy to participate in individual and group interviews; without your willingness to share your stories, suffering, and successes, I could never have begun this research. I am grateful to the two organizations and the support group facilitators, who agreed to introduce me to their support group members and provide a location for interviews. The guidance and advice of my supervisor and committee members, and the encouragement of the administrative assistants in the Anthropology department are also appreciated. Finally, my thanks to my family and friends who have supported me during the research and writing of this thesis, without all of you, I could not have completed this research.

DEDICATION

This thesis is dedicated to my husband, and the countless other men and women who live the conditions known as “bipolar affective disorder” and “schizophrenia,” and to those who ended their lives when living their illness became impossible.

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No obstacle between his head and God;
At all hours open to th' Almighty's Word.
He bootless wandered streets to heal the world;
He found no Shoeless waiting at his door.

He never was the kind to rock the boat,
Yet questions have a way of all upsetting;
When ideas blow the language all apart
There's then no way of our communicating.

Then seven seals came calling from the east,
And the western patriarch was more than welcome.
On the mountain of the Lord he found his ease.
Still the precincts of the mad are never home.

He could not leave apocalyptic vision,
But, defying death, he learned to love his mission.

Mark Arvid Fullerton, "Jubilate Agno"

CHAPTER ONE: INTRODUCTION

In contemporary times, more anthropologists are doing anthropology “at home,” but there are still few anthropological studies in Western cultures examining the relationship between religious/spiritual beliefs and understandings of mental illness. It is imperative to examine the interface of anthropology and psychiatry in light of recent societal trends. For example, patients are claiming more independence in “taking charge” of their illnesses, and lay conceptions of illness are being valued in opposition to and sometimes over medical conceptions of illness (Herzlich 1995:167). One way this is manifested is the growth of alternative medicine, which is often preferred over the biomedical paradigm, indicating a growing disillusionment with medical theory and practice.

Moreover, a recent shift in perception on the part of the psychiatric community can be seen in the addition of the diagnostic category, “religious or spiritual problem,” to the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1994. This change signified that psychiatrists were given official authority to deal with issues of religion and spirituality, rather than dismissing them as pathological as has been the norm since the time of Freud. Spiritually-oriented psychiatrists, who believe a broader view of “abnormal” states must be adopted, viewed the addition of this category as a victory. Rather than labeling religious delusions as signs of illness needing suppression, these therapists encourage patients to identify the spiritually valuable parts of their experience, thus finding meaning in their madness (Shorto 1999:15-16).

Before I define my research problem, definitions of terms such as “religious beliefs” and “spiritual beliefs” are needed. Religious beliefs will be defined broadly,

based on Rodney Stark's (1987:354) definition of religion as "any socially organized pattern of beliefs and practices concerning ultimate meaning that assumes the existence of the supernatural." The notion of "spiritual beliefs" is similar, but emphasizes the individual's exercise of faith and often includes the idea of individuals creating their own set of beliefs as opposed to adopting an organized, institutionalized "religion." For individuals who do not attend church services for various reasons, particularly if they have had negative experiences in institutionalized religious organizations, use of the term "spiritual beliefs" is more appropriate.

The purpose of my research is the exploration of meanings in "madness." It is religion, according to Weber (1922:59), that is able to address the problems of meaning in the world; since meaning is found primarily in religion/spirituality, my research will focus on the relationship between religious/spiritual beliefs and understandings of mental illness. I personally became interested in this topic after visiting three or four different hospital psychiatric wards, where I saw a number of patients, including my husband, for whom religious and spiritual beliefs appeared to play a significant role in their disorders. As Malinowski (1922:25) advised, "the final goal, of which an Ethnographer should never lose sight ... is, briefly, to grasp the native's point of view, his relation to life, to realize *his* vision of *his* world." Accordingly, my research explores the models and metaphors employed by individuals suffering from mental illness, specifically bipolar affective disorders and schizophrenia. Two support groups in this western Canadian city for individuals affected by these conditions were the primary focus of my fieldwork.

Theoretical Considerations

A phenomenological approach is used to explore the realm of meanings as they are experienced in the “life-world” of the mentally ill (Schutz 1962:246). By a “phenomenological approach,” I mean the study of experience by trying to directly understand human experience, without privileging any modality of human experience (Goldstein 1961: 225-226). “Phenomenology” was originally a philosophy developed in the early 1900s by Edmund Husserl, the aim of which was to describe how experience is constituted without the contamination of scientific theory or other preconceptions. Or as Luckman (1978:9) has stated, “the goal of phenomenology is to *describe* the *universal* structures of *subjective* orientation in the world, not to explain the *general* features of the *objective* world.” To resolve the problem of the cultural and historical relativity of our knowledge of the world, Husserl came up with the method of phenomenological reduction. This “epoché,” involved a suspension or “bracketing” of “the natural attitude,” or the ordinary cognitive attitude we have toward the “life-world,” where we do not question its meaningful structures (Benson and Hughes 1983:49). The phenomenologist, then, must not accept the validity of any conceptual scheme, but adopt a philosophical stance, which suspends judgement of socially accepted knowledge (Benson and Hughes 1983:50).

Since its inception, followers of phenomenology have propelled it in many different directions, and I draw from a number of phenomenologists’ writings, including Husserl, Schutz, and Merleau-Ponty. Primarily, I follow the guidelines set forth by Jackson in Things as They Are: New Directions in Phenomenological Anthropology (1996). In short, phenomenology is the scientific study of experience. Neither

subjectivism nor objectivism can be privileged, as the “phenomenological method is above all one of direct understanding and in-depth description – a way of according equal weight to all modalities of human experience ... and deconstructing the ideological trappings they take on when they are theorized” (Goldstein 1961:225-226). As Berger and Luckman (1966:26-27) have pointed out, what people usually recognize as real is not theoretical knowledge, but commonsensical knowledge, and *this* constitutes the practical reality of life. A shift in emphasis must be made from what beliefs mean *intrinsically*, to what they are *made* to mean, and what they accomplish for those who use them (Jackson 1996:6).

It is in the “micro-contexts of daily life,” where macro-level social, economic, and political forces are played out in individual life-settings, and illness experiences are constituted *intersubjectively* as particular moral realities (Kleinman 1992:171-173). According to Kleinman (1988:26), “the cultural meanings of illness shape suffering as a distinctive moral or spiritual form of distress.” The German phenomenologist, Plessner (1970, cited in Kleinman 1988:26) addresses the link between culture and suffering in modern Western culture in his notion that illness leads the sick individual to recognize an important aspect of the divided nature of the human condition: that each of us *is* her body and *has* (experiences) a body. Culture fills the gap between sickness as physiological process and its meaning-laden experience as human phenomenon. This body-self dichotomy explains how illness takes on meaning as suffering because of how the relationship between body and self is mediated by cultural symbols of a religious, spiritual or moral nature (Kleinman 1988:26-27).

In the case of mental illness, this Western cultural dichotomy is even more relevant. From Plato onward, there has been a separation of the body and the mind, and there continues to be general agreement on the Cartesian view that mind and body are separate but affect one another. Neo-Cartesianists insist upon the dualism of mind and body, and like Szaz (1978:xvi), some believe that “there is, properly speaking, no such thing as psychotherapy. Like mental illness, psychotherapy is a metaphor and a myth.” Such theorists cite evidence showing that psychiatric patients have emotional problems in living that result from problems of industrial civilization, and these problems should not be regarded as illnesses (Albee 1977:721). Others have gone so far as to say that not only is mental illness a myth, but imposing the socio-cultural norms of the majority on a minority, the “mentally ill,” is used to control deviant behavior and force people to conform to society’s norms (Tancredi 1983:294).

On the other side of the mind-body debate are those like James and Jung who believed that the mind and body (and the individual and the world) are connected in ways recognized by religious mystical traditions (Shorto 1999:43). The mind-body dichotomy is also in stark contrast to the philosophies of other cultures, such as India, where Hindu philosophy emphasizes the identity of mind and body (Kakar 1982:242). Currently, consciousness studies and the psyche-spirit movement profess the collapse of Cartesian dualism and outline the need for a new way of understanding what human beings are, how they know, and what constitutes knowledge. There is a recognition that the objective, scientific view of reality is, as Nagel (1986:4) puts it, “a view from nowhere,” or a view from no one’s perspective, and “not all reality is better understood the more

objectively it is viewed.” The challenge is to find an approach to knowledge that includes both objective and subjective experiences.

Methodological and Ethical Concerns

Preliminary research began in January 2001, when I met with members of a support group for individuals with schizophrenia to introduce myself and explain my research. Next, I met with the members of the support group for individuals with bipolar affective disorder, and a short time later I began attending both support group meetings to get a sense of “what is at stake” (Kleinman 1988:233) for consumers. (“Consumers” is the term used in the medical community as well as by many consumers, themselves, to refer to individuals who have mental illnesses.) In addition to this participant observation, conversations with consumers before and after support group meetings, provided another chance for me to develop rapport with my informants. Following Bernard (1994:141), this kind of participant observation was intended to decrease reactivity and increase the validity of the data, help me to design sensible interview questions, and enable me to understand the *meaning* of my observations.

To comprehend how individuals with mental illnesses understand schizophrenia and bipolar affective disorder, and how these understandings relate to religious/spiritual beliefs, I included participant observation, life history interviews, semi-structured interviews, and group interviews in my methodology. Following Sullivan (1998:27), “the use of qualitative methodology was consciously chosen in order to elicit data entirely from the respondents’ perspectives. This method allows for unforeseen data to emerge and recognizes the consumer as the expert on the recovery process.”

In his study on the role of spirituality in the course of serious mental illness, Sullivan (1998:26) relied heavily on life history interviews:

if the experience of serious mental illness and the course of the recovery process is deeply personal, the best sources of knowledge are those individuals struggling to recover. And this knowledge, particularly in the formative stages, cannot be drawn simply from responses to a set of predetermined questions but instead must reflect the life story of informants.

Life histories are also important because they are “a means to give voice to people, ...to capture institutional and historical forces as they ... are experienced by individuals; and to guard the wholeness and integrity of individuals rather than slicing them into analytic pieces which are packaged into generalizations” (1996:165). This is particularly important considering my research subjects belong to a group who have been stereotyped and stigmatized since the fourteenth century, and perhaps even earlier (Foucault 1965:8).

Phenomenological approaches seem uniquely suited to life history interviews: “methods grounded in phenomenology, which takes account of subjective experience as a phenomenon in its own right, seemed especially well suited and were examined in a series of works dealing with life histories” (Watson and Watson-Franke 1985:13). I attempted to conduct non-directed interviews, as this method helps one learn what *informants* think are important, and how *they* conceptualize and think about their lives (Langness and Frank 1981:48). Kleinman’s (1988:232) guidelines for those who treat the mentally ill are useful: he proposes conducting a “mini-ethnography” to enable the clinician to locate herself in the lived experience of the individual’s illness, which amounts to an experiential phenomenology. Ethnography, according to Kleinman (1988:28), is the appropriate research method to create knowledge of the inner world of illness and suffering. The “mini-ethnography” reconstructs the individual’s illness

narrative, including the life history, which should be as broad as possible, including the individual's life course, major continuities and changes in attitude, life goals and obstacles and experiences of coping with illness (Kleinman 1988:236). The illness narratives must be analyzed in terms of the different modes of illness meanings, including symptom symbols, culturally significant illnesses, personal and social contexts.

Following the life-history interviews, semi-structured, informal interviews were conducted with support group members. The focus of these interviews was how religious/spiritual beliefs affect (or do not affect) consumers' understandings of their mental illnesses. Following Kleinman (1988:239), I asked questions about the onset of symptoms at a specific time, lay understandings of what caused the symptoms, and expected course and seriousness, as well as questions about the treatment, both ideal and real. Following Good and Good (1981:180), I asked questions about what other people think about one's illness, and how one feels about their reactions. Other issues emerged, and respect was shown to what consumers believed were important areas to discuss. Finally, as Kleinman (1988:185) points out, to understand the meaning of illness, content cannot be the focus as it is infinitely variable; one must explore the *structure* of illness meanings, including processes of creating meaning, social situations and psychological reactions that determine and are determined by the meanings.

The fourth method was group interviews. Four group interviews were conducted, two with the members from the support group for those suffering from schizophrenia, and two with members from the support group for those suffering from bipolar affective disorder. These interviews occurred following both the life history interviews and the individual semi-structured interviews, in order to shape the focus of the group interview

according to issues that arose previously. Because this study was an inductive one, I created interview guides (see Appendix) with the realization that they would be altered according to what informants feel to be important topics and themes. Langness and Frank (1981:47) note that “it is possible to do group interviewing, and in most situations the participants stimulate each other in a very productive way,” and I found this to be true in the group interviews that I conducted.

Social Workers, Rauktis, Feidler and Wood’s (1998:76) “Focus Groups, Program Evaluation and the Mentally Ill: A Case Study” was informative because they explain how focus groups have been used “as a means of understanding a client’s experiences of mental illness.” These authors also give valuable suggestions about ways to modify traditional group interviews, when working with people suffering from mental illness. For example, the illness and use of psychotropic drugs may affect energy and mood, making it difficult for participants to concentrate or feel comfortable in a group setting. Others may have difficulty expressing ideas clearly, while some may be quite capable of expressing ideas clearly (1998:81). Thus, the structure of the group interview requires flexibility, as well as some use of body language, and verbal prompting on the part of the interviewer. Many other valid suggestions are made, but perhaps the most important one is that “the moderator conveys genuine interest and respect for the knowledge and experience of the participants” (Rauktis, Feidler, and Wood 1998:89).

From the beginning, ethics was a major concern, as the people with whom I wanted to work are part of a vulnerable population. I quickly rejected my initial idea of doing fieldwork on a hospital psychiatric ward, as I would have been required to pass a complex ethical clearance there, as well as at the university level. As it was, passing the

university ethics clearance was difficult enough, and an uncomfortable situation arose when I had to make changes in the way I did participant observation to comply with the ethics committee's requirements. I had received permission to attend support group meetings as an observer, which did not require formal ethics clearance at the time. After becoming a "regular" by attending support group meetings for a few months, I now had to leave the room while the facilitator asked if anyone was opposed to inviting me back in, a formality which did nothing to help me blend in as an unobtrusive observer.

The fieldwork experience was both frustrating and rewarding. Frustrations included interviews cancelled or simply forgotten, something every interviewer has to deal with, but which was perhaps more common with the particular group of people with whom I was working. Even a few support group meetings were cancelled, and I was glad I had not come for support, only to find there would be no meeting that night. A few consumers dropped out of the study half way through, which was disappointing. A number of interviewees were reluctant to talk about their disorders and even to elaborate on their lives in general, and I had the disconcerting feeling that my interviews were ending far too quickly. The frustration arose primarily from the fact that most consumers were not comfortable talking about either their religious beliefs or their "religious delusions." When I asked about religious/spiritual beliefs, many consumers had difficulty expressing their belief system; it was as if they had never been asked to describe this aspect of their lives. As for describing experiences of a religious nature when ill, these were things that many would rather forget: they were "*embarrassing*," delusional, "*crazy*" thought patterns that needed to be "*deprogrammed*" and "*when you're not in that space, it's frustrating to think you were in that space because you*

might have done something even dangerous thinking you have supernatural powers.”

Some consumers offered more insights into their beliefs and experiences during group interviews.

Rewarding moments included the minority of consumers who really wanted to talk about these issues. Tom, in particular, was very excited by the opportunity to share his understanding of the spiritual nature of his mental disorder. Up until this point he kept such thoughts to himself, for fear he would be institutionalized: *“this is the first time I’ve talked about it this way, because never had no one to talk to about it.”* While some, like Tom, were recharged, others found the interviews draining. On the other hand, after the first group interview with consumers who have bipolar affective disorder, a few interviewees told me they had really enjoyed it because they could talk to their peers on a deeper level than that which occurs at support group meetings. Their questions about whether I was going to organize another interview for those who were not able to come, and their interest in attending again, resulted in the organization of a second group interview for both consumers with bipolar affective disorder and schizophrenia.

Informants’ Backgrounds

While I attempted to get an adequate sampling of informants with regard to age, gender, ethnicity and socio-economic status, I was limited to those who were willing to participate. When my research was finished I had interviewed twenty-four consumers, twelve women and twelve men who have either schizophrenia or bipolar affective disorder. The majority of informants were in their thirties and forties. A small group of informants were in their fifties, two were in their early twenties, and two were in their

late sixties. Informants came from diverse socio-economic backgrounds. Some worked part-time at furniture stores, copy centres, organizations that provide support to people with schizophrenia, canvassed, painted, in addition to receiving AISH (Assured Income for the Severely Handicapped). Others relied upon AISH completely as they were unable to work because of their mental disorders. Still others worked full-time for companies such as the airport, Registries, and phone companies. One informant is a doctor who works at a health centre as well as running her own private practice part-time. Another works as a legal secretary as well as taking college courses to upgrade her skills, and hopes to become a nurse. A few were retired from positions as engineers, teachers, homemakers, and industrial first aid attendants. A few informants relied on AISH, but were taking college courses. A brief description of these informants is provided in order to familiarize the reader with this diverse group of individuals, and to make the material that follows more relevant. Each description also includes a short experiential account of schizophrenia or bipolar affective disorder. All names and other biographical details that might jeopardize informants' anonymity have been changed.

Dee grew up in Western Canada and is currently divorced, after being married a number of times. Raised in the United Church, Dee has distanced herself from conventional religion, partly because her mother, who has a mental disorder, had very disturbing religious delusions. Dee looks to yoga and various traditions to make up her unique spirituality. She was diagnosed in her early twenties, and has experienced grandiose thinking, hearing voices, seeing visions, and having flashbacks from her adolescence. She also experienced obsessive thoughts, such as thinking she had met a pop culture icon, who was the only one who understood what she was going through, and

wrote the songs on one of his albums solely for her. Dee also believed that the television was sending special messages just for her.

Lam is single and has one child. He grew up in Nigeria before moving to Western Canada. In the past, he struggled with alcoholism, drug abuse and a “*spiritual addiction*.” He is Catholic like his father, but also subscribes to some of the indigenous beliefs of his mother and grandmother. Lam recalls being really happy or really depressed as young as six years of age, and he was diagnosed in his late thirties. He remembers periods when he would spend money without discretion and when depressed, he “*couldn’t do one single thing*.” Lam believed that he was the Chosen One, and heard whispers, which he first thought was God’s voice, and later, the voice of the devil. Lam suffers from paranoia, and at one point he believed that the building he was in was going to collapse, and when he left he actually “*saw*” it collapse.

Rebecca grew up in a rural community in Western Canada. She is divorced, and has struggled with alcoholism in the past. Raised in the United Church, Rebecca became Christian “*for real*” in her thirties, and describes herself as a “*born-againer, fundamentalist*.” She was diagnosed in her early twenties when she started having paranoid thoughts that people could read her mind, and heard voices and believed they were demons. Rebecca has had religious delusions including the belief that Jesus was her boyfriend, as well as the idea that she was being given insight into the creation of the world.

Lyle grew up in Eastern Canada, where he got married at an early age. He was raised Anglican, but stopped going to church when he got married, and has just now returned to church. His experience with mental illness began in his early twenties, when

his mood became so elevated that he was medicated, and then he became so depressed that he was given a series of ten shock treatments to bring his mood up. After being hospitalized for six months, Lyle was well without medication for a number of years before he required medication again. He heard voices, and had delusions of grandeur, including the belief that he was related more closely to God and He was going to direct him, and the belief that he could walk on water.

Dianne was also raised in Eastern Canada in a religious cult where she had to keep her homosexuality hidden. Dianne has now broken away from this religious group and her religious addiction, and is in the process of developing a new faith. She struggled with alcoholism in the past, and is now single. Dianne hopes to return to university and expose the cult in which she grew up, and help people who have addictions to drugs and alcohol. Dianne remembers primarily the depressions, where all she wanted to do was sleep. She spent periods as long as six months, during which she would wake up in the morning and lay on her couch for about eight hours, after which she would go drinking.

Tom grew up in Western Canada. He is divorced, and has struggled with alcoholism in the past. Raised Lutheran, Tom was “born again” at eighteen years of age and now attends a charismatic church. He first experienced symptoms including paranoia, feeling like he was in a movie, and seeing snakes, spiders and eyeballs, when he was twenty-eight years old. He was diagnosed shortly thereafter. When he needed stitches in his head, he believed the doctor was going to insert a computer chip that had the mark of the beast. Another time, he heard a sound at the hospital, and was sure they were giving shock treatment to people who refused to take the mark of the beast. Tom also believed he was a prophet, “*like Elijah.*”

Sarah was born and raised in Western Canada. She had an ecumenical upbringing in the Christian faith, but sees herself as more Native, or naturalist, and like others, she takes the “*best parts*” from all religions. Sarah recalls having visions and hearing voices from the age of seven, when she understood these phenomena as her “*little ghosts*.” Her symptoms became intense in her early thirties, and she was diagnosed with depression. It was not until she heard another patient explaining his mental condition that Sarah told her psychiatrist about her “*little ghosts*,” and received her current diagnosis. Sarah experiences anxiety, severe paranoia, delusions of grandeur, and at one point believed God was talking to her. Another time, she believed she was abducted by aliens. During illness episodes, Sarah believes “*the powers of the unknown are stronger within me*.” She told me that to get a glimpse of what her condition is like, just turn on (at a high volume) all the televisions and radios in your house, and try to have a conversation with someone.

Lisa lived in Eastern Canada with her mother until the age of ten, when she moved out west with her father. Lisa suffered abuse perpetrated by her father, and neglect by her mother, who was later diagnosed with a mental illness. While her first religious experiences occurred in the United Church, Lisa has developed a strong relationship with God, and says she believes in relationship, rather than religion. She had her first hallucination at the age of six, when she saw an image of the devil’s face on the wall and heard voices. Lisa remembers having mood swings and being suicidal as early as ten years of age, and she was diagnosed in her late twenties. Lisa has heard up to six voices yelling in her head, telling her to hurt or kill herself; she also experiences paranoia, and hypersensitivity to noise and touch.

Jeff grew up in Eastern Canada. He was raised as a Christian, but did not have a personal relationship with Christ until much later in life, and now attends a Baptist church. In the past Jeff abused drugs and alcohol. Jeff is married. He got sick when he was about twenty years old, and believed people were following him and trying to kill him. He also had delusions of grandeur, and even believed he was God. Jeff also had what his psychiatrist called a “built-in entertainment system”- some of the voices told him jokes.

Jenny has been married for over twenty years. She grew up in a very religious, Lutheran family in Western Canada, and now attends the United Church. Jenny was almost forty years old before she experienced her first major depression, and has also experienced racing thoughts, hyperactivity, and delusions of grandeur.

Gary was raised in Eastern Canada in a strict Roman Catholic family. He rebelled against religion for a long time, but now attends the United Church. Gary is single and has attended three different support groups for compulsive addictions. He was diagnosed in his early forties. He had delusions of grandeur and described his experience as hearing tapes of past events played over and over in his head. He has also heard sounds, smelled smoke, felt like he could fly, and as far back as his early teens, Gary saw flashes of light.

Alexander was born and raised in Brazil, and came to Canada ten years ago. He has been married for three years, but is now separated after realizing he is gay. His religious/spiritual beliefs are eclectic, as he draws from a number of different traditions including yoga and the notion that the world is composed of something beyond the chemical and the material. Alexander remembers feeling depressed as young as twelve years old, and believes he has had this condition since he was in his twenties, but in

Brazil he was not diagnosed. He has seen visions, such as intense bright light, heard noises in his head resembling an airplane engine, took on projects that he could not complete, and experienced delusions of grandeur.

Patricia grew up in Western Canada and is single. Raised in the Jewish faith, she continues to be very religious, but sometimes she does not keep kosher to escape prejudice. Patricia believes she has had this illness since she was born, but she also noted that she was happy until she turned seventeen, when she thought people were trying to hurt her. When she was in her early twenties she was diagnosed, and believed that the nurses and doctors were the Mafia. She experiences feelings of persecution and torture, and believes that “*pushers*” are trying to get her on junk food. She also hears voices that that instruct her to hurt or kill herself, and has hallucinations.

Andrew, who is single, grew up in Western Canada. He abused drugs in the past before becoming sick when he was about seventeen, and was diagnosed a short time later. Andrew is Christian, and stresses the importance of how we live as opposed to what we believe. He experienced delusions of grandeur, delusional thoughts, and said, “*when I’m sick it’s kind of like I’m in a different reality.*”

Frank grew up in a small town in Western Canada. He has been married for over twenty years, and has three children. While he was raised in the Catholic Church, Frank stopped attending church about ten years ago, and explained that he believes in living a moral life here, rather than focussing on the after-life. He remembers the “*highs*” when he got very productive, tried to do more than he could handle, and was hyperactive. Once he believed he could fly, but says it was half a dream.

Marilyn was brought up in Western Canada in a Catholic family, and she continues to adhere to these religious beliefs. Marilyn is single and has one child. In the past, Marilyn had anorexia. She started getting sick when she was nineteen years old, following a car accident. She became paranoid, thinking the KGB was trying to kill her, experienced olfactory hallucinations, such as smelling coffee, and her food tasted funny, leading her to believe it had been poisoned. She also saw visions of the Devil like she had as a child, heard voices, and believed she was God's chosen daughter. When she was in her mid-twenties she was diagnosed.

Tina grew up in Eastern Canada and while she was raised Catholic, she now combines these beliefs with yogic philosophies. Following her divorce and her mother's death which occurred close together in Tina's late twenties, she suffered low-grade depression, and was diagnosed in her thirties. Tina became happy-reactive and angry-reactive, and experienced mixed states, where she was manic and depressed simultaneously.

Tyler was raised in Western Canada and is currently single. He has recently returned to church after a twenty-five year absence, and says that for the last ten years, he has believed that God is female. He started "*being kind of unique*" in his mid-twenties when he had dreams that he believed would come true. In his late thirties, Tyler was diagnosed, and now he hears voices that "*say weird things I don't really understand, so I just let it go.*"

Rachel grew up in Western Canada, where she was raised in the Anglican faith, to which she has returned after exploring other belief systems. Rachel is single. She got sick when she was twenty-three years old, and was convinced that she and her parents

were in danger. She heard commanding voices directing her back in time, and believed she was being watched by video-cameras. Rachel did not sleep for three days and was certain she was being attacked by the devil.

Stacey grew up in Western Canada, where she and her brother were placed in foster homes when Stacey was about twelve years old, after it was discovered that the children were subject to abuse by their parents. Stacey's mother was diagnosed with Munchausen syndrome by proxy, a condition where the parent makes the child feign symptoms or intentionally makes her sick to get medical attention. Stacey was baptized in the United Church but now attends a Christian Reformed Church. While Stacey had been treated for anxiety and depression in her early teens, it was not until she was in her early twenties that she was diagnosed. She describes her condition as "*being on this huge roller coaster that doesn't end...*" She remembered a year when during the day she did not eat or sleep, did not in fact, do anything but exist. Stacey was paranoid, hallucinated, heard and saw things, did not sleep at all, and was completely out of control.

Brendan grew up in Western Canada, where he was raised in the Baptist Church, but now he identifies more with Pentecostalism. As a child, Brendan was emotionally abused by his father. Brendan is single. Quoting Forest Gump, in the 1995 movie of the same name, he said, "*life's like a box of chocolates – you never know what you're gonna get.*" In his early twenties, he started to have delusions, such as the belief that his cousin was a famous singer and Brendan's family was trying to hide this fact from Brendan. He was diagnosed a few years later, and suffers from depression and disorganization.

Ethan, who is now divorced, was born in Western Canada to immigrant parents. In his youth, Ethan abused drugs and alcohol. Raised Lutheran, he has rejected

conventional religion, seeing it as a form of control, and subscribes to a more individualistic spirituality. He believes his symptoms started as early as twelve years of age, when he began to self-medicate with alcohol. He was treated for anxiety during university, treated for depression in his early thirties, and a few years later, Ethan was diagnosed. He would stay up for days working, or entertain notions of making money. He also experienced rapid thoughts, intense visual and auditory stimulation, grandiose thinking, suicidal depression, was highly sexually charged, and spent money.

Carolyn grew up in Western Canada, where she was brought up in the United Church. Though she still believes in God and Jesus, she no longer attends church. Carolyn is single. She started getting depressed in her late twenties, and was diagnosed in her mid-thirties. Carolyn had delusions of grandeur and believed that, just by imagining, she “*was doing wonderful work for the world.*”

William was born in Western Canada and raised in the Anglican faith, and he was “born again” as an adult. William is divorced. He noticed tendencies of his mental disorder, such as impulsiveness, beginning in his late thirties, but has only heard voices once. He was not diagnosed until his late forties.

Summary of Chapters

“Stigma and Loss: Relationships, Work and Time” comes first partly because it contains a lot of personal information, to enable the reader to get to know the consumers. Moreover, it concerns “what is at stake” (Kleinman 1988:233) for individuals diagnosed with schizophrenia and bipolar affective disorder, as the theme of loss, particularly in terms of relationships and work, arose in virtually every life history. The chapter

addresses how mental illness affects consumers' ability to work; in some instances, it is the treatment rather than the illness, itself, that limits one's ability to work. Conversely, a few consumers spoke of the benefits of mental disorders to one's productivity. Stigmatization is discussed both in terms of discrimination in the workplace, and in consumers' personal relationships. The difficulties involved in creating, maintaining, and salvaging relationships after "fallout" from mood swings and illness episodes are explored. Finally, perceptions of time, and notions of lost time in particular, are addressed.

In the next chapter, "Questioning Whether Mental Illness is a 'Gift' and Criticizing the Current Treatment," the contested issue of the value in mental illness offers a stark contrast to the devastating losses outlined in the previous chapter. Some of the "blessings" include creativity, a sixth sense, a closer relationship to God, and the ability to empathize with and help others. For some consumers, this understanding leads to a criticism of the regimentation and stifling that occurs in hospitals. Other criticisms include the lack of information provided regarding diagnoses and medication.

In Chapter Four, "Ideal Treatment and Religious Coping," consumers express their struggles with side effects from medications, leading some to make suggestions about ideal treatment that include alternative therapies. Fourteen consumers believed that the medication-based treatment of mental illnesses was the appropriate approach. Seven consumers believed this approach should be combined with alternative therapies such as herbal remedies, Reiki healing, or that, at the very least, there should be research into other factors that may affect mental illness, with the hope that this will lead to improved treatment. The other three consumers rejected the traditional medication-based treatment

for a variety of reasons. This chapter also addresses the issue of religion/spirituality as it relates to consumers' mental disorders. Most consumers found religious/spiritual beliefs to be helpful in providing strength and preventing suicide, in short, helping them to cope with life. Paradoxically, a number of these same consumers had negative experiences with religion/spirituality, as religious delusions led to harmful behaviours, or spiritual addictions, and "overdosing" on religion.

In Chapter Five, "Self-Identity, Disability and Normalcy," diverse self-identities are explored, including the traumatized self, stigmatized self, the fragmented self and the self that is alienated from his illness. Following phenomenological psychologist Merleau-Ponty (1969:369), I understand the "self" to be an orientation to the world that is embodied, a focal point for perception. Notions of disability as applied to oneself, and one's mental disorder in particular, are examined, and there is a range of acceptance and rejection of this characterization. Similarly, there is a spectrum of "normalcy," ranging from complete rejection of notions of normalcy, and recognizing its constructed nature, to the other end of the scale, where consumers strive tirelessly toward normalcy.

The sixth chapter, "Of the Brain, From Beyond or Both: Models and Metaphors of Mental Illness," offers a phenomenological account of consumers' understandings of their conditions. Along this continuum lie those who subscribe to the medical model of mental illnesses, who first and foremost, insist that their conditions are physiological illnesses. These illnesses, they believe, arise from bio-chemical imbalances in the brain, which need to be corrected through the use of pharmaceutical medications. Somewhere in the middle of the continuum are those who combine this medical model with an alternative understanding of their condition, one that often involves a religious or

spiritual element. Moving still farther, we find a group of consumers who appear to find no value in the medical model. Their alternative understandings range from the belief that their conditions are a sixth sense or shamanistic ability, to the perception that the illness is an external agent, to the view that the condition is caused by religious oppression.

The conclusion aims at tying together the themes addressed thus far. Differences between the understandings of consumers with schizophrenia and those with bipolar affective disorders are highlighted. It is suggested that if religious/spiritual beliefs inform how individuals understand and live their mental illnesses, such beliefs should be taken into account in the treatment of mental illness, rather than following the psychological framework, which is grounded in the Western biomedical paradigm.

CHAPTER TWO: STIGMA AND LOSS: RELATIONSHIPS, WORK AND TIME

A recurring theme in the individual interviews, and to some extent in the group interviews and support group meetings, was that of loss. The two main losses spoken about concerned relationships and work. Many people experienced difficulty establishing or maintaining relationships because of their mental illnesses. Similarly, many people had difficulty working or were even completely unable to work as a result of their disorders. Some of this could be attributed to the symptoms of the disorders or the side-effects of the medications; however, much of the loss resulted from the stigma that consumers faced when their illnesses became known at work, disclosed to friends or caused difficulties in personal relationships. At one support group meeting, in particular, the theme of loss dominated the discussion. One man explained how he lost his apartment and another man described how he had lost everything and ended up on the street, and even in jail. Other members spoke of the loss of “productive time” that they experienced since being bipolar seriously interfered with their careers. Some people could only take on contract work, but even then, illness episodes had to be dealt with. Others had a lot of education but no work experience because of the illness.

To Work Or Not To Work

At one support group meeting there was a lengthy discussion about the lack of resources in the city for people with mental illnesses who are trying to find work. While various support groups and programs specifically designed to help those with mental disorders find work are available, none of these agencies are integrated; even with such programs in existence, it is difficult to find out about them. Partly as a result of this lack

of integration of programs, many people I spoke with were on AISH (Assured Income for the Severely Handicapped), but as a consumer who was struggling to fix her furnace, noted at another support group meeting, “AISH covers your shelter and food ... and clothes once in a while, but that’s it.” At times, AISH was a contentious issue, as one member of a support group highlighted. This woman has what is called a “dual diagnosis,” as she has a mental disorder in addition to an addiction to an illegal narcotic. While she had been accepted to attend a dual diagnosis clinic, she declined because it would mean going on welfare, which simply would not be enough to support herself. Not enough, that is, unless she were to receive AISH. However, she did not desire this option as she felt that not all people with her disorder were sick enough to be on AISH all the time.

At the opposite end of the spectrum, Brendan, who was diagnosed ten years ago, feared a world without AISH, even if mental illnesses were cured:

if they come up with a cure and you’re on AISH for ten years – poof! You’re stuck without AISH. How is that going to leave everybody; I mean, it’s stressful to me to think I’m gonna be floatin’ out there someday. I want the good cure to happen but what does that do with your life ... there’s going to have to be support of some kind even if there is a cure, financially ...

Tom just started working part-time after being out of the work force for nine years. His understanding of why people rely on AISH addresses issues alluded to by Brendan:

on AISH, I’m allowed to make \$200 more than my income – that’s motivation enough to make me want to work more ... food on my plate, better for me so why shouldn’t I. The tough part is motivating people; stuck in a rut for so long, people think they can’t do it no more. If it wasn’t for my family and support people, I wouldn’t be ... today, I could be six feet under, I sometimes think.

Qualifying for AISH came as a relief to Gary, as stress often precipitates illness episodes:

“finally I got on AISH, which gives me a little more flexibility and financial support than

before. I don't have to worry about having the tension of finding a job, thinking I won't have money to pay bills, where am I gonna go ..."

Dee has been dealing with her mental illness for over twenty years. When I asked about the main way her condition has affected her life, she said, *"the work profession – it really limited me – I can't hold down a job longer than two years."* Shortly after Dee graduated from college she became sick and was diagnosed with a mental disorder. She was unable to work, and it was difficult to get back into the field after the loss of productive time. She then worked part-time at various jobs, but after, *"a year or two, then I'd get sick again ... I have a very difficult time fitting in with the work structure in society. Now I'm spending most of my time in an art class."*

Sarah had experiences with work very similar to those of Dee: *"I always seemed to be able to go in and apply for a job and get it, probably because I had so many different jobs ... I'd get paranoid after a year or two and switch jobs."* Like Dee, Andrew was unable to pursue his desired career. While he initially went to college, he got sick and dropped out. Later, Andrew finished a year of university, but his mental disorder again interfered with his ability to continue. He worked *"for four or five years, if you string it all together,"* (he has been hospitalized at least ten times), and he now works part-time, *"plus I get AISH."* When I asked Andrew about his life goals he said, *"to get some sort of education so I could get a decent job. But it didn't work out with my illness. I wish I could do better but I can't really do better than I'm doing now."*

Lam also must now rely on AISH. While he initially went back to work after being diagnosed and put on medication, he had a relapse and *"things went all the way down. I couldn't get a job anymore – I was really fried. ... since I couldn't complete a*

career, I thought poetry would be the answer. I'm trying to write poetry ... Like many other consumers, it was stress that brought out the illness and prevented Lam from being successful at work: *"I try to find a job and then I get stressed and I get fired."* Marilyn was also prevented from pursuing the career of her choice because of her mental disorder:

I was a good student. I loved school. I wanted to be a lawyer, but I got sick and I couldn't concentrate at university. I find the stress of memorizing so much and writing exams brings out the illness, for me anyway. I'd love to go back to university but in practicality, that's what causes me stress.

Later, she expanded on why a return to university seems impossible: *"I don't know if it's even possible to go back because of all the damage that's been done to my brain. I couldn't remember any of the math to do chemistry ... I'd have to repeat high school."*

For Marilyn, Andrew and Dee, the illness, itself, has made it difficult to exist in the working world; however, Dee also notes that the treatment has contributed to her segregation and difficulties in working. She recalled her time at an employment preparation centre following a hospitalization, where she spent full days for a number of months, after which she was given a job that involved very repetitive work:

I flunked. They said I was too lethargic ... it was because of the medications. A Canadian Mental Health worker wrote down the meds and took it to a psychiatrist at Canadian Mental Health ... wrote my doctor and said if he didn't take me off all those meds, like, I was showing signs of brain damage!

This over-medication was a possibility feared by many of the people I interviewed.

Over-medication was also a major problem for Rebecca, who started getting paranoid after her first year of college, and had to drop out, and was eventually diagnosed with a mental disorder. Later Rebecca completed a diploma, *"but I can't remember any of it ... on all these pills."* Besides affecting her memory, the medication caused other problems: *"I kept trying to work, but I was so sleepy that I couldn't ... I didn't have a*

decent doctor and at that time the medication wasn't as good." Rebecca had many jobs that were short-lived as a result of over-medication or medication that was not right for her: *"I kept tryin' to work instead of tryin' to get my medication straightened out – that's why none of these jobs didn't work out because my medication didn't work yet. For some reason I would never say, 'I'm not well enough to work' and get myself well ..."* While Rebecca now receives AISH, her spousal support is deducted from her AISH allowance, making things difficult.

Along with many consumers who were affected by schizophrenia or bipolar affective disorder, Rebecca regrets the loss of a career, and wonders about realistic dreams and goals for the future:

... having some sort of career. At this point, I'm not sure I've still got the energy, don't know if that's a realistic dream ... something I wished I could have done by now ... I almost don't have that much drive left in me. It's just been too hard. I just kind of want to get a job I can do with the illness. I have trouble taking in a lot of information going on around me, so types of jobs I need to do is ones I can focus in on one thing – I have trouble multi-tasking.

Likewise, Marilyn is angered by the fact that mental illness has prevented her from pursuing her career of choice. She spoke passionately about the "lie" she had always been told – that you can be anything you want to be:

*you don't count on getting sick. People aren't equal! Some people have more breaks than others, know more people, are born into different situations ... maybe God created us equally, but we are not treated equally. Once you've got a label of mental illness, your life is changed. You get treated differently. Some of the people are getting married which **never** happened before...*

Like Rebecca, Patricia laments the loss of a brighter future because of her condition: *"I lost my intelligence because of the illness ... I could have been an artist by now, but I went downhill."* Now in her forties, Patricia wants to work, but says, *"I don't work*

because the medication takes away my will to work ... I can only work one to two hours a day ... the illness is really awful."

Losses of intelligence and one's will to work, pointed out by Patricia, were also felt by other consumers. While Rachel is able to work full-time, she noted that having a mental illness has caused her to lose her confidence: *"it affected me psychologically – I used to be able to go at things one hundred percent, used to be able to get up the internal energy. Now mentally, I don't have the attitude, 'yes I can, yes I can.' Now I feel like, 'I'll do my best.' I've lost my confidence."* Similarly, Gary explained that his condition has *"prevented me from exploring my possibilities."* He also listed other losses, such as concentration and motivation: *"my concentration has been affected to the point that I didn't have any. My motivation has been affected to the point where I was very antisocial."* As Tom puts it, *"with this illness, you almost lose yourself, some of yourself and I can see some areas that won't come back maybe ... can see some areas that are being restored."* One of those areas that Tom *could* see coming back was his sense of humour.

Dee reflected on what her life might have been like if she did not have a mental disorder: *"I had gone to college so that I could get a better job. My whole life would have been different ... I've had to really slow down and really examine a lot of things, but I think maybe I've become a different person because of it."* While she does reflect a sense of loss, unlike Patricia's perspective, Dee's comment also points to something of value in the disorder, which will be explored in the next chapter. While expressing a sense of loss, Andrew also looks on the brighter side, evident in his response to the main

way his condition has affected his life: *“I don’t work. I don’t make good money working, but I do have a lot of free time, which is nice.”*

Rebecca believes that it is all a matter of perspective. While her mother still laments over why Rebecca has to have such a “crappy” life, Rebecca feels differently: *“I don’t look at it that way anymore. I don’t feel my life necessarily is that crappy; sure, I can’t hold a job, but a lot of people have to go to work every day and I don’t!”* At another point during our interview, however, Rebecca expressed a contradictory perspective: *“I get upset because I’m divorced, I don’t have children and have trouble holding a job; feel I’m not contributing so why am I still alive? Might as well, if heaven’s such a great place, why don’t I go there now?”* Rebecca’s questions recall a statement made by one of Kleinman’s (1988:215) informants, a family physician, who told him that “medicine is concerned with the problem of keeping you alive; but serious illness asks the question for you, What is life for?”

For consumers who were able to work, stigmatization was sometimes experienced when their conditions became known to co-workers or employers. Lisa recalls the following incident of stigmatism in a former workplace: *“I only worked there for five weeks and then they fired me ... I made the mistake of telling two students ... I thought they were my friends ... I thought I could trust them ... they gossiped.”* Lisa believes that one of these students who was hired by the same agency informed her supervisor of her mental disorder because, *“they fired me for some really stupid reason ... I knew they fired me because they found out I have a mental illness.”* Lam also experienced stigmatization in the workplace: *“I got fired when people found out about my illness. A person I*

worked with started talking about mental illness in her family ... I wanted to help her ... then everyone knew, and all of a sudden I didn't have that job anymore."

While Brendan had not experienced stigmatization at work, the fear of this possibility was great enough that he used the following strategy: *"I say, for work, that I have a learning disability, so I don't lose my job, because I'm afraid of the stigma."* Rachel had not experienced discrimination in her job but she, too, was apprehensive about the possibility of being stigmatized in the future: *"I'm a little bit fearful...I'm worried about the stigma, in my workplace. If they ever found out, then I'm worried that they would think I'm a freak ... I don't know what they would think."* For Rachel, this fear is likely heightened because when she first became sick, it was in the workplace that her symptoms manifested themselves: *"I felt as though I was being persecuted on the job – probably it was all in my head – I felt inferior, stressed. A couple of people in the workplace were very negative. I felt like I was being abused...."* These words recall Warin's (2000:125) comments in "The Glass Cage: An Ethnography of Exposure in Schizophrenia," concerning one of the participants in her research study: "it was because she was confronted with a change to her sense of being that she presented herself to a doctor. It was not because she sensed an increase in dopamine transmission in her brain, it was her changed experience of her everyday world." Mental illnesses are often experienced as a change in one's lifeworld, a lifeworld that then needs to be remade, which is a task that often requires more than medication.

Not surprisingly, Alexander does not speak of loss in relation to his mental disorder, as he views the condition as *"kind of good because it's special ... I enjoy it a lot."* However, he has experienced some stigma:

It really feels good when I get high. People think this disease is very negative, like it's crazy, strange ... because I guess, because we do act something embarrassing ... it's not our fault, just like cancer. People get scared, just like gays – people think gays are scary ... we don't do anything. People think gays are always thinking about sex, but it's not true. I have so much negative things, I'm immigrant, I don't speak perfect English, I'm gay, I have mental illness ... nothing good, but it's okay.

Like many others, he has not disclosed his mental illness to anyone at work, yet he is open with his friends and acquaintances about both his sexual orientation and his mental disorder. During the group interview, a consumer made a statement that Alexander would likely agree with: *“we are capable of a much greater range of behaviors and expressions whether other people around you like it or not ... I feel I get cheated out of my highs.”* The element of loss at issue is not caused by the disorder, but by the loss of potential of the disorder itself. Estroff (1981:107) who took a phenomenological approach to understanding mental illness, came across this sentiment in one of her informants: *“you know why I have to take lithium? It's so I won't get high. Society does that. Society can't get high, so they don't want me to; they can't understand. Being high is like physical heaven on earth. I can get so high. I'll have that all my life ...”* While the sentiments of Alexander were in the minority, his beliefs are important and will be discussed further in the chapter that follows.

A few people, including William, did not express serious difficulties working as a result of having a mental illness. He went through life not even realizing he had a mental disorder until he was diagnosed a few years ago. Previously, he had worked at many different jobs: *“I would rank myself as being very borderline, because I can function and I can do a lot of things ... can still go out and work, I worked this summer...”* Similarly, Jeff noted that he receives some AISH, but is able to work three days a week: *“I'm in the*

top one percent of people with this disease. I can handle it excellent – very high-functioning ... I guess lots of them try to kill themselves too, eh?” Carolyn was able to work full-time; however, she did note, *“I am not impressed with my performance’ ... lack of concentration ... could come back to me. I don’t feel I’m worth my weight in salt.”*

Tina successfully completed a number of degrees and now works full-time. She did not feel that her mental disorder interfered with her ability to work in any way; on the contrary, she partially attributed her success in the working world to having the illness. Frank would agree with Tina about his disorder being potentially beneficial to one’s capacity to work. He recalled that during his “*high*” moods he became very productive, and was able to do a lot of work. Frank started having symptoms about fifteen years ago, and was only diagnosed about nine years ago. In his following comment, Frank recognizes the difficulties that some may face, but stresses that for him, his mental disorder was helpful rather than a hindrance in the working world:

it seems to be a hell of a problem if you’re young, people with young families, like, I can see where it would be, you know, difficult to hold a job. And if you have a young family, some of the mothers raising children, I can see this being a real problem ... I think some companies are pretty good. A lot of em, more men, maybe, can be very productive in work ... the volume of work that I accomplished – it was appreciated. They’ll put up with a few things they might discipline someone else for.

During a group interview a consumer pointed out the value of work in coping with her disorder:

work of some sort has got me through most of my illness. Without work, through my depressions, I would have done absolutely nothing and stayed in bed twenty-four hours a day. No matter how much I couldn’t stand the concept of getting up, as long as I was at work, as horrible as I felt, I was still going, I had a purpose. And as long as I had a purpose for being alive, then I stayed alive.

This comment lends support to the idea of “work as a haven from pain...work is a means not only to fend off the intrusion of daily pain and depression...but also to conquer the essential traumas of personal life. Work...has the potential to be transformative as well as therapeutic (Good 1992:69). Similarly, Dianne said of her mental disorder, “*I’m okay with it because I do function as far as a job is concerned,*” implying that she is able to cope with her disorder *because* she is able to work; this statement reveals how important work is to her, and highlights the value our society accords to the ability to be productive. During one of the group interviews a consumer offered the following insight into the connection between work and her disorder:

there are other theories about bipolar – people with bipolar are able to work without reward. I find I’m like this. I go to work, man, and I’m like a plough horse – you can’t bug me, I’m workin’! It has been a really beneficial thing for me. I have tremendous stamina for work. I don’t have to be told I’m good at something. I don’t know if there’s an obsessive component to that ...

For Jenny, work was also very important; in fact, “*work is the most important thing in the world except religion ... now I’m a workaholic.*” Jenny experienced much loss in the working world, where she kept “*taking on these David and Goliath battles.*” Her first experience occurred when she “*decided that it was time the Lutheran church had another Luther, so I didn’t nail my theses on a door,*” but she did read a controversial letter at a youth conference. The letter, allegedly from a friend, outlined her resentment at the Church’s teaching that dancing was wrong. Such teachings were hypocritical, Jenny believed, because “*all good Lutherans danced anyway.*” Unfortunately, she was suspected of being heretical and suspended from her job.

Later a second traumatic event occurred: “*the next sort of revolution I decided to wage was I wanted to stick up for what was right.*” One day, she lost her temper and did

something that she still insists was a harmless act; while many people wanted her back to work, she was forced to resign, which resulted in a depression lasting several years. Still later, Jenny was working at two jobs: *“enough work for about three people, working on adrenaline ‘til Christmas time ... hyperactive, then back to school and I was really depressed. Then the next day I thought, I can handle this ... went like that when the whole thing started.”* Eventually, Jenny had to resign from her job at the school. These job losses were very traumatic; paradoxically, like Stacey, Jenny has found that work has helped her remake her lifeworld: *“work has helped me probably keep things ... the fact that I had work and this German work ethic, helped me cope.”*

For Ethan, work was not helpful in coping with his illness. He simultaneously completed two Bachelor degrees, which he was able to accomplish because he was “ill.” Later, he completed an education degree, and had a number of jobs, but the stress of work often brought on illness episodes: *“the problem is that I got sick all the time ... I tried to teach but it was too stressful ... I was going to get my Master’s degree, but there are only a few positions available to teach ... too stressful.”* In a striking statement that encapsulates experiences of loss in terms of both relationships and work possibilities, Ethan explains the impact that having a mental disorder has had on his life:

I’ve had to change lots of things ... work – I have to take it easy, relationships are a little difficult because currently I don’t fit in the world. I don’t exist in the real world ... I’m on the edge, I’m on AISH, I’m marginalized, I live in a marginalized community ... I don’t have a good regular job like everyone else. I have to live with what I’ve got. I don’t have a spouse because it’s difficult for me to meet people.

Lam also said that he felt marginalized, and experienced a lot of stigma: *“my close family and friends stopped talking to me completely. I feel a lot of isolation ... only thing that gets me going is therapy groups ...”*

Relationships, Carnage and More Stigma

It should not come as a great surprise that the theme of loss in terms of relationships arose for the majority of consumers, for “illness is deeply embedded in the social world, and consequently it is inseparable from the structures and processes that constitute that world. For the practitioner, as for the anthropologist, an inquiry into the meanings of illness is a journey into relationships” (Kleinman 1988:188). At a support group meeting, one member commented that his mental disorder, *“wreaks havoc on relationships.”* This *“carnage”* was evident in the experiences and the stories of others in the support group. During the group interview, a consumer angrily spoke of his mental disorder: *“I’m taking drugs to try to control it so maybe some day I’ll have a relationship – my relationships were destroyed by this! People that I loved! I see them and think, ‘I could have been with them.’ But it was because I was really sick and they couldn’t handle it.”* Lam was also very sick when he was hospitalized and *“that was the end of everything. My wife was distressed and wanted nothing to do with me, thinking she and my son were in danger ... I wasn’t really looking after my family properly.”* Lam sees his condition as having negative impacts on all dimensions of his life: *“it’s affected every single aspect of my life, socially speaking, religiously speaking, ... I used to have a wife, a car, a job – like the American dream ... now I’m a single dad.”*

Lam also pointed out that the treatment of the disorder can lead to relationship difficulties. Like many others, he complained of the numbing effects of the medications, which were highlighted during an uncomfortable visit:

my friend said, 'why don't you smile? You look tense all the time.' I didn't tell him I'm taking a lot of medications. I'm trying to force myself to smile; my son sees this glum-faced daddy all the time and might wonder if this is the normal way to be in life, without smile. I don't want my son to see daddy who never smiles.

Brendan outlined another way that medications can lead to relationship difficulties: “*for me, they make me fat and kill my sex drive; it's hard, because you want a relationship some day.*” Brendan had experienced loss in terms of personal relationships as a result of becoming ill and being diagnosed with a mental illness: “*I lost my first girlfriend of four years because she couldn't handle it.*” Later in the interview, he again laments the loss of a family life: “*I figure if I hadn't been sick, I would have been married. I probably would have had one child with somebody.*”

Similarly, Tina, attributed failed relationships to her illness:

I got married once, but the marriage didn't last very long – his main complaint was that I came from a dysfunctional family ... I have trouble accepting that as a reason ... another relationship didn't work out – that's when I really got sick and I was diagnosed. My depressions are related to failed relationships ...

Tina, who was successful in the working world, stated that the major way mental illness has affected her life has been in her relationships with men: “*I've always been accused of being over-emotional, I can get depressed quite easily ... that's always puzzled me, I don't know if it's the disorder ...*” Her confusion is over how much of her relationship difficulties are a result of her illness, and how much are a result of her personality or life circumstances: “*I can't blame it all on the illness – lots of people have this illness and are married and have children – I think the illness has a lot to do with it.*”

Dee, who had been married a number of times, also experienced much loss in terms of relationships:

...each time the person looked much better before the marriage ... masks will slip and you see the worst side; that, plus having to deal with the illness was too much for me. I just don't do well at relationships. I find the illness doesn't contribute very well to having a stable relationship, because I'm showing parts of myself when I get sick that I'm not even aware of.

Similarly, Patricia commented on the incompatibility of relationships and mental illnesses: *"I almost got married once ... you can't hold down a relationship when you've got an illness."* Andrew expressed resignation over this incompatibility: *"I've lost a lot of expectations that I could do for work or relationships ... I don't meet many girls."* Although in the past he has had a *"few girlfriends, nothing ever really worked out."* Like Andrew, Jeff has also lost many expectations regarding both work and relationships: *"I used to see myself with a family, a good-paying job and all that. I guess that wasn't in the cards ... I'm happy to be married, but it's different than I would have thought when I was a teenager."*

Dee explained how the process of being ill affects one's life and relationships after a breakdown: *"it takes three months to get out of it and then six months to recover from the breakdown. After that you look around and think, what have I done to my relationships."* It is this "fallout" from illness episodes that people spoke of as having tragic results, such as ending relationships which sometimes led to more illness episodes, and shrank the support network that many consumers so desperately need. Lyle also pondered this phenomenon when he questioned the efficacy of pharmaceuticals: *"there's so much residual fallout from a mood swing, you have to deal with so many other things,*

not just the pills. You have to work on relationships, routine, job ... so many things that can be affected.”

Many consumers could identify with Dee’s statement that, *“a lot of people don’t understand it at all ... I lost a lot of friends...”* Dee also mentioned that those who understand her condition the most are her friends that also have the illness. While Tyler had not experienced stigma because of having a mental disorder, he too, had few friends who did not have the same condition, and he explained that they understand because they are experiencing the same challenges. Like Tyler, Andrew stated that *“I don’t really have a lot of my old friends; most of my friends are people in the system who have the illness too.”* Similarly, Sarah says that, *“basically all my friends are persons with schizophrenia or bipolar, or some other kind of thing.”* She recalled relationship difficulties when she was quite young; she only had one or two close friends during her school years, and was *“basically a loner ... I didn’t trust people. I know now I had this condition then.”* Sarah also noted that having a mental disorder is *“hard on relationships and friendships; people who don’t understand the illness and doesn’t want to know – it’s hard to communicate.”* While other friends drop out of their lives, though, consumers are segregated in a world where everybody is mentally ill, leaving the mentally “healthy” with their misunderstandings and stigma.

Dee experienced the stigma of mental illness at an early age, as her mother also had a mental disorder: *“when mom had a breakdown everybody treated the family like we had the plague or something.”* When she developed the disorder, her *“brother and sister told me they were ashamed that I was their sister.”* Even her father, after drinking, commented that she *“was the biggest disappointment he had ever seen, because I was the*

first one to graduate ... I felt I had let everyone down.” Continuing in the next generation, the stigma seems too much for Dee’s son to bear: *“since he was twelve, he’s been on the streets ... he’s been so afraid to have the illness that he’d rather have anything else instead.”* Dee’s son would *“rather have a life with drugs than be diagnosed with mental illness,”* and being on street drugs, he does not have to worry about being diagnosed with a mental illness since a prerequisite for diagnosis is being drug-free for a certain length of time. The label, it appears, is more frightening than the symptoms. As Marilyn said with bitterness, *“once you’ve had that label of being in a psychiatric hospital, your whole life is turned around.”*

Lisa also experienced much loss: *“rejection has followed me all my life ... I haven’t developed good relationship skills because of my childhood, that’s what I’m thinking.”* While Lisa’s childhood was a very difficult one that included much abuse, she also relates her rejection and loss directly to her mental disorder. Lisa described what it is like living with her mental disorder:

sometimes it’s a living hell ... it’s hard, it’s meant losing a lot of friends. At church I had a lot of friends, but I started getting sick and the invitations got fewer and fewer and fewer. I had comments made to me, like, ‘how come you can’t control yourself,’ ... the attitude was, ‘get a grip,’ ‘you’re just letting your emotions run your life.’

Lisa recalls her reaction when her friends started avoiding her because she had a mental illness: *“I felt like it was my fault ... if I was a better person, and didn’t have this illness, then I wouldn’t have turned these people away.”* Because most people were avoiding and excluding her, Lisa eventually left that church: *“I don’t think there’s any place in the church for people with mental illness.”* While the stigmatization that Andrew experienced was not as explicit as it was for Lisa, it was enough to cause him to avoid

religious organizations: *“for awhile I went to church and Bible study, but the funny thing is, I never felt like I fit in there, eh, with my illness.”* Later, when Lisa asked God to find a church for her, and God directed her to a church, she, *“made a decision right from the beginning – I’m not going to tell people about my condition... there’s just still a lot of stigma about mental illness.”* Jeff made the same decision after he was rejected by friends and acquaintances: *“I used to tell everybody I had a mental illness, but they thought I was either crazy or dangerous, so now I don’t tell anybody because I don’t want that to happen to me again.”*

William is also very cognizant of the potential consequences of revealing his identity as someone who suffers from mental illness:

I never would tell my boss, or pastor, or anybody else that I have a mental illness, because of the stigma ... because of their warped views of people who have this condition. People might think ‘he might go weird any day now, and my children might be influenced by him, or have a bad experience with him, so we better spread that around and let everybody know’ ... and then I’d never find a nice lady to marry.”

William’s concern about not finding a mate was voiced by others, like Tom, who reflected on his failed marriage: *“she had me fooled right from day one; on my wedding day I still had doubts. I did it, maybe, because of my age, I thought I would never meet nobody ... getting too old.”* Brendan spoke of his search for a church, *“where I can fit in. A lot of people my age are married – that sucks for me because you feel like a third wheel.”* Similarly, when I asked Rebecca about her life dreams, she replied:

I would like to meet the man of my dreams, but in some ways I’m content to be single. I know now just getting married isn’t going to fix everything. Sometimes I don’t feel physically well enough to have a relationship. My dream is just to have someone to share my life with, a companion and hopefully a husband.

Rebecca is divorced and I asked if her marriage had broken up as a result of her mental disorder: *“he would say that ... a lot of it was due to both of us drinking alcohol, totally different value systems ...”* Tina, who is also divorced, looks toward the future with apprehension and questions that lack easy answers:

I had always wanted to be married and have kids and I’m getting old now; pretty well impossible to have children given this illness ... genetic factor in the illness. Should I adopt children? Is that a fair thing to do? What about getting married – how do you meet somebody knowing that you have this illness?

Similarly, Lisa looks toward the future with fear in terms of how her disorder will affect her relationships: *“I fear how it’s going to affect my relationship with my boyfriend ... sort of on the edge, never quite sure what’s around the corner. I’m afraid if he does see a lot of mood swings it’ll scare him off.”* Patricia also spoke of the element of fear that leads to stigmatization and lost relationships: *“you don’t have many friends with this illness ... people on the street don’t talk to me – the illness scares them off.”* Gary maintains that it is this fear of the unknown that is at the root of stigmatization, as people are *“afraid to discover something they don’t identify with.”* During the group interview the issue of stigmatization arose and one member commented that others think they should avoid her and are scared of her. Another member laughed, *“yeah, like you can catch it by touching ... like AIDS or something.”*

While Lisa, Jeff and William decided to keep their mental disorders hidden from everyone, when I asked Tina if she experiences stigma because of the illness, she said, *“I kind of know who to tell and who not to tell ... cause I have this other friend who’s totally alternative and I know if I told her I’m on medication, she would freak.”* This strategy of revealing one’s mental disorder to certain people one knows one can trust was also used

by others. When I asked Tom if he had experienced stigma, he replied that he has experienced some stigmatization, but has also, *“avoided it a bit because I’m afraid of being rejected. I won’t even go to high school reunions because I don’t feel I’m successful as far as everybody else perceives ... got nothing to show that I’ve bettered myself since high school. I know I have.”* On the other hand, Tom’s family members and friends who he has chosen to tell about his mental disorder are very supportive.

A number of consumers had experienced not stigmatization, but denial of their conditions by family members. As Ethan put it, *“my sisters and brother didn’t believe it; they just thought I was a malingerer ... my brother didn’t like the idea that he’s got a brother who’s nuts, not only a flake artist ... until his wife was diagnosed with the same illness, now the tables have turned.”* Sarah’s brother had a similar reaction: *“he says, ‘no, you’re not sick, you’re just lazy. You don’t have any mental illness, you’re not ill or deficient - just lazy’.”* When I asked if he had experienced stigmatization, William replied, *“only from my aunt and possibly my wife wouldn’t believe that I was mentally ill. Her idea might be that those people are loony tunes ... go up and down alleys collecting bottles and wear dirty clothes and smell bad.”* Similarly, Lam’s family in Nigeria do not, *“believe that I have such an illness, they just don’t. They say ‘you look normal to me.’ I said, ‘look at the bunch of pills I take.’”*

While Jeff’s family does not deny that he has a serious mental disorder, they refuse to become involved and learn what his disorder is all about: *“they didn’t want to talk to me about voices and that; said it’s crazy and we don’t want to talk about it, which I can kind of understand.”* Rachel’s family does not, *“necessarily believe that I have it and if I do have it, it doesn’t put a damper too much on who I am.”* Despite the fact that

her family may not be convinced that she is mentally ill, unlike most of the other consumers, she experiences anything but stigma as a result. In fact, being treated for her disorder has made Rachel feel much closer to her family: *“these are the people I have a history with – they know who I really am. They’re not going to treat me a certain way or have stigma about me – they’re loving and accepting.”*

On the other hand, Tina notes that many of her friends and family members, *“have been depressed, or in some way understand it,”* so she has not experienced much stigmatization. Lyle initially told me that he feels, *“blessed that I have my family and friends. Life is good. It isn’t good for everybody with this illness. Some people have suffered a lot of losses, lost everything they had ... I’m lucky I have the same wife.”* However, when I visited him months later in the hospital, he had a different perspective. Lyle wondered where all his friends were and why they had not come to visit. And his wife, who he had earlier felt lucky to have, had now betrayed him by having him hospitalized against his will. Frank has also experienced stigmatization by his spouse: *“my wife has actually declared me incompetent or whatever they call it and she’s cancelled me out of a couple of our chequeing accounts, which I was very upset about.”*

The persistence of this stigma was explained by Ethan, using a historical perspective: *“there’s a connection through hundreds of years of psychiatric illness, connected to Satan, evil, madness, witches ... medieval folklore that still exists now. I’ve had people who’ve said, ‘you must have done something in a past life to perpetuate this.’”* Marilyn, whose family members were *“good Catholics,”* recalls that her mother believed she was possessed by the devil, and had a priest pray over her; however, Marilyn now feels that such beliefs are rooted in ignorance: *“People associate mental illness with*

possession and they're nothing the same. You may feel like you're possessed but they are truly symptoms of a disease." Later Marilyn repeated her belief that many religions have superstitions about mental illness, and that *"we really need to educate religions about mental illness."*

Brendan, who was raised Baptist, also believed that it was important to educate pastors and other religious leaders about mental illnesses so that they do not attribute them to demon possession. This misconception was also spoken of by another consumer during the group interview when she explained that she did not disclose to members of her church that she has a mental disorder:

*If I told everybody, I might be ostracized, or they'd try to cast demons out of me. It's really hard to convince some people that you can have voices because of your mental illness, and it's not demonic. I believe in spiritual warfare and praying against demonic attacks – if you pray and the voices leave, they may have been demonic, but if you pray and they don't leave and you take medication and **then** the voices leave, it's biochemical. Demons don't respond to Haldol!*

This subject also arose in another group interview where one member stated that *"the church criminalizes you, not really criminalizes you, but if you have a delusion, they think you're possessed. If you're talking to me, they think you're talking to demons."*

Others agreed that some churches are still *"in the dark"* with respect to mental illnesses.

Other attitudes Ethan has come across included the idea that people like himself with mental illnesses, are mentally criminally insane. When I asked Sarah whether she experienced stigma because of her condition, she replied,

in some ways, yes. One time I was arrested ... because I kind of had an outburst. They thought I was drunk and disorderly, but it was my illness ... yelling and screaming. They threw me in the drunk tank. The police are now starting to understand it, taking more courses. The bus drivers, at first they didn't understand; thought people were being obnoxious on the bus.

Brendan felt that the media continues to criminalize individuals affected by mental illness: *“the media hypes it up and makes us all look like axe-murderers if one guy with schizophrenia or bipolar murders his mother ... I can’t even kill a bee.”* Gary also spoke of the news media as being sensationalist, and noted that back home in Eastern Canada where he grew up, *“I was not diagnosed because the condition was considered taboo, and the mentality there was lock ‘em up and throw away the key.”* He later explained that along with the media, the doctors and some of his family members also felt this way.

Jenny’s story did not express loss in terms of relationships; indeed, she has been married for over twenty years. However, she did indicate that her relationship was strained. In particular, her husband gets upset when Jenny takes most of a day to do what usually takes only a few hours; she gets distracted and time goes by unnoticed. Her husband is also distressed over her habit of excessively scrimping and saving: *“my husband often says, ‘you don’t want to waste anything and yet you’re wasting yourself’ ... it’s true.”* When I asked Jenny whether she had experienced stigmatization because of her condition, she said, *“I don’t encounter it because nobody’s got the guts to say it to my face ... my husband sure encounters lots of it.”*

Carolyn was one of the few consumers who did not really feel stigmatized as a result of having a mental disorder. Perhaps this was because she was high-functioning in the sense of being able to work full-time, and could get by without many people knowing that she had a mental disorder. While Carolyn was single, she did not feel that her condition had caused loss in terms of relationships. On the contrary, Carolyn noted that she has benefited in the social arena, as she has been forced to slow down and take more time for people. Tyler also stated that he has met a lot of new friends who have the same

mental disorder as he does, and did not express loss in terms of relationships. Indeed, he believed his condition enabled him to better understand and relate to others, a conviction that a number of other consumers also expressed, and will be explored further in the next chapter. Stacey also expressed no loss of relationships as a result of having a mental disorder: *“I’m blessed. I’ve got lots of significant friendship relationships. My friend Shawn has been there through suicide attempts ... blessed with the most wonderful friendship structure that anybody could ever ask for.”* She also spoke of the support that her church provided her: *“it was anything but stigma that I got, it was empowerment.”* While she spoke of getting into abusive relationships, Stacey attributed this to the abuse that she experienced as a child, rather than to her mental disorder.

Perceptions of Time

Schutz (1962:214-218) explained that the experience of having a “common time perspective,” is a feature of the “everyday world.” However, when individuals are faced with mental illness, time is reassessed and people experience time differently than others. Time is perceived as lost when one has an illness episode, particularly when one is hospitalized. Lyle, who has been dealing with his mental disorder for over twenty years, addressed this issue when he spoke of how the illness has been an obstacle, and *“made life more challenging, because there would be mood swings to deal with. At the time, I just kind of got through it ... in a way, it has shortchanged me of large chunks of time out of my life because I had to be hospitalized or the medication - didn’t feel well on.”* Lost time is also lamented by Marilyn, evident in her explanation of how her condition has prevented her from returning to university:

I'm already too old. The illness and the time lapse ... twenty years have gone by. If I had gone right back to university after the first break, it would have been different. Because of the time lapse and the amount of life experiences I've lost and knowledge ... makes it very difficult to go back.

Time is often perceived differently from before one became sick. Brendan expressed a sense of time rushing by when he spoke of his desire to sleep when depressed: *"I want to hide from the world and try to sleep it off, but it can be overkill – you sleep too much and life's passing by."* As Marilyn notes, time does not flow, it "flashes:" *"you wake up and twenty years has gone by – time has a different meaning when you have this condition. It's like time flashes by like a blur."* Referring to periods she called *"the dark side of the soul,"* when she stayed in bed in a semi-catatonic state for a year, Marilyn said, *"it left a twenty year vacuum, like being in a coma for twenty years and waking up and all you've done is been dormant for twenty years."* While time "flashes" by outside of one's reach, one is "slowed down," internally: "inner and outer time, what Schutz calls "duree" and "cosmic" time, seem out of synch. ... Pain slows personal time, while outer time speeds by and is lost" (Good 1994:126). Rebecca, who had a similar experience of lost time, said that one medication gave her insomnia, *"but I was so desperate at that point, I said, 'I don't care, because I don't want to sleep another two years of my life away.'"*

Time is also perceived as interrupted. Speaking of his inability to work at a job long-term, Brendan says, *"I feel like every couple of years, I'm starting over."* While the losses that consumers experience are many, to view chronic illness only in terms of loss is a simplistic assessment, as there is usually a response, the goal of which is to preserve one's identity (Sacks 1998:6). Sarah expresses this reaction, at the same time

highlighting the perception of time as interrupted, when she talks of one of her hopes for the future:

I would like to see an end of the stigma of mental illness. At first I wouldn't do any interviews ... I believe that if we talk more about the illness and let them know we're not wacko, we're not insane ... we have our moments when things are interrupted, but we can cope. And we can do and understand as much as the next person. It may take longer because concentration goes back and forth. I believe any person with a mental illness can achieve anything.

Tom had the same response to the question of stigmatization: *"gotta just crush the stigma, cause we aren't psychos, you know ... it's good to see people even thinkin' about the spiritual aspect – is there somethin' to it?"*

The various comments concerning suffering caused by losses of work opportunities, relationships, and time, as well as the pain caused by misunderstanding and stigmatization confirm Kleinman's (1988:28) viewpoint that taking a scientific or medical perspective fails to help one deal with the problem of suffering: "they arrange for therapeutic manipulation of disease problems in place of meaningful moral (or spiritual) response to illness problems." This chapter has also demonstrated that what most of us take for granted – the ability to work, develop relationships and experience time as a steady unfolding – are for consumers great challenges that are often unrealized.

CHAPTER THREE: QUESTIONING WHETHER MENTAL ILLNESS IS A ‘GIFT’ AND CRITICIZING THE CURRENT TREATMENT

As noted in the previous chapter, there are many difficulties faced by individuals affected by schizophrenia and bipolar affective disorder, which often seem insurmountable. As we will soon see, the treatment can cause even more problems. Despite all of this, or perhaps because of it, the majority of interviewees were able to identify something of value in their disorders. The “gifts” that will be discussed include creativity, a sixth sense, becoming closer to God, friendships, an understanding that everyone suffers from something, and the ability to empathize with and help others. In the second half of this chapter, consumers’ thoughts on hospitalization will be explored, as will the lack of information given to consumers regarding their diagnoses, and complaints about individual psychiatrists, such as lack of empathy, disrespect for religious beliefs, and over-medication. While some consumers were satisfied with the treatment that they had received, others had many complaints.

Gifts and Blessings: The Value in Mental Illness

The notion of mental illness being a gift was a topic that had the potential to provoke much controversy. In the literature I had read prior to starting fieldwork, I came across the notion that mental illness, particularly during psychosis, could be viewed as a “gift” in terms of helping people to find meaning in their madness and lead them to recovery. I was also aware of the popular notion that people with mental illnesses are more creative than others, and in some way, “touched by God.” I also spoke with a psychiatrist who takes patients on spiritual retreats, and asks them what gifts their illness

has given them; initially offended by the question, at the end of the weekend they identify a number of the same “gifts” that my informants discussed.

As part of my individual interviews, I included the questions, “Is there a deeper meaning to your illness?” and “Can you think of any parts of your illness that have value in a spiritual sense?” During the group interviews this issue arose again, and there was some debate over the validity of the notion of mental illness being a gift. When one consumer insisted that mental illness was not a “gift,” another consumer responded with the following:

I believe I have been enriched by my illness because I think I've had a wider expression of emotion because of it ... I feel it is very progressive, it's very creative, it's very advanced and I think you can relate in a different way to things because of it; your perspective is different. The experience gives you enrichment, you could say it's a gift; well, I guess you're dealt whatever you have to deal with.

On the other hand, when someone suggested that mental illness could be a gift from God, another consumer cited suicide statistics: “no one ever talks about it in these rooms – seventeen to twenty percent, one out of five bipolar people die by their own hand! I don't know if it's **God** giving you bipolar illness – he must be evil or she must be evil because I think it's pretty bad!” He went on to say, with a sly smile, that, “I'll admit that it has given me incredible advantage ... abundance of energy and incredible fun – which I won't go into.” Later, this consumer elaborates on his challenge to the perspective of mental illness as a divine gift:

I don't think it's a gift, but I can understand why people say it's a gift. I think it's because they've seen people who have been “ill” and very productive and creative, but ... they don't understand the torture that has gone on in that time of creativity ... and it doesn't last long. If the person had a steady existence, I think they'd be much more productive and creative...

Frank would likely agree. During an interview, he recalled some members of his support group who spoke of his condition as a “gift,” but insisted, *“I don’t see it as being a gift or a penance – to me, it’s just something that happened.”* Ethan would agree with Frank. He explained that the belief held by many that his mental disorder is a wonderful, God-given gift that enhances creativity, is a misnomer:

From my experience, a lot of people who think they are creative aren’t...it’s enabled me to have more energy, clarity, be more ambitious ... Exhibition deadlines, I cranked out a lot; I don’t think that in a normal state, I could have done that ... I’d prefer not to have this illness because then I could have normal consistency in the way I work. ... this so-called “gift” is not very much different from someone who is “normal” who decides, ‘I’ve got a deadline and I’m going to crank this out and I’m going to work hard,’ and they do good work. ... only thing is that the perception of the person who has the illness is heightened, sensations, seeing things faster, experiential understanding of what’s going on is different.

Ethan’s comments on the “gift” of his mental disorder also shed light on his views about normalcy, an issue that will be explored further in the chapter, “Self-Identity, Disability and Normalcy.”

In contrast, a number of people believed that mental illness is a “gift,” and discussed the association with creativity. Sarah noted that even her doctor told her that people with mental illnesses are generally much more creative than others. And another consumer explained that before he became ill, *“it was hard for me to do things, like normal things, like reading, or watch a program ... later, forget about it. It’s a gift because I could concentrate easily, almost like guidance – do this and this – like the path to do poetry ... when I was ill I could do it.”* During the individual interview he explained that he writes poetry, and when he was ill he created a unique style: *“the illness helped in creativity – one blessing, I really have to give credit to the illness.”*

William agreed that there was a link between mental illness and creativity: *“a lot of people with mental illness are more creative. I’m creative when I write, but then I don’t want to have a lot of other things to do.”* Similarly, Brendan attributed his creativity to his mental disorder: *“I’ve always felt like a scatter-brain, but when it comes to writing music, it makes it pretty beautiful, actually.”*

Of all the interviewees, Alexander was the most convinced of the link between creativity and mental illness; he told me that when he is manic he can write very strange and creative stories, the origin of which he is unaware. Alexander’s mental disorder was viewed in a positive light and seen as special:

Only one per cent of population have this disease. And lots of writers and painters and composers have same disease. That mean maybe I could be a good writer some day because of this disease. It’s strange. I don’t think ordinary people feel this colour and this light and these crazy things in my brain – it could be really good for creative work.

If it is true that “sickness begins when the condition becomes unwanted ... sickness is in the mind and heart of the beholder – the patient” (Hahn 1995:31), we would have to admit that Alexander is not “sick” at all. Later during the interview, Alexander expressed amazement at his ability to harness the energy of the illness and use it for his creative work: *“now I enjoy this disease too much – I’m using this for my creation. Write stories, ideas come faster than my writing and after a few days I read this again, and it all makes sense! How can I write this?”*

Dee expresses similar astonishment about her artistic ability: *“a lot of times my art will piece different things together for me; a lot of times I’m amazed by what I create and didn’t realize I had that in me.”* The idea of mental illness enhancing creativity is given a new twist by consumers like Dee, who believe that mental illness is part of a

unique ability that has not been developed in a nurturing environment. For her, part of the value in her condition was feeling like a healer in the hospital. Her activities of “healing” people with damp cloths, handing out garlic if a vampire was sighted, and making a magic hat, led a nurse to insist, “ ‘Dee, you’ve got to stop what you’re doing ... because the other patients think you’re something that you’re not’ and she never did explain what that was.”

Tom believes that mental illness could be a “gift” that is not nurtured in our culture, and when I asked if he believed there was a deeper meaning to mental illness, he said, “yeah, like a medium type thing, medicine man; that’s not taught or nurtured because it’s all materialistic things nowadays. If we nurtured [pause] it may turn into a gift instead of something that’s out of control and not known about.” Tom began to suspect that there was more to his condition than merely a chemical imbalance because of the, “different things I see, sometimes I think, ‘young men will see visions and old men will dream dreams,’ that’s how I used to think before I was medicated. I still believe it to a certain degree but I don’t share it with everybody or I’d be locked up still, you know.”

Tom expresses ambivalence about the nature of his mental disorder and the “gift” that it may bring, which includes creativity:

I sometimes think it’s a blessing and a curse as far as my head being full of snakes, seeing eyeballs, or comin’ up with neat ideas and they actually work; other, thinking people laughing at me and stuff ... there’s good things about it but there’s bad things about it too. No! How can I say there’s good things about it! No, no I can’t say there’s good things about the illness, but I know, just the way I am, there’s good things about me. ‘Blessing,’ I don’t know if that’s part of the illness or if that’s the gift, or me. It is a curse, it is.

Tom was initially convinced that his disorder was a gift from God, and that he was hearing God’s voice as the prophets did, and he continues to believe that mental illness is

both a chemical and spiritual imbalance. Tom would probably agree with Boisen (1936:115) when he reflected on his own “exploration of the inner world.” “I believe therefore that this experience of mine, with all its pathological features, was akin to that of the prophets of old. Furthermore, even though the psychologists disagree, I believe that such experiences do serve to reveal new truth.”

Tom’s beliefs were reflected by another consumer, who described a program she had watched:

It went as far back as caveman times where mental illness had shown up ... maybe God wanted people like this here and there’s a reason for them to be here. Like shamans in native Indians, or medicine men in Australia ... they share visions and people realize twenty percent of the visions have something to be listened to ... without all that creativity and insight ... we’ve lost that and now call it a disease and not recognizing these people are creative need our help.

During the next group interview, this consumer offered a more concrete and contemporary example to support her belief. She told the group about an article concerning a physics professor who had bipolar affective disorder. When he was manic his students wrote down his ideas, and found that twenty percent of them were intelligent and opened a new area to explore in physics. Another consumer expressed agreement in her comment that “*as God takes away, He also gives us; other parts of our brains are more creative.*” These consumers, along with Tom and a number of others discussed earlier can likely relate to the statement that Boisen (1936:115) makes about his “disturbances:”

The theory which I am advancing still rests largely upon the deep personal conviction regarding the value of the two experiences through which I have passed. Even though there has been mental disorder of the most profound and undeniable variety, they have yet been for me problem-solving experiences. They have brought to me the right answers to certain important personal questions. These periods have, moreover, been fertile in all sorts of ideas. They have opened

up, as by powerful flashes of insight, new avenues of service and new vistas into the great unknown.

The idea that individuals with mental illness may possess more creativity and intelligence than “normals,” was interpreted differently in the 1940s and 1950s, and is summed up in a statement by Dr. Abraham Myerson:

I think it may be true that these people have for the time being at any rate more intelligence than they can handle and that the reduction of intelligence is an important factor in the curative process. I say this without cynicism. The fact is that some of the very best cures that one gets are in those individuals whom one reduces almost to amentia [simple-mindedness] (cited in Whitaker 2002:73).

Jung and Boisen believed that religion, or the “quest for wholeness,” is at the root of many mental illnesses (cited in Shorto 1999:68). It is not surprising then, that a number of other consumers explained that mental illness had value in a spiritual sense. Initially, when I asked Tina whether she saw a deeper meaning in her mental disorder, she replied, *“I don’t – I’ve looked, I’ve tried. Thought there must be something good to come out of this. I just think it’s been bad luck – sounds fatalistic. I’ve never seen it as a learning opportunity. Oh, initially I was into it as soul-searching. Not now ...”* At the end of the interview, however, when I asked if her illness had value in a spiritual sense, Tina explained that her spiritual beliefs had deepened: *“I feel closer to God. I know this sounds kind of, um, trite, but, I really feel I’ve gone through tremendous amount of suffering with this – it does bring you closer, you can’t help but cry out for help. And God did respond in a comforting way, and God did respond!”* In particular, it was the mixed states, where mania and depression are experienced simultaneously, that were unbearable without the help of a higher power. Tina agreed with a psychiatrist who said that mixed states are the most intense human suffering anyone can experience.

Lam, who had experienced mixed states too, also saw value in mental illness in that it turns one toward spirituality and draws one closer to God:

when you're really down and you go beyond your rope ... you start crying and start asking God for help – 'look where I am, look what I am, look who I am, I need help' ... sometimes even thinking about family doesn't help, so then you have to reach for spirituality, for something that created you, to say, look, look at me ... what's going to happen to me? It's just a very desperate cry.

Similarly, Stacey developed a stronger faith, which helped her cope, knowing that she could survive with God's help. It also helped her to know that there was a purpose for her suffering. Stacey reflected on her experiences with mental illness, noting that, *"I have a greater appreciation for life because of the fact that I'm getting help and things getting more stable and I've been that close to death. I watched a lot of my friends attempt suicide; greater appreciation for what life is – not something to throw away."*

Following Gary's second suicide attempt, he realized that God was giving him the message that He still had plans for him on earth, and a spiritual renewal occurred shortly later. Gary spoke of trying to put his condition in perspective: *"I don't see the illness as a curse anymore but as a blessing because of my spiritual awakening."* Rachel interpreted the disorder itself, in a spiritual light, believing that she was under attack by the devil, and that experiencing the symptoms of the disorder was bringing her closer to Jesus. She described the value in the illness as, *"making me want to grow more spiritually; I guess the thought that the devil was attacking me and demons attacking me has made me grow more spiritually – gave me a bit of a scare."* Jeff also believed at one point that his mental disorder was demonic, and pointed out the value in the illness: *"it has made me come into a relationship with Christ. I wouldn't have become a Christian or met my wife, if it wasn't for this condition. I'd probably be drunk right now, and into*

drugs.” These responses to the question of whether there is value in disorders lend support to Kleinman’s (1988:144) conclusions regarding coping with chronic illness:

shocked out of ordinary reality by handicaps or the threat of death, we turn to those sources of meanings that inform our life world. Meaning is inescapable: that is to say, illness always has meaning. The experience when ill need not be self-defeating; it can be – even if it often isn’t – an occasion of growth, a point of departure for something deeper and finer, a model of and for what is good.

When I asked Jenny if she could find anything of value in her mental disorder, she said, *“oh, I think so; Lutheran church is so strong on this – never forget that you’re a sinner. It keeps me humble, like the Western song, ‘Lord, it’s hard to be humble, when you’re perfect in every way.’ I got a perfect way that everybody and his dog can see ...”* Similarly, Brendan felt that his illness keeps him humble, and equated his mental disorder with the *“thorn in the flesh”* that God told Paul would make him stronger. Brendan believes that the disorder can be seen as a *“blessing”* given by God so that he would always desire closeness to Him. He also believes that like Paul’s thorn, his illness will make him stronger, *“because it helps me to depend on Him all the time, even if I was rich, I’d have a better understanding of how I could help others like myself because I’ve had to walk through all the shit ...”* Here, Brendan brings up another *“gift:”* understanding others, compassion, and the desire and ability to help others.

Considering what we have learned about how having a mental illness can wreak havoc on relationships, Carolyn’s response to my question of whether there is any value in her condition, is paradoxical: *“I’ve slowed down mentally; taking more time for people. It has really helped me socially. When working hard I’m not as sociable ... now, not as curt, or thinking about work and money. I make good times with people.”* Not only is she fastidious about making her leisure time count, but Carolyn’s entire attitude

about people has changed and she speaks of the “gift” that Brendan brought up: *“the illness has brought out compassion in me and understanding. People in their twenties – very little compassion for illnesses, but they are just starting out and they’re busy, don’t want to have anything to do with anyone with illness. I was definitely in that area.”*

Similarly, Tyler spoke of his recent return to church after a period of over twenty years during which he did not attend church services:

it could be God trying to tell me that you have this certain gift which sometimes this condition is, and sometimes it’s a pain in the neck. Can be considered as ‘gift,’ a good thing, because it brings you back somewhat to reality; you can understand what other people are going through – helps you sort of relate to other people.

Clearly, “things are what they are experienced to be” (Dewey 1905:228), rather than what they are theorized to be; despite the fact that the literature on schizophrenia and bipolar affective disorder points to extreme difficulty in establishing and maintaining relationships, several consumers report that their disorders actually help them socially.

Lyle was one of these consumers. Reflecting on his experience with mental illness, he noted, *“it put me on a learning quest – supporting other people that have had depression, difficulties, being helpful with whatever skills or ways I can.”* Lisa had experienced a lot of stigmatization by church members, and initially felt anger towards God for allowing her to develop a mental disorder. She now realizes that there may be higher purposes for her having the illness: *“... in the future, I could help others because of what I’ve gone through ... I believe it opens up doors to see the world in a whole new way. It’s made me a stronger person and helped me to identify with so many people; I’m able to relate to a whole new group of people.”* At the end of the interview, Lisa repeated her belief that her mental disorder has, *“made me a stronger person, more*

compassionate, made me who I am today. I see part of what I've been through in my life as a 'gift.'” Along with a number of other consumers, Lisa has responded to the “problem of suffering,” with a “religious response.” Geertz (1973:108, emphasis added) explains that unyielding pain and loss cause us to suspect that order does not exist in the world, leading to the “religious response:” “the formulation, by means of symbols, of an image of such a genuine order of the world which will account for, *and even celebrate*, the perceived ambiguities, puzzles, and paradoxes in human experience.”

Sarah explained that the value in her mental disorder has included the fact that she, “*can help explain to others who are newly diagnosed ... tell them it's not all that bad. I made some really nice friends. Where I thought I would be nothing because of this disorder, I've learned I'm able to cope and learn.*” Like Sarah, another consumer felt that part of the “gift” was getting to know all the wonderful people he has met since being diagnosed. Even Ethan, who is adamant that mental illness is not a “gift,” noted that some good things resulted from his mental disorder: “*it has allowed me to meet a lot of really interesting people – kind of a blessing. When I'm high, I feel great, feel very intense, things have resonance. People I've met have become important to me.*” These words, which contrast so sharply with his earlier statements, support the idea that “the world is never something finished, something which thought can bring to a close; the world is always in the making, and our thoughts, like our actions, have meaning only in relation to the practical and social life in which we are engaged” (Jackson 1996:4).

For some, compassion was also extended towards oneself. As Tina put it, “*I think I've become more gentle and loving towards myself and other people. Before I thought I was so much in control ... used to be kind of hard on myself.*” The motivation for such

compassion and helping behaviour seemed to be one's own suffering, and the realization that because one has stood in the "place of excrement" (Yeats 1933), one has the unique ability to relate to and help others who have mental disorders. Only one interviewee expressed an antithetical response regarding compassion for others. The only value that Patricia was able to find in her mental disorder was that some of the voices were pleasant; she had become less religious after developing her illness because, "*when you suffer that much you don't care about people.*" Patricia's experience contrasts sharply with Dee's experience with mental illness. When I asked whether there was a deeper meaning to her illness, Dee replied, "*we're all connected, we're all part of each other and with the illness, you become more aware of that – can try to use it as a learning tool.*" The common response to this feeling of unity was compassion, and like many other interviewees, Dee noted that she feels a natural desire to help others.

A number of interviewees responded to the question of whether there was anything of spiritual value in their disorder, by citing the realization that they are not alone in suffering; everyone must struggle with their own problems, and many realized that their suffering paled in comparison to that of others. As Tom explained, "*I've learned that everybody's got a hurdle they have to overcome – it made me accept my fellow man. Nobody gets off scot-free. Some people have bigger hurdles than others, but we also got bigger springs, we can bounce over the hurdles!*" Later during the lengthy interview, Tom repeated this understanding: "*I talk to people and realize everybody's got something they got to overcome, or cross they've got to bear. Some people are way worse off – got all the money in the world and yet the crosses they got to bear – wouldn't want to be in their shoes.*"

Some consumers came to this realization while in the hospital. Brendan recalled being angry with God while he was on the hospital psychiatric ward, and, *“then I’d see a guy with no legs and I think, ‘why am I complaining, I could be in Africa and starving and eatin’ bugs for supper.’”* During the group interview, one consumer recalled that he had been a *“staunch worrywart”* before the eye-opening experience of being hospitalized following a suicide attempt. He insisted that when he left the hospital he was, *“not any better, but the experience opened my eyes that there were people far worse off than I was.”* Jenny was also motivated to make changes because of a parallel realization resulting from her mental disorder: *“been an eye-opener – makes me realize I’m not nearly as bad off as so many other people; maybe I should get off my ass and do something with my life and my husband – for my husband.”*

William, who attributed his condition to birth trauma, noted that there are, *“lots of people that are in the same boat that I am – skiing accidents, etc. and they couldn’t help it.”* Stacey goes as far as stating that everyone is created with some type of disability; no one is perfect, and everyone has weaknesses to deal with in order to function in society. In a related vein, Marilyn noted, *“we’re not brought up to understand that as well as the heart can become broken, so the brain can become broken; and, nobody gets through life without getting something.”* While we are not taught these lessons, these consumers make clear that they are learned when one is faced with serious illness:

the moral lesson illness teaches is that there are undesired and undeserved pains that must be lived through, that beneath the façade of bland optimism regarding the natural order of things, there is a deeper apprehension of a dark, hurtful stream of negative events and troubles. Change, caprice, and chaos, experienced in the body, challenge what order we are led to believe – need to believe – exists. ... For the seriously ill, insight can be the result of an often grim, though occasionally

luminous, lived wisdom of the body in pain and the mind troubled (Kleinman 1988:54-55).

It is not my intention to romanticize mental illness by insisting that it is a “gift.” However, being open to the possibility that for some consumers, schizophrenia or bipolar affective disorder gives them something of value, such as creativity, deepened spirituality, or compassion for others, is necessary if a phenomenological approach is followed. Moreover, the issue is not whether the “gift” actually arose from the illness, but that faced with serious mental illness, consumers create meaning and believe that there is value in their experience of suffering.

Institutionalization: Care and Healing or Control and Abuse?

In some cases, it was the understanding that mental disorders were “gifts,” that led to harsh criticism of the way conditions were medicalized and treated as illnesses. Before relating the following vignettes that paint a disturbing portrait of the quality of care in hospital psychiatric wards, it must be noted that a number of consumers expressed neither satisfaction nor dissatisfaction with hospitalization experiences and a few interviewees spoke of positive experiences while hospitalized. Carolyn, for instance, was very appreciative of the nursing staff from whom she gained much information about her condition. She also found socializing with others who had mental illnesses to be very “*enlightening*,” particularly when discussing the efficacy of medications. Dee would likely agree with Carolyn, and went so far as to say that, “*it’s through talking more with patients on the ward that we get well; realizing, hey, we gotta get this into perspective.*”

On the other hand, Marilyn's description of her experience in a psychiatric ward outlines the many losses of freedom that contributed to her feeling like a "caged animal:"

Back in the late eighties, still such a stigma associated with being in a psych ward – it criminalizes you. They like to criminalize you, like it's your fault; put you in there, you can't wear your own clothes, can't leave the ward, force drugs down you. I felt like I had done many things wrong to be there, felt like a caged animal. It's a whole different life in the psych ward. On my unit, a couple of girls got raped. I was just terrified, angry about having to be there, having all my privileges taken away, angry because I knew this would affect the rest of my life.

Marilyn's statement offers a glimpse of what the stigma of being in a psychiatric ward feels like. During the group interview, one member recalled negative experiences when he was hospitalized: *"I always felt like somebody else is your caregiver or takes over – I'm not sure that it always is in your best interest. It maybe is for all of them ..."* He also expressed his distaste for the controlling atmosphere in the hospital psychiatric ward and offered a view that some other consumers would agree with, about why individuals like himself are hospitalized:

... other people can't cope and it's medically correct to put you in the hospital and give you Haldol and bring you down, make you sleep and keep you from buzzing around twenty-four hours a day. Putting you back in a normal sleep mode of eight hours, a certain time at night they want you in bed, three meals a day – you get regimented when you're back on the unit in the hospital.

The discussion during the first group interview concerning psyche-spiritual therapists who believe that individuals with mental illnesses should be allowed to take what is spiritually valid from their experiences, rather than be medicated, may have been remembered by this consumer. During the next group interview a month later, he insisted that *"we are capable of a much greater range of behaviours and expression whether other people around you like it or not – what if they put all of us in one place and let us be high?"* He is referring to treatment such as that introduced by the Quakers of York,

England in 1796. Unlike the bleeding, blistering, purging, and “drowning therapy,” to name only a few of the previous treatments, the Quakers ensured that patients got lots of fresh air and exercise, and were given opportunities to read, write and play games, methods which led many patients to recovery (Tuke 1964:123,181). This “moral treatment” was revived once more in 1971 when Loren Mosher opened the Soteria house in California. Like the Quakers’ retreat, this house was staffed not by professionals, but by empathetic people, who would simply “be” with the patients, without trying to convince them that their beliefs were irrational (Mosher 1978:716). Symptoms decreased similar to those on medication, they stayed well for longer periods, and functioned better in school and at work (Mosher 1978: 722-723).

Sarah would probably prefer this “moral treatment,” as she disliked the regimentation, which is outlined in her description psychiatric hospital wards: *“you can’t wear what you want, gotta eat when they say, gotta do this, can’t do that, starts laying down regulations – I’m not good at that ... I’m very rebellious.”* Sarah did not like the strict rules governing patients’ behaviours because they infringe on personal freedom of choice. On the other hand, one of the consumer’s opposition to what occurs in psychiatric wards was largely a result of his belief that people should not be stifled when experiencing heightened creativity: *“to some extent I think it is inhumane the way psychiatric wards do that – straitjackets, medications, shock treatments ... I don’t know – is it because the doctors don’t know what to do with you anymore or your children or spouse just can’t cope?”* Another member of the group interview agreed, but added a cautionary note: *“I can understand what you’re saying, because restraint – it’s criminal*

actually, in many respects, to shut people down. On the other hand, when people are way out of control, it doesn't serve any purpose; they're a danger to themselves ..."

Distressingly, hospitalization was often experienced as controlling and harmful, rather than as a haven for recovery. Dee also had memories of the lack of help she received while in hospital: *"all your clothes are taken away, all the sheets, you're just with a mattress and nude, and they flash a light on you every fifteen minutes ... all because you didn't want to live. How do you recover after something like that?"* Dee added that hospital staff believes they are kind now, as they did far worse things in the past. Patricia, too, recalled being locked in a side room in the hospital, and noted that it simply is not fair.

Stacey had been very impressed with the treatment program that she had attended in the United States. However, she had nothing good to say about the, *"Alberta approach,"* which she described sardonically: *"you don't really get therapy, you get hospitalization, you get to see your psychiatrist and yeah, you can talk to the nurses if you want."* Later, Stacey expanded on the state of this mental health care system with this scathing critique:

It's completely idiotic! What do you expect when you take a bunch of people and throw them in a locked psychiatric ward with a bunch of other sick people, you understaff the nurses, you give them a whole bunch of meds and if you're lucky, they'll see a psychiatrist every day for ten minutes ... that is so substandard. We don't have the type of treatment necessary in Canada to deal effectively with the disorder. A lot of people would be a lot further if they got the type of treatment they needed right off the bat instead of being allowed to go downhill ...

Stacey had a similar criticism about the day programs in the hospitals, which she said provide *"mediocre-level therapy."* The problem, according to Stacey, was the seemingly irrational regulations governing the group sessions: *"they talk about life skills, but you*

can't have any communication with people about anything that relates to being sick, anything about your life. I just don't understand how you can function in a group environment effectively if you don't know anything about them!"

In the Dark: Psychiatrists 'Fishing in a Hole' and Patients Left Wondering

Ethan was also pessimistic about the possibility that consumers could receive help while in the hospital, and highlighted a common complaint among consumers – the paucity of explanation and information given out regarding their illnesses:

The doctors, they don't explain anything. ... I should have been hospitalized for two more weeks. I was blitzed! A nurse gave me a pamphlet that was poorly written, and told me I have this mental disorder. I go 'no shit.' I talked to some other people and they've said the same thing – they're virtually kicked out the door and here's your meds and see you later.

William had a similar experience, in that none of the hospital staff explained what his disorder was all about: *"the psychiatrist doesn't explain it – he writes out a prescription for me and that's it; not even the nurses, two nurses put a brochure in my bag that said 'Face it, you have schizophrenia!'"* Rebecca was not even given the benefit of reading material on her condition. She told me about going to see a psychiatrist when she started hearing voices at about twenty years of age; he assessed her and gave her a letter in a sealed envelope to give to her family doctor. When she and her mother opened the letter, it stated Rebecca's diagnosis: *"no explanation of what it was, or 'get yourself on medication;' it seems weird to me that a doctor would do that, and not sit down with mom and I and explain it."*

The fact that his doctor gave little explanation of his mental disorder was understood pragmatically rather than critically by Gary, and his comment offers one

possibility of why this pattern occurs: *“the doctors did not explain it too much; I found out about it on my own. The guy that diagnosed me ... he gave me medication, but very little explanation of what it was. I get the impression they did not want to give me too much information for fear of frightening me.”* Carolyn had another theory about why psychiatrists deal with symptoms and offer little information and explanation: *“a lot of people are very afraid of doctors, so they try to keep it simple.”* Andrew and Lam both stated matter-of-factly that their doctors explained very little, and told them to stay on their medication. It must also be noted that approximately half of the consumers interviewed expressed neither positive nor negative views about their psychiatrists.

Jenny, who believed she had created existential despair for herself, resulting in her mental disorder, also felt uneducated about the medications. With more than a little indignation she described a psychiatrist she met as a *“pill-pusher:”* *“he just handed me a drug he thought I should try!”* The day before our interview, Jenny had not taken her medication, as she feels that it lowers her mood if she takes it on her *“down days.”* Consequently, she was *“hyper”* during the interview and jumped from topic to topic, discussing medications, life crises, experiences from childhood, then back to medications, a critique of society, religion, another critique of society, to self-recrimination, with emotions, ranging from pride to anger to sadness. At one point Jenny blurted out, *“I don’t know how you’re keeping your mind working in this tirade I’m giving you.”* During this difficult interview, she returned to the subject of medication: *“I certainly am not gonna take this one he recommended! I’ve heard people have had hallucinations ... no way, at least not without him explaining a whole lot more why he thinks I should.”*

Like Jenny, others questioned the knowledge possessed by the psychiatrists. During the group interview one consumer stated her belief that the “*doctors really don’t understand ... it’s taken me fifteen years to understand all the things happening! How can a psychiatrist learn it all in six weeks?*” Another consumer gave a similar criticism of psychiatry during a group interview, where he asked, “*what is psychiatry? It’s fishing in a hole – you don’t know what bait to use or hook to use.*” Someone responded by speaking of a book, the title of which she could not recall, which explains that “*psychiatry is more or less bunk.*”

Another book that suggests that “psychiatry has no clothes,” is Whitaker’s Mad In America – Bad Science, Bad Medicine and the Enduring Mistreatment of the Mentally Ill (2002). Whitaker (2002:227) cites a study initiated by the World Health Organization in 1969, that found that patients with schizophrenia in the poorer countries of India, Nigeria and Colombia, did much better than patients in the United States and four other developed countries. There was a much greater likelihood that the former group of patients would fully recover. Hahn (1995:37) also discusses The World Health Organization’s International Pilot Study of Schizophrenia, and suggests that the differences may have been a result of expectations of patients, and social environments which were supportive and included strong family bonds. However, he also notes that these hypotheses were not tested.

A follow-up study confirmed the results of the first study: while almost two-thirds of patients with schizophrenia in India, Nigeria and Columbia had good outcomes, and a little more than one-third became chronically sick, the reverse ratio was found in rich countries (World Health Organization 1979:369). The reason, according to Whitaker

(2002:229), could be found in the fact that only 16 percent of the patients in the poorer countries were treated continually with neuroleptics, while in the rich countries, 61 percent of patients were kept on these drugs:

The studies had proven that recovery from schizophrenia was not just possible, but *common* – at least in countries where patients were not continually kept on antipsychotic medications. The WHO studies had demonstrated that the American belief that schizophrenics necessarily suffered from a biological brain disorder, and thus needed to be on drugs for life, wasn't true.

Perhaps there was too much money at stake in the pharmaceutical medications to say that they were “bunk,” since the United States and other countries *increased* their use of antipsychotic medications (Whitaker 2002:232). When I ventured that etymologically, psychiatry is “soul-doctoring,” one of the group members was quick to respond that, “*psychiatry is giving you pills and saying ‘see you next week!’*” Most of the group laughed in agreement, offering a view of their physicians that contrasts sharply with Kleinman's (1988:267) vision; the ideal physician is present in the “experiential realm of suffering” with her patient, and takes part in the moral parity of what the experience of illness means for both patient and family.

Distrust of the efficacy of psychiatry, in general, raises interesting questions for the future of “*fickle pharmacology*,” and opens the doors to alternative treatments for mental illness, which will be discussed in the following chapter. Consumers also had other complaints about their psychiatrists. As Ethan explained, “*I was treated very awfully at first – I had a bad psychiatrist – it was very disturbing until I fired him. I think every psychiatric patient has their complaint about how they're treated because it's sort of an art and science, not conventional medicine – fickle pharmacology.*” Lisa also had to “fire” a psychiatrist because his treatment was so disturbing: “*I left him. He really*

annoyed me. I think I even had a psychotic episode outside of his office and he just laughed it off, treated me like I was just trying to get attention or something.” Later, Lisa noted that currently she has a good psychiatrist:

he’s very supportive about my religious beliefs, says ‘I believe prayer works.’ He’s totally open to all that ... I was surprised to find that in a doctor. I have a friend who’s Christian and her therapist is really pushing her, ‘you should get hypnotized.’ She says that’s against my religion; he’s not respecting her beliefs.

Tom also had a negative experience with a psychiatrist, who asked him about his beliefs, *“and then he ended up naming my belief anyhow. I thought, ‘this guy thinks he knows it all.’ Every time I seen him, I felt belittled, felt he was too controlling. That’s the only doctor I’ve felt that way about.”*

Jeff had a negative experience that was unique among the individuals I interviewed: *“this crazy doctor that I went to see, he had me on oxygen, and the other thing, what’s the thing that plants breathe? ... yeah, carbon dioxide, through a mask – pretty strange, eh?* While this treatment may seem strange today, in the 1930s and 1940s when insulin coma was the treatment of choice for the mentally ill, some researchers believed that oxygen depletion might explain how insulin coma “cured.” Consequently, one doctor attempted to induce this trauma by having his patients breathe oxygen through a gas mask, and then replacing the oxygen with nitrogen, causing a loss of consciousness for short periods of time (Whitaker 2002:89-90). Jeff was pleased with his next doctor who thought the former doctor was an “idiot,” and treated Jeff with medication.

When I asked Marilyn if the psychiatrists ever ask about her religious beliefs, she offered another criticism of the psychiatric profession:

*Not usually, and maybe they **should** ask us about our religious beliefs and they **should** teach us the difference between what is delusional and what is acceptable.*

They need to deprogram the delusions – ‘those are delusions, this would be a more moderate, acceptable version.’ ... Psychiatrists have not done enough of this, just like they’ve not done enough educating the general public about mental illness – they did nothing. Why haven’t we told people how the brain shows itself when it becomes sick? ... it should have been up to them; they had the resources, the knowledge to educate the public – what was their excuse?

While the consumers discussed thus far seem to have had only one negative experience that was so disturbing that it was never forgotten, Dee had more than one negative experience with psychiatrists. As was discussed in chapter one, Dee’s first doctor had prescribed so much medication that she was exhibiting signs of brain damage. Recalling this psychiatrist, Dee said, *“he had the reputation of diagnosing everybody the same and giving everybody the same medication, and if the medication wasn’t working, just giving a higher dose.”* She later tried alternative medicine, but complained that it did not work because her psychiatrist was not working with her.

On the other hand, a few consumers reported having positive experiences with their psychiatrists. Tina, for example, believed that talking to her psychiatrist has been very helpful: *“when you get these weird ideas, he talks you out of them.”* Alexander spoke positively of his psychiatrist as well: *“my psychiatrist and I have very good relationship. Have so much in common, we enjoy talking and I can tell him everything. He treat me like everyone else – that was good ... encourages me to write stories.”* Similarly, Lyle stated that, *“the doctors, they are very caring, the ones I’ve had.”* However, this statement was made before he was involuntarily hospitalized, which resulted in his attempt to fire his psychiatrist: *“I said ‘you’re fired,’ ... but he wouldn’t be fired!”* Two other psychiatrists assessed him and agreed that he was having an illness

episode, leaving Lyle to empathize with Nathaniel Lee: “they called me mad, and I called them mad, and damn them, they outvoted me” (cited in Whitaker 2002:211).

During my hospital visit, Lyle maintained that he was not having an illness episode, yet his wife was able to get a mental health warrant to have him assessed and certified. He rejected the epistemological assumptions of the medical model, saying to the young doctor who eventually certified him, *“I’ve been dealing with this illness longer than you’ve walked the earth ... I don’t need an M.D. to be an authority on this illness and on my body, and my relationships...”* Lyle’s message is that first-hand, experiential knowledge is of more value than secondary knowledge taken from a generalized medical textbook, even if that knowledge is held by someone in a position to know. His statement is reminiscent of the one made by another consumer about how psychiatrists cannot understand one’s condition, because they have only studied a particular mental disorder for a few weeks, rather than living the illness for years. Both consumers prioritize lived experience over theoretical knowledge, just as this research is a phenomenological study of illness as it is lived, rather than conceptualized by medical science (Jackson 1996:6).

CHAPTER FOUR: IDEAL TREATMENT AND RELIGIOUS COPING

Religious and spiritual beliefs and experiences were often cited as aiding in coping with schizophrenia and bipolar affective disorders. Fourteen consumers agreed with the medication-based treatment, even though some had a variety of complaints about these medications. Seven consumers believed that reliance solely on pharmaceuticals was not the best way to treat mental illnesses, the side effects of these medications being a major concern. These individuals either supplemented their medications with alternative remedies and practices, or insisted that more research needed to be done to find treatment options with fewer side effects. The remaining three consumers rejected pharmaceuticals entirely, and either did not take them or spoke of the desire to stop taking them, if only there were a support system in place for them to do so.

Accepting the Current Treatment and Spiritually Searching

While many individuals hoped to eliminate side-effects of medications by finding what some called the right “*chemical cocktail*,” a minority did not speak of problems with medications. In fact, William, who believes that he had tendencies of his mental disorder from the time of his traumatic birth, says that since starting medication, “*I’m the same as I was before, only now I can remember better.*” William also said of his condition, “*I think it was treated very well. I don’t suffer from many side effects and if I do have a couple – so what! People are always hunting for the perfect drug to take so they don’t have a headache in the morning ... Maybe they’re more sensitive than I am.*” Unlike many others with his condition, William does not hear voices and was able to function quite well in the working world, which led to his self-ranking of “*borderline.*”

William does a lot of volunteer work with people who have mental disorders, where none of the consumers suspect that *he* has a mental illness. Because William subscribed, for the most part, to the medical model of mental illness, it makes sense that he believes in the treatment propagated by this model.

However, William, a born-again Christian, also looks toward religion to cope with his disorder; he explained that without his religious beliefs, he might have committed suicide. Having grown up in the Anglican Church, William pursued a spiritual search, a questing that was undertaken by a number of other consumers:

I went to see a Catholic priest and asked him about exorcism ... just wandering, I didn't know where I was going ... burning desire for something; there was a hill of gravel there they'd cut in half to use on roads, patients in the hospital had hollowed out a section and plastered up the ceiling. Hand carved altar, chunk of lodestone from Lourdes, France, and nobody told me it was there and I found it!

Later William described the results of his spiritual searching. While in jail for trying to steal an over-priced item from a department store, he regularly visited the chaplain's office to "*read books on the Gospel according to Jenny, Matthew - that's what I did when I was in jail, copying out parts of the Bible ... like my heart was expanding, finding a feeling of fullness; my religious beliefs are getting stronger all the time.*"

Like William, Andrew spoke of how his illness instigated a spiritual search: "*I did kind of search for answers once I had my illness – through books and reading the Bible and various philosophers and stuff.*" Describing himself as a Christian, he also cited religion as helping him accept his "*fate*" and cope with his mental disorder. Andrew shared William's belief that the pharmaceutical medications are *the* treatment for his condition: "*I'm on a good medication now – a lot better than the old medication – that's basically the only way you can treat it.*" Besides subscribing to the medical model

of mental illness, Andrew's own experiences with medication likely contributed to his realization that medication is crucial for treatment. At about seventeen years of age he got sick and was put on medication, but a few months later he had improved and the doctor told him that he no longer needed medication. Two years later Andrew became sick, and upon improving, went off the medications, until, *"I got sicker more often, now I have to be on medication all the time."*

Gary shared Andrew's belief about the way that his mental disorder should be treated: *"it can only be treated by medication – it works by trial and error, some works for some and not others."* Haldol was one of the medications that did not work for Gary: *"I felt like jumping out of my skin after the third day."* At the end of our interview, he spoke again of the importance of medication: *"the treatment has improved my life. I don't know if I'd be alive today without medication considering I've attempted suicide on two different occasions."* Gary explained that if he had been diagnosed earlier in life, his religious beliefs would have hindered his attempts to cope with his mental disorder: *"I had resisted any kind of religious contact because it was shoved down my throat, the way I was brought up in the church."* When he was diagnosed in his forties, Gary was ready to return to religion. A spiritual renewal following his last suicide attempt resulted in a newfound faith that helped him to cope: *"accepted religion and spirituality more – makes me open to understand more, not only my condition, but about a lot of other conditions that used to scare me."*

Frank also agreed with the use of pharmaceuticals to treat his condition: *"...it's a big help to me."* He did note, however, that before he was diagnosed and medicated, he had lived with the disorder for over forty years, and it had not caused many problems.

Frank did not complain of any negative side effects of his medication. While he was raised in the Catholic Church, Frank does not attend services. Still, he thought that his religious beliefs have helped him to cope with his condition.

Lisa initially believed that she would be treated with psychotherapy, but came to realize that medication is the treatment for mental disorders; she noted that after four years, the doctors are finally starting to find the right medication combination. Lisa hears voices, and used to believe it was the devil or demons talking to her. Now she asserts that she is able to distinguish between voices that have their basis in her illness and those that signal an attack by demons. She has had a close relationship with God from the age of fifteen, and referring to her mental disorder, said that her religious beliefs have, *“definitely helped me cope with it, because I used to be suicidal all the time and now I have a lot of hope in my life – unexplained hope, peace.”* One spiritual experience that Lisa described occurred on her way to commit suicide by jumping in front of a train: *“I just felt this hand on my chest stop me – there was nobody there – and I heard this voice, ‘remember, you promised that counselor that if you ever get this bad you would go and see her.’ I really believe to this day that that was an angel who stopped me.”*

Carolyn also appears comfortable with relying on pharmaceuticals for treating her mental disorder, particularly after trying a herbal supplement called St. John’s Wort, which *“didn’t even come near to touching my depression – didn’t work at all.”* While Carolyn believes strongly in the medical model and the pharmaceuticals that are used to treat disorders, like others, she complained of the side effect of weight gain. While she is not a churchgoer, and does not embrace religion, Carolyn, who was raised in the United Church, felt that her spirituality helped her in coping. She also mentioned a significant

group to which she once belonged: *“You probably know about Job. I was involved in a religious organization in my teens – ‘Job’s Daughters.’ Job lost everything; spiritual stories about Job and others who suffered a lot of hardship give you the base to keep on going and keep trying harder...”*

Ethan, who also believed in the medical model of mental illness, was also a firm believer in the use of pharmaceuticals. When I asked if he had tried alternative medicine, he said, *“I refuse to because I’ve seen the repercussions of people doing alternative therapy. Natural supplements ... better than something made in a lab, but not specifically designed to hit the right sites.”* Unlike the previous interviewees, Ethan discussed side effects that were more than a little disturbing; he noted that what he regretted most about having to take medication was that *“you get dulled – you’re not the same way you used to be. You want to do things and you don’t have that extra energy.”* Ethan did not think it was necessary to speak with his psychiatrist about spiritual beliefs, perhaps because he spoke about such things with a therapist. In any case, his psychiatrist, *“is too busy writing script [prescriptions] ... I don’t think that he cares. Most of them don’t have time to ever ask you about your religious beliefs, nor do I think it makes any difference in how much medication you’re given.”* Ethan did believe that spirituality helped him cope with his condition, but he was careful to avoid religious groups that might encourage him to substitute medication with prayer: *“prayer does not help when you have a biochemical disease; I’m not going to pray myself out of being mentally ill!”* Spirituality does not heal, but it does give Ethan a sense of peace and clarity: *“for example, why do I find myself drifting into church once in a while for calmness, reflection – not on God, but on my life. Maybe it is God, I don’t know.”*

Lam considered trying alternative medicine, but after witnessing friends and acquaintances being hospitalized after taking Nutraceuticals, vitamin and mineral supplements, fear caused him to remain on pharmaceuticals. Lam also experiences dullness from medications: *“I feel flat or depressed, but I don’t get high - I miss that. I do this which is wrong - sometimes I go off my meds to try to get high. I miss being happy, like, laugh, smile and feelings.”* Therapy and support groups are an important part of Lam’s treatment program, and he attends at least two groups a week, which helps to offset his feeling of isolation: *“the only thing that gets me going is the therapy groups; I have more trust now in the groups than I do in religion/spirituality.”* Perhaps he puts his trust in these groups rather than religion because he encountered religious leaders whose advice was to stop taking medication, find a Christian psychologist and pray. Lam’s response was, *“that’s like telling a diabetic not to take their medication.”* However, religion and spirituality played an important role in Lam’s illness narrative, and he continues to meditate and pray to God, which have helped him cope with his disorder.

Lam grew up in Nigeria, where at the age of five or six, he started having mood swings, and behaving abnormally. While his father is Catholic, Lam’s mother continues to follow the indigenous beliefs of her mother, which included superstitions and witchcraft. Following his abnormal behaviour, Lam’s mother gave him into the care of her sister, who, *“put me through this witchcraft with a bunch of old ladies, doing a lot of crappy things.”* Later Lam began to abuse drugs and alcohol, and he, too, began a spiritual search: *“it was a twisted world I was living in; quest for an answer was so strong. I needed to know the truth ... what’s life? What are you doing to your life? I started going to different churches and they sort of promised me they could cure me from*

drug and alcohol addictions.” This spiritual quest did not lead Lam to the answers he was seeking; instead, “I started kind of going nuts about it. I stopped my drinking and this was like my drinking thing, and my wife didn’t like that. Spirituality became an addiction – going to different churches, Bible studies from different denominations ...”

When Lam was diagnosed with a biochemical imbalance, he refused to take medication: *“I was so absorbed with my AA program I didn’t want anything – thought my AA program was going to solve absolutely everything, because if you ask God for things, He’s going to relieve you from any pain or whatever.”* During a hospitalization, he encountered religious leaders who he recognized from the “outside,” and came to an important conclusion:

I saw them really sick, they were nuts in the hospital. Gave me a different perspective. It took me a little time to come to this conclusion – it’s okay to be a little spiritual, but it’s not okay to go to extreme ... I balance my spirituality now; don’t want to go too deep into it because I think I’m as human as neighbour, as much a sinner as the next person. Before, trying so hard to be sinless.

Lam continues to be cautious that he does not delve into spirituality too deeply, as he does not want to overdose on spirituality again. However, his spiritual search continues:

I question Christianity; lately, I’ve been thinking maybe Christ is just a human being like me ... no, I’m just blaspheming ... devil is putting these thoughts in my head, so I read the Bible. But then I question the Bible – who wrote it? Sometimes I’ve come to the conclusion that there’s no God at all, there’s nothing. Depending on the waves, where they are throwing me – it’s a lifetime search.

Patricia had experienced a number of disturbing side effects such as dry mouth, muscle tension and weight gain, and she explained that she was going blind and deaf. She did admit, though, that the medication has eliminated the voices and hallucinations; without that relief, she suspects that she would probably have jumped off a bridge by now. Patricia stated that her Jewish faith has helped her cope with her mental disorder,

but this help is limited; God helps her feel better by being kind to her, but *“I’ve seen the Jewish God – He’s a good guy but the illness scares him ... good God – doesn’t bully me, push me around. I think God doesn’t help me now is because He’s scared of my illness.”*

The potential of Patricia’s religious beliefs to help her cope with her disorder is also limited by her fear that if she keeps kosher or performs other rituals, she will be persecuted.

Jeff believed in treating mental illness with pharmaceuticals: *“you have to be on a good medication ... it’s changed my life totally. I used to sleep all day, all I could do is sleep and I’d shake, like this, all the time. A new drug’s coming out that’s as good as the one I’m on, but without the side effects.”* The side effects Jeff was referring to included hypersalivation, or wet mouth, and memory loss. Jeff had struggled with drug and alcohol addictions, and recalled that he had met quite a few people with his condition at one of the support groups he attended for these addictions. Unlike some other consumers, Jeff believed that substance abuse caused his disorder, rather than this behaviour occurring after one already has the disorder as a way to self-medicate.

Like many consumers, Jeff experienced religious delusions: *“I thought my mother was the Virgin Mary and I was God and would be crucified every thirty-three years, and it would keep happening over and over – it’s embarrassing to talk about. I had some weird delusions, pretty severe.”* Jeff was treated for demon possession, and at one time he believed his illness was demonic, but has now rejected that association:

People telling me I’m demon possessed and oppressed and all that kind of garbage. I went through that for a long time. Had these guys tryin’ to remove demons from me ... but I don’t believe people with mental illnesses are all demon-possessed.

Jeff thought it would be helpful if he could talk more with his psychiatrist about religious beliefs; he finds that doctors do not broach this subject, but most will listen if one brings it up. Jeff attends a Baptist Church, and he tries to pray regularly with his wife. Jeff is positive that his religious beliefs have helped him to cope with his condition.

Like Jeff, Brendan was treated for demon possession. Raised in the Baptist Church, he recalled that when his symptoms first appeared, his “*parents’ church thought I was possessed and they were praying for me, and I had to go in front of the Board – they weren’t educated. It was very embarrassing.*” He also recalled a former girlfriend who became very sick after listening to members of her church, who told her that they would pray for her and she could stop taking medication. I asked Brendan whether psychiatrists ever inquire about religious or spiritual beliefs, and his response was similar to that of virtually all the other interviewees: “*I think they’re so scientifically trained about drugs and stuff that they just don’t want to have the time – just not interested. All they seem to do is get you on the right path with the drugs to keep you healthy.*”

During the group interview, a number of interviewees moved from a belief that researchers do not yet know of alternative treatments, to a suspicion that they do not care to find out. As one consumer put it, “*my fear is with pharmaceuticals, because they are such a cash cow, I wonder how much they are doing to look at other areas like stem cell research, et cetera.*” While she agreed with using pharmaceuticals to treat mental disorders, she felt alternative therapies with fewer side effects could be developed:

we need more research into hormones and the role that plays. We should look into nutrition to help us along with medication. Brain stem cells – inoculate us with it or something. There’s vitamin therapy – mom put me on it and I got so sick – overdosing on pills. It was just ludicrous; struggling to find an answer but it was not a good answer ... what works is basic pharmacological advances.

Another consumer reflected the former comment when she questioned whether researchers were focussing on anything other than pharmaceuticals for treating mental disorders: *“government’s pouring all that money into pharmaceuticals – it’s a cash cow – my prescriptions are as much as my rent!”* When I asked about the ideal treatment for her mental disorder, she suggested that, *“instead of, when we’re having side-effects from a medication, giving us another medication to control the side-effects – look into decreasing the other medication.”* She also repeated her belief that, *“the younger people should have that choice – see if they can go through more of a natural way of healing rather than being put on medication for the rest of their life.”* A more natural way of healing was used by a doctor who has a spot in the country, *“where his patients can come to go crazy. They can paint the walls, do whatever they want. I don’t like that feeling of being out of control; if I did go to something like that, I’d want really good support.”*

One consumer noted that he is trying to convince his doctor to decrease his medications, because he has difficulty painting when his creative energies are dulled by medication. He described his disorder itself, as *“evil”* and *“insidious”* but agreed with others that the medications made him feel flat. With anger in his voice, he explained, *“I’m tryin’ to get off of some stuff so I can get some emotion back – and that’s because someone’s got me addicted to taking Benzos. Some psychiatrist wants me to take Benzos and I can’t take them any more because I’m trying to regain some emotion!”*

At the next group interview, he spoke of pharmaceuticals in a way that clashed with his earlier support for the use of these medications. He explained his understanding that in the past and in other cultures, people having religious delusions would simply be accepted as having religious ideation; in contemporary times, however, these people are

viewed as needing to be controlled, so they are put on drugs, whether they need them or not. Treatment, he suggested, depended not on the nature of the “illness,” but on how society viewed the individual while she was having the experience.

I asked the group what they thought of the suggestion that people with schizophrenia or bipolar affective disorder should not necessarily be medicated. According to psyche-spiritual therapists, consumers should be allowed to go through experiences such as psychosis, and glean what is spiritually valid from their illness, thus finding meaning in madness (Shorto 1999:15). One consumer was not impressed:

that goes against [pause] I can understand why they're sayin' it from a contextual thing about trying to find enlightenment, spirituality, getting that high. But from a treatment protocol standpoint, you can't stop people from taking medication – they gotta be on a steady stream or they're gonna' end up in the psyche ward!

This consumer was likely able to empathize with the desire to find enlightenment and spirituality because he had similar leanings. In his youth, he abused drugs and alcohol which he later saw as self-medication; use of drugs and alcohol to regulate mood was also reported by other consumers. However, he also perceived this behaviour as “*spiritually questing – usage of LSD, MDA et cetera. To try to experience nature in a different kind of way – sublime nature.*” Many of his acquaintances had major religious epiphanies during illness episodes, but when he is psychotic, there is a “*sense of the sublime, looking at nature and overwhelmed by nature – more than any drug I've ever done. I went from severe depression to high mania and could understand music again, read anything and understand ...*”

During the group interview, a consumer shared his theory about the prevalence of religious delusions in the illness narratives of people with schizophrenia and bipolar

affective disorders. He had met many people who believed that they were prophets or Jesus Christ, and believed that they had been traumatized in the midst of psychosis:

... they have residual guilt – a lot is religious guilt and there is a longing for redemption and sense of salvation. Feel overpowering sense of being connected with some kind of power they never had before. They identify themselves with some kind of true ideal of what Christ ... strict moralistic background...incredible amount of knowledge about religion – gives them a lot of ammunition when it comes to being in psychotic state to suggest that they have a lot of power ... because they don't have power in their own lives ... how religion also functions in way of helping people to deal with their lives – things they can't control ...

He also recalled the following experience when another interviewee mentioned her feeling of being more connected with a “soul” during severe depressions:

I don't know about emotions and connections to the “soul” but I felt some kind of connection with something that was very powerful when I was high. I felt as if I had a lot of drive and it was part of a greater something that I can't describe ... when I got depressed I was so sapped, so drained of emotional energy, connection, that I was like lost, “soul” was lost, soul was sick.

Brendan, who described his religious beliefs as “Christian – Pentecostal, 80% and Baptist, 20%,” believed his faith had helped him to cope with his disorder by encouraging him and giving him comfort, and “*knowing that finally we'll get to heaven at the end of the road and suffering will make sense.*” Unlike many of his peers, Brendan did not experience religious delusions: “*I've heard of people doin' that but I've been able to separate my religion from the illness – never really mixed them.*” While Brendan agreed that his condition should be treated with pharmaceuticals, he feels unknowledgeable about the ongoing treatment of his disorder: “*I don't feel educated about drugs. I find it frustrating. It helped going to hospital meetings, but a surgeon talkin' about dopamine and this word and that word goes over my head ... the pills I'm on cause memory problems.*” The primary reason that Brendan wants to better

understand the different medications is his hope of finding a combination of medications that lack disturbing side effects. Brendan is able to take some courses at college, but he can do so only because there are few exams: *“the medication I’m on sucks your memory – like a mosquito; sucks it up like a thermometer.”* In addition to causing memory problems, fatigue and loss of sex drive, the medications cause weight gain; much to his dismay, he gained over one hundred pounds after he started medication.

Rebecca had experienced similar side effects from her medications. For example, she recalled having difficulty working because the medication caused memory loss. As a divorced woman, hoping to find a partner in the future, she also commented that one of her dreams is to lose weight: *“I just want to be slim ... yeah, they’re telling me it’s a side effect of medication but I always think, surely if I exercise and didn’t eat so much, I’d lose weight.”* Rebecca recalled that one medication gave her insomnia, but she preferred that to the side effect of the previous medication which caused her to sleep all day. Along with other consumers, Rebecca was treated for demon possession:

I started going to church and got mixed up, thinking God was going to heal me, so I went off my medication. I got very, very ill, ended up in the hospital that whole summer ... my own idea, but the bad part was I found some people who would support me in that, prayed for me, ‘this demon get out, that demon get out’ ...

If we examine her delusions, it is easy to understand why she would resort to exorcism:

when off medication ... I think crazy stuff, think, like, oh, Jesus Christ is my boyfriend and he’s in me – just really sick; I start thinking weird things. I think they’re all talking to me; sometimes I think demons are raping me ... euphoric mood, thinking Jesus is my boyfriend and getting amazing insight into how the world was created, how molecules got together,... funny stuff about how our bodies work – thought I was receiving all this insight into creation.

Unlike the previous consumers, Rachel seemed more open to the possibility of alternative treatments; however, she was recently diagnosed, and explained that she did

not really know what the options were. Reflecting on her treatment, Rachel said that it consists of *“just medication – I just talk to the doctor once a month. I would be open to psychotherapy; I don’t know a lot about it or if it helps.”* Rachel had a familiar complaint about the medication:

it dampens my creativity. My feelings are quite constant. I used to have feelings of joy, exuberance, ... Now I can’t feel a range of emotions. That puts a damper on my ability to dream and hope and wonder, cause it’s a happy feeling to have that and I don’t really feel I have access to those feelings.

When she became ill, Rachel was convinced that her experience was spiritual and that the devil was attacking her: *“I thought that it was making me closer to Jesus ... feeling of being a disciple of Jesus.”* Thinking that she needed to grow spiritually to get well, Rachel went to a church whose leaders prayed for her healing and that eventually she would not require medication: *“I was in denial that I had this condition so I wasn’t taking medication at one point in time, because I thought I’m going to be healed and everything’s going to be okay. But I relapsed ...”* Like others, Rachel spoke of spiritually searching, and becoming more religious following her first illness episode. Raised in the Anglican Church, Rachel thinks she was given a lot of information before she was ready: *“I was probably always on a spiritual quest – looking at different religions. I strayed, so the door was always open for other beliefs to enter in, because I didn’t really know what I believe in.”* Now that Rachel has returned to her childhood faith, her spiritual beliefs provide her with peace and hope for the future.

Marilyn was even more open to the possibility of treating mental illnesses with alternatives to pharmaceutical medications. Like others, she had experienced serious side effects from medications including loss of concentration and memory. The worst side

effect was the fatigue that accompanied the medication she took in the eighties: *“it’s a horrid medication. It made me very stiff and robotic, practically comatose – all I’d want to do is sleep. I still sleep twelve to sixteen hours. Sleeping ... most impact on my life; I wish I could be awake longer ... it’s the medications.”* Marilyn recalled that in previous years, mentally ill patients were so over-medicated that they could not even move, a treatment administered for the comfort of the hospital staff, rather than the patients. Because of this legacy, Marilyn does not think people are available to support consumers, being as they are habituated to over-medicating. She also refused to believe that the current approach went far enough, which she made clear in her earlier comment about deprogramming thought patterns. The thought patterns Marilyn referred to began when she was at university, and believed that communists were infiltrating into the university and trying to kill her because she knew their plans.

Marilyn also saw visions of the devil and later, *“believed I was God’s daughter, thought I was close to God and believed I was morally better than everybody ... I was on a mission ... Chosen One and gonna educate the world. Now I’ve got back to the middle – brought myself back to the centre, which is a lot better.”* This statement is reminiscent of Lam’s need to balance his spirituality; while she remains Catholic and continues to feel special in God’s eyes, Marilyn notes that she is no longer on a mission. Marilyn had been treated for demon possession and confided that at one point she believed she was possessed by demons. Now, she makes what is, in her mind, a crucial distinction: people with mental illnesses are more vulnerable, a trait that is exploited by the devil, but is not the same as possession.

Questioning the Current Treatment: ‘Mad’ About Side Effects

Along with a number of other consumers, Sarah believes that both pharmaceutical medications and alternative therapies are necessary:

I really don't like medications, but I have to take them for my condition. And I do know when I take my Echinacea, et cetera to help me relax, it also helps out my medication – gives me more energy, more clearness of thought. ... I believe in homeopathic/herbal as well as pharmaceutical. I use things like Chamomile, cranberry – it's good for getting rid of all the toxins that the pharmaceuticals, medication put in your system ... they're really bad on your kidneys.

Ironically, alternative medicines were used to deal with the side effects of pharmaceuticals, such as fatigue: “a lot of medications leave you drowsy and dozey and like a zombie.” Sarah also recalled that her first medication gave her extremely painful migraine headaches. While she saw promise in an herbal approach to the treatment of mental disorders, she lamented the psychiatrists’ lack of understanding of possible treatments with vitamins and herbs. The treatment that Sarah feared most was dubbed, “getting blasted,” by some consumers. While many consumers feared the results of having their brain “scrambled,” such as memory loss, Sarah opposed the very idea of ECT: “Electro-shock therapy – I’ve heard horrifying stories of doctors saying they have to have it and they didn’t want to have it ... it’s morbid. It’s just like the lobotomy – it’s better to talk to a person and help ‘em calm down, than to shock them to calm down.”

Sarah had attended churches of many different denominations, but had rejected institutionalized religion, and described her religious beliefs as “Native” and “naturalist.” Her beliefs had been immensely helpful in coping with her disorder:

when I get scared or paranoid I fall back on mantras, hold my protectors of my soul ... starting to get sick, I smudge with sage, juniper, pine. You smudge your house to get rid of all the bad ... same thing as you have a herbal tea that takes

toxins out of system. Definitely helps me cope, my little bits of religion here and there; mantras, native prayer...

In the past, Sarah experienced, “*spiritualistic things like God is talking to me,*” which she now interprets as delusional. However, she has also had spiritual experiences such as visitations by a guardian angel, which she is less sure are part of her psychosis. A few weeks after the interview, when Sarah and I were chatting outside, she insisted that some of her experiences are spiritual, and now that she is on medication, she can distinguish the psychotic from the real. Like the majority of consumers, Sarah said that psychiatrists do not ask about religious beliefs. When I wondered if she wished they would ask, Sarah said, “*maybe, maybe not – depends on how they ask it. If they came out and said that I’m full of bunk because of my beliefs I’d probably get a tad irate.*”

Like Sarah, Tina believed that mental illness is best treated with a combination of pharmaceutical and alternative approaches: “*medication, psychotherapy; I’ve been doing a lot of alternative stuff too, which I think has been helpful – connected to yoga, doing meditation, controlling my lifestyle and diet ... just wanted to do everything possible.*” Like others, she spoke with frustration about the weight gain caused by medications and the fact that they make her feel very flat, limiting her range of emotions. Like Ethan, Tina did not feel that it is necessary to discuss her spiritual beliefs with her psychiatrist, but she does see an alternative practitioner with whom she would like to discuss these beliefs: “*I think it depends on the psychiatrist; if they were interested in that, they would ask about it.*” While Tina was raised Catholic, like others, she now combines these beliefs with yogic philosophies. She explained that the goal of the exercises is to bring one to knowledge of God, and to recognize the divine within ourselves and others, an

understanding of spirituality similar to that of Sarah. Tina realizes that this understanding clashes with the Catholic view of God as exterior to humans, but she is able to accommodate both beliefs: *“at this point in my life, it’s more comfortable for me to recognize that God is within; hard for me to do that all the time. When I have had that, the world clicks along as it should ... even though there is God within us, they’re all connected and there’s one universal God.”* Tina expanded on how her religious and spiritual beliefs help her to cope with her disorder:

from a yogic point of view – acceptance – this is just the way it is; love yourself. Thing about results aren’t really that important ... what’s important is how you feel inside, how you care about others, comes from yoga – that I’m the same person whether or not I have this illness ... Catholicism helped for strength, asking God for strength to help me cope. After going through suffering maybe there will be joy on the other side.

One experience that was very significant for Tina was a trip to Europe when she was recently diagnosed. It was a great comfort for her to learn about the saints, particularly about their imperfections including what would today be called mental disorders. Tina had what some would call a religious experience during Mass at a famous cathedral: *“I think I did kind of hear God, actually – don’t know if it was hallucination or not – ‘You’re fine the way you are.’ Put me on a high; I still, when I think about that, it gives me a lot of comfort.”* At one point Tina referred to her spirituality as an addiction, but unlike Lam’s experience, her “addiction” is viewed as helpful rather than harmful: *“similar experiences in church and meditation – sense of love, peacefulness, direction; it’s almost like an addiction. I love going to churches or going out to meditate – highly addictive place to go because it’s full of good things.”*

Stacey shared Tina's eclecticism in terms of health care. She had tried meditation, Tai Chi, Reiki, and herbal supplements, and gained some healing from these remedies:

I don't believe that Western science and synthetic drugs have all the answers. I do believe there are answers within our spiritual being and within nature itself that affect our disorders. People survived a long time before any of these drugs were ever invented or discovered. I believe it's worth trying just about anything. Why should you pass up an opportunity to gain some healing?

These comments allude to an issue that Jackson (1996:13) explores: "what makes the phenomenologist uneasy is the assumption that beliefs and ideas have to have some kind of ahistorical, supraempirical validity if they are to be workable." The suggestion is that ideas can bear meaning and utility even when they are unwarranted, epistemologically. Stacey's comments were echoed during the group interview when consumers reflected on the nature and ideal treatment of mental disorders. Like Stacey, another consumer took a historical perspective when considering the treatment of his mental disorder: "*it has a lot to do with the fact that we want to diagnose everything today. Two hundred years ago they didn't know anything about bipolar; people went up and down.*" This consumer seems to be prioritizing lived experience over the scientific knowledge that both problematizes and medicalizes such experience.

Another consumer offered his vision of the future of psychiatry:

It's turned into more neurology. I think it should be more endocrinology ... if they would take our blood sample, growth hormone – there's so much about the human body and is the mind really in control of all that? We are nerves and the brain is supposedly the largest nerve ending, but – so much they don't know.

He also reflected on the religious component to his illness, a pattern common among people with bipolar affective disorders and schizophrenia:

I would feel that I had some kind of a destiny or related more closely to God – that He was going to direct me to do something. Maybe I could even walk on water...lose touch with reality – hearing voices and talking back to voices ... where religion or spirituality would come in with me would be afterwards, the gratitude that I am still alive or have quality of life now...

Like others, this consumer's religious beliefs enabled him to cope with suicidal feelings, helping him to cling to life, and appreciate the gift of life when suicide attempts failed. A number of skeptics, and one or two sympathizers listened, while another explained how she believed her mental disorder should be perceived by psychiatrists: *"in a psychic way or the development of a sixth sense, and the Eastern point of view – kundalini, the body's energy opens at a certain stage and if you have blocked areas or it opens too quickly, you have all the symptoms of mental illness."* She believed in this to the extent that, *"if I had someone well-educated in these things, I would try going off medication."*

Stacey's fear of psychiatric medications is all too real, as she has experienced severe side effects: *"crawling around saying I was a bug ... losing the ability to speak, uncontrollable shaking, difficulties with my eyesight ... One medication I'm getting off of, they think is responsible for causing polycystic ovary disease."* This disease can make one very infertile, which may prevent Stacey from experiencing motherhood, one of her most important life dreams. Stacey also remembered that *"half the time I'd be dazed out...on one medication I ended up in the hospital in restraints having my stomach pumped because they thought I'd OD'd, but it was just a side effect."* Like most of the consumers I spoke with, Stacey feared E.C.T. (Electro-convulsive therapy): *"I wouldn't ever want to have to do that, ever, ... I don't like something scrambling my brain, sense of losing control. It's a greater risk factor – the outcome can be irrevocable. You're giving up so much more control."*

Stacey would disagree with both Tina and Ethan, who found no reason to discuss their religious beliefs with their psychiatrists; in her view, at certain times it would be beneficial to discuss these beliefs because they play a role in her life. She made the following assertion regarding the doctor-patient relationship:

there should be a lot more interaction when you're dealing with a psychiatrist; it shouldn't all be medication, they shouldn't leave all the counseling and how your life is going up to a psychologist, or psychotherapist or psychiatric nurse. In order to accurately medicate you and assess where you're at, they should know what is going on in your life and show a genuine concern for how you are integrated into society and how you are operating socially and significant events that are happening in your life.

Estroff (1992:280-281 cited in Sullivan 1998:26), who uses a phenomenological approach to understand the lived experience of mental illness, would agree with Stacey, as she believes that we should “learn about the various ways that people who have schizophrenia live in the world, actually and symbolically, in their own terms.”

Now attending a Christian Reformed church, Stacey explains how her belief in God helps her to cope with her disorder: *“it gives me comfort and solace and strength. Every night when I pray I find it is good to be able to thank someone, someone is there – and ask what you need ... that you don't have control over. It keeps me going, having a belief...”* Unlike many consumers who experienced stigmatization by members of religious organizations, Stacey had a positive experience during which both her home church and other churches took up collections to help Stacey attend a treatment program in the United States. She reflected on how the emotional support from her church empowered her: *“it gave me a stronger sense of willing to understand and work with it and realize it's not the end of the earth and doesn't have to be as debilitating as it is for a lot of people ...”*

Lyle had also tried alternative therapies, such as traditional Chinese medicine, herbs, and acupuncture, and expressed doubt on several occasions that the pharmaceuticals actually worked. The side effects also led to Lyle's dislike of this traditional treatment, and he was particularly disturbed by the dulling effect of a medication that, *"worked but it gave me psoriasis, acne, and I felt very flattened out, very unemotional, no real range of expression. I know I couldn't really cry if I wanted to."* He also experienced stiffening of the joints when he was taking Haldol, which caused him to walk very rigidly. Other side effects can even include physical damage to bodily organs; Lyle was taking a particular medication but, *"they said it was ruining my liver enzymes, 'you just can't take this,' so I changed to a different one. It's hard to know when a treatment plan will work ... my other medication never screwed up my kidneys, which is what it can do."*

Alexander agrees with the use of pharmaceuticals to treat conditions such as his, even though he believes that there is more to his disorder than a biochemical imbalance in his brain. He has not experienced negative side effects from medication: *"my case is very mild, not too much, not too much, some people say, no, I don't want to take medication. But I'm okay because some part I believe this is just chemical in my brain, so chemical can do something with chemical."* Unlike others, he did not discuss how his eclectic religious beliefs, including Buddhism, guardian angels and yoga, enable him to cope with his mental disorder.

Tom experienced disturbing side effects from his medication, including the dulling effect. He initially refused to take his medication because, as he told his mother, *"it's nullin' my spirit."* Weight gain was another problem for Tom, and while he

attributes much of his extra eighty pounds to side effects of medications, he also notes that he is less active than he used to be. Side effects, it seems, know no boundaries, as they can even include other diseases and disorders: one medication resulted in Tom's *"counting a lot – it's a side effect – obsessive compulsive disorder. I couldn't let a car go by without counting the windows. They gave me an antidepressant to counteract that ... I sweat all the time too."* Tom's first medications made him feel like he had lockjaw, and his eyesight is diminished. Another fear is that medication that is working for one now, will "burn out" and one will have to constantly change medications. As Tom explained, *"I become immune to the medication after every two to three years, so I have to change."*

While Tom was raised in the Lutheran Church, he described his family as *"Sunday Christians,"* and it was not until he turned nineteen and became *"born-again,"* that religion became an important part of his life. Tom had been attending a non-denominational, charismatic church, when he started reading the book of Revelations: *"all of a sudden, this other language started just flowin' out of me; in the Lutheran faith, we had confirmation, but that meant nothin' to me. My confirmation was in my bedroom – knew I was struck with the Holy Spirit."* Tom explained that his faith has helped him cope with his mental disorder, as he became *"more aware of my uncontrol and more aware of His control, after the illness."* From the beginning, Tom understood his symptoms in a religious light, *"as if I was full of the spirit of Elijah in the end times. I was another type of Elijah coming to the earth, a gift from God, hearing the voice of God, like a prophet. If it is true, I don't care, I'm gonna be the same simple man."*

Tom has come to the same conclusion about spirituality that Lam arrived at, in that he knows he must keep his spirituality balanced in order to stay mentally healthy:

“it’s a fine line between a chemical and spiritual imbalance. Medication keeps me balanced so I don’t go one extreme or the other.” Later Tom returned to this subject: *“books and stuff, I could just jump right into them, but I hold back – don’t want to go in too deep; shy away from prophetic type books ... if I went into them, I don’t know if I would start talking to family and friends – be like a voice cryin’ in the wilderness.”* He mentioned that one of the only things that kept him sane was reading the Psalms: *“my tears would be blue – part of the illness, they say. But then the other extreme, get into Revelations, prophetic writings and read into them, almost like dabbling ... Real sick; numerology, ... out-of-body experiences – seemed like they were happening.”* Here the ambiguous nature of spirituality is highlighted, as the darker side of religion can lead to negative experiences.

On the other hand, Tom realized the value in both spirituality and mental illness, noting that if he lived among native people, medicine men would teach him because they would recognize his potential:

if our culture could start grasping that, not just the dark part of spiritualness, but the good part too, if they would understand it more. I’ve heard people say prophets, missionaries – they’re mentally ill – I’m thinkin’ is this just something that’s not taught or balanced or what. If we can understand that part of it, maybe we can start teaching the next generation how to raise them so they can benefit the rest of our people.

This statement is comparable to one made by James (1958:137-138) a century earlier:

... healthy-mindedness is inadequate as a philosophical doctrine, because the evil facts which it refuses positively to account for are a genuine portion of reality; and they may after all be the best key to life’s significance, and possibly the only openers of our eyes to the deepest levels of truth.

Several times, Tom stated that the medications really help. But because of his understanding of mental illness as a spiritual imbalance or gift that our culture has failed

to nurture, he believes mental disorders could be better treated in other ways: *“you’d need, like, a herbal type of thing to keep the balance and also teaching.”* He spoke of how naturopathy was being used in Europe, and *“they are havin’ success in that area. It’s so expensive, not covered by AISH, not considered medicinal. I think it should be treated with more natural herbal ... it could help a lot.”* Tom restated the need for education a number of times, and at one point he said that in the present, *“we need medication to keep it under control, but maybe in the future we can teach more about it.”*

Dee, who shared to a large extent Tom’s understanding of the nature of mental disorders, drew a parallel between medicine men, psychics and individuals with mental illness, and mused, *“I think when it first starts, if they get the right kind of support, they may never need to take medication. Maybe they can keep themselves balanced enough in their life.”* Dee’s approach was a holistic one, where the individual should be perceived *“as a whole ... sometimes they just look at the body and get you medicated right. A nurse once told me the doctors call medications “chemical restraints.” The doctors don’t know what it feels like to be chemically restrained!”* This effect, which accompanied the older medications, or over-medication, was like, *“being bound up with ropes internally.”* Other side effects that Dee experienced include fatigue and Tardive dyskinesia, or involuntary movements of the tongue and mouth, and as she noted in an earlier chapter, over-medication can even cause brain damage. Dee also mentioned the weight gain, and was not as optimistic as some of her peers about the possibility of controlling this side effect through exercise and diet: *“it’s a struggle to fit into society. All the doctors seem to think you should be able to take off weight, but the meds made it very difficult; a lot of people have so much weight, I think their physical health is really in jeopardy...”*

Dee seemed to recognize that there was still a role for pharmaceuticals, albeit a very different one from that which exists today:

I think the psychiatric field has a long way to go before it's really healing and nurturing. What I'd really like to see happening is the holistic and the traditional medicines coming together – hold hands in the form of a prayer – the psychiatrist finding out what the patient wants to try. I tried alternative medicine but the psychiatrists were not working together with me.

Dee's experience lends support to Umoren's (1990:399) observation that unlike the holistic approach to mental illness taken by the Annang of Cross River State Nigeria, Western therapies lack the assumption of the wholeness of life, leading to treatments lacking the holistic approach.

Dee responded to my question of whether doctors inquire about spiritual beliefs with a comment that reflects the way psychiatrists have viewed religion since Freud declared it to be an illusion: *“psychiatrists never ask about religion – they're just interested in symptoms. But I don't feel too natural about talking about those things with them because it's like, you may be put on more medication!”* However, even as a child, religion had played a significant part in Dee's life. Her mother, who also had a mental disorder, would become ill and, *“everything became quite religious – religious part of it became really skewed and frightening because she would see things ... sacred hearts – mom saw a live one and trying to describe to us what she was seeing and she made it so vivid that we children actually saw it!”* Later Dee had a number of negative experiences connected to churches, and while she eschews organized religion, she has found her own faith, which helps her cope with her illness. Dee spoke of jewelry made of crystals and other healing stones, and explained that she needed something tangible, because there are, *“times when I know I can't pray – voices like it if they can get in there and negate my*

prayer by putting awful things into my prayer; I work with my prayers when I'm well and put prayers into something physical that I can hold on to." Dee also shared Sarah's coping technique of repeating mantras, and like Tina, she found yoga to be helpful, as it involved much prayer and balanced her body's energies.

Dee described a number of experiences, which might be called psychic, religious or delusional, depending on one's perspective. At one point she thought she, "*was sent to hospital because the ward really needed me because they didn't have a healer on the floor at the time,*" and she would proceed to "heal" patients, usually eliciting laughter. At other times, Dee believed she was in angel school, and once when, "*things got really bad on the ward; I went out and stopped traffic and prayed in the middle of the street. So I got brought back in and put in that room where you can't come out and they watch you ... 'I don't believe this - I'm being punished because I prayed!'*" Like other consumers, Dee may be on a spiritual quest, which is suggested by the following:

I can't figure out why when I get sick it's like I'm searching for something; I run towards something, but it's not there. One time I ran from the hospital and they found me in [another town]. I don't know how I got there. Running from something and running to something, or searching for something ... One time at the hospital, I just felt I had too much, so I started giving things to other people ... all these people are getting released and I'm still here helping them ...

The importance of spirituality and holistic medicine, as opposed to the traditional way of treating mental disorders, are clear in Dee's description of her first experience of sculpting:

I have to put something spiritual in it or else it's just too much ... I was amazed because it came from a place separate from the illness, beyond the illness, so beautiful, I realized there's things that I don't understand about the illness. It's better to try and nurture it and control it in a balanced way, than throwing a bunch of pharmaceuticals at it!"

Rejecting the Current Treatment: 'Mad' About Medicating

Jenny would likely agree with Dee regarding the use of pharmaceuticals; she quoted psychiatrist and Holocaust survivor, Viktor Frankl (1959:105), who stated that “the psychiatrist should avoid burying the patient’s existential despair under a heap of tranquilizing drugs.” Jenny believes that she created existential despair that the doctors should help her deal with, rather than muting it with medication. However, “the idea in the DSM is that suffering can not and should not be endured. It should be brought to an end ... there is nothing that needs to be endured ...” (Kleinman 1995:180). Jenny is facing the fact that the suffering of patients and their loved ones is not attended to as a burden of a moral nature, or an existential experience that gives life definition (Kleinman et al 1992:14). Rather, it is the, “*existential that scares everybody off.*”

Boisen was not scared off by the existential, perhaps because he had gone through an experience similar to that of Jenny. His conclusions include a treatment that Jenny would approve of, one that realizes the significance of the patient’s ideas and feelings: “they are to him reality, grim, terrifying, torturing, mocking, fascinating, and if we are to arrive at any true understanding of our patient and of the world in which he lives we must know what is on his mind. This is in fact the inner world which it is our task to explore” (Boisen 1936:30). Jenny’s idea of her disorder as a quest for meaning can also be viewed as a spiritual search or addiction: “*I keep looking for these Goliaths that I want to be David to ... because it needs to be done, like, you know – I will because I can. I sure hope they did ... I kind of like to think I’m doing what God wants me to do.*” Raised in the Lutheran Church, and now attending the United Church, Jenny insisted that her religious beliefs have both led to her disorder, and helped her to cope with it. Like

Carolyn, she recalled Job in the Bible, who, *“went through a lot of shit – end of his life he was rewarded by God,”* implying that she anticipated rewards bestowed by God.

Dianne, one of the few interviewees who rejected medication, had tried herbs because her medication made her very tired; she also made dietary changes such as becoming a vegetarian in earlier years. Like other consumers, Dianne spoke of having a religious addiction. Her *“drug”* was the exclusive cult in which she grew up: *“religious addictions and cults – it’s a drug ... it’s all negative programming ... I’ve broken away and gone back and broken away and gone back, but now I’m away for good.”* Now that Dianne is confronting issues arising from this religious upbringing, *“I don’t have to be obsessing and grieving about things, so I don’t feel I need all this medication, where it was to keep focused off these things.”* This comment is reminiscent of Jenny’s disagreement with the psychiatrists’ tendency to bury existential despair with medication. Dianne’s new faith enables her to cope with her disorder, but she implied that her psychiatrist does not respect her religious beliefs:

I don’t go to Dr. Smith because his brain is set – you have to take medication. I want to get off medication, and he said, ‘what if something happens.’ My experience now is like walking through the door with Christ – this is where I’m at. If there is this Christ or God or whatever He is, teach me, show me ... the hospital is there if I bottom out, but let’s see how I can function here.

Tyler feared the many side effects of medications, including weight gain. He treats himself by using, *“mind power to throw myself into other things so that I don’t seem to worry about the illness, which is a real tough trick. Sometimes I even turn the illness upon itself so it feeds on itself.”* Tyler, who went to church as a child, believed that his illness might have played a role in his return to church, as he felt that he needed to get in touch with God. He believes that his religious beliefs have helped him to cope

with his mental disorder. Tyler offered the following details about his unique beliefs: *“I believe there is a Supreme Being – the last ten years I’ve been saying it’s female ... God is forgiving and mostly women are forgiving; always striving to keep them on your good side, not on your bad side.”*

Many consumers with schizophrenia or bipolar affective disorder experience such side effects from pharmaceuticals that one is left wondering if the treatment is worse than the disorder itself. Religious and spiritual beliefs occupy an ambiguous position. For most consumers, such beliefs help them to cope with their disorders. As one consumer put it, *“my religious beliefs have prevented me from ever being suicidal.”* These beliefs, however, are never inquired into by psychiatrists: *“they don’t even get to first base – that would be like sneaking home from third.”* Illness narratives support Geertz’s (1973:104) definition of religion as a “system of symbols” that answers the “problem of suffering” by making agony bearable: “as a religious problem, the problem of suffering is, paradoxically, not how to avoid suffering but how to suffer, how to make of physical pain, personal loss, worldly defeat, or the helpless contemplation of others’ agony something bearable, ... sufferable.” In contrast, many others had religious delusions that had the potential to lead them to troubling situations, while a few “overdosed” on spirituality, which coincided with them becoming ill. Still, the spiritual searches that a number of consumers undertook often led to valuable insights and a sense of comfort and peace.

CHAPTER FIVE: SELF-IDENTITY, DISABILITY AND NORMALCY

For individuals who have been diagnosed with serious mental disorders such as schizophrenia or bipolar affective disorder, which continue to be stigmatized in our society, it is natural to reflect on issues such as self-identity, disability and normalcy. Each of these notions will be examined in this chapter, where we will find various responses to the questions, 'who am I?', 'am I disabled?', and 'am I normal?' Issues of selfhood range from a complete separation of the self from the disorder, to varying degrees of incorporating the illness into the self. In every case, we would have to agree with Hahn (1995:39) that, "the soul of sickness is closer to the self than to the cell." Similarly, disability is contested and accepted to various degrees; in some cases, the label of disabled brings financial security, from Assured Income for the Severely Handicapped (AISH), in addition to a sense of relief as one is excused from the stressful productive arena. Questions of normalcy raise some interesting possibilities. For example, some consumers seem to be creating postscripts that challenge the authority of normalcy, which provide them with positive ways of viewing their "illnesses."

Negotiating Identity: Disorder, Disability and Selfhood

The effects of the stigmatization of mental illnesses on one's sense of self have already been explored in the chapter, "Stigma and Loss: Relationships, Work and Time." Suffice it to say that a consumer may, "resist the stigmatizing identity, or he may accept it; either way, his world has been radically altered" (Kleinman 1988:160). While Estroff (1989:194) does not refer explicitly to stigma, this branding is necessarily inherent in her description of how schizophrenia impacts one's conception of self: "becoming a

schizophrenic is essentially a social and interpersonal process, not an inevitable consequence of primary symptoms and neurochemical abnormality.” Her comment explains how the reactions of others and the way these reactions are internalized, contribute to the creation of one’s self-identity as schizophrenic; thus, she can conclude that all of us participate in “making it crazy” (Estroff 1981:39).

For the majority of consumers, the stigmatized identity was all too real. Perhaps because of this stigmatization, few consumers had attempted to incorporate their illnesses into their self-concepts. A rarity, Tom had incorporated his mental disorder into his self-identity, to the point where he felt a sense of loss when he was medicated: *“when I get better, I almost miss the illness, or feel alone; such a change in the way my head felt.”* In contrast, he noted that the illness causes you to lose some of your self, areas that will never be restored. A member of one of the support groups also brought up this issue. She explained that her family did not want to read anything about the disorder or attend meetings: *“they want to recognize me as me, but there might not ever be a me again.”* This comment lends support to the idea that chronic illness disrupts the world of everyday life, which can be seen as an assault of an ontological nature. This assault affects the very concept of self, and not simply the performance of work or the ability to relate to others (Garro 1992:103-104).

Tom used a metaphor of fragmentation when he said, *“I feel as if I’m broken and don’t know how to fix myself no more; try to figure out how do I fix myself? Do I paint more or get into landscaping? ...”* Tom refers to this fragmentation of the self again when he states that his disorder is *“humbling, makes me feel lesser as a person; not all there or something.”* Marilyn expressed the belief that the older medications temporarily

extinguished part of her self. Like Tom, she was “*not all there.*” “*the drugs made me almost non-existent for a long time. I was there in body, but in intelligence or spirit, it slowed down everything; I was just blank inside, dull, blank. I couldn’t contribute, I couldn’t express myself; now, the medications are better.*”

Tina ascribed to both the tenets of Catholicism and yogic philosophy. At first glance, it appeared that she had incorporated her mental disorder into her self-identity to a certain degree:

it comes from yoga – that I’m the same person whether or not I have this illness ... we are a series of sheaths before you get at the core – physical, mental, emotional, spiritual, divine. They’re saying you can still get at the divine; just in a different energy sheath where you have the disorder. This is not who you are at all, it’s just part of it. You are the Divine, that’s who you are.

However, Tina later agreed with the sentiments of a number of others that she is separate from her illness, leading to a re-reading of the above passage. Similarly, William referred to a poster listing famous people who had mental disorders, and commented on his mental disorder: “*when you see Beethoven up there, and Tolstoy, I think, it’s just a condition that I have ...*” Another consumer noted that he had read a book that describes many artists, composers, poets, and writers who had serious mental disorders: “*at first it validated my position, made me feel a lot better as a human being. But I don’t think one needs to be validated.*”

The tendency to view one’s mental disorder as separate from one’s self was more common than the incorporation of the illness into one’s sense of self. Phenomenologist Plessner (1970 cited in Kleinman 1988:26) addresses this issue in his explanation that, “illness ... brings the sick person to the recognition of a fundamental aspect of the divided nature of the human condition in the West: namely, that each of us *is* his or her

body and *has* (experiences) a body.” In terms of mental illness, we could substitute the term ‘mind/body’ for Plessner’s term body: “the sick person is the sick body and also recognizes that he or she has a sick body that is distinct from self and that the person observes as if it were someone else. As a result the sick both are their illness and are distanced, even alienated, from the illness” (Plessner 1970 cited in Kleinman 1988:26).

This alienation was apparent in the self-identities of a number of consumers, some of whom were so detached from their disorders that they spoke of the illness as having selfhood of its own. Tyler believed that his mental disorder was a separate being from himself, and said that he is able to cope because he can, “*turn it on itself, it starts feeding on itself, so it’s sort of like a dying entity. Humour acts as a buffer ... try to make it so no spot for the illness to dart in and get to me.*” One of Tyler’s final comments about coping with his illness reiterates the notion that the disorder is an invading agent, distinct from his self: “*try to understand the illness, but don’t let the illness understand you.*”

Similarly, Patricia speaks of her illness as being completely divorced from herself, and having an agency of its own: “*the illness tries to kill you ... illness tries to put me in the oven, eat waste out of the toilet, really terrible ... the older I get, the closer I get to death with the illness. I think it will kill me, it’s that bad.*” Another statement that Patricia makes reveals her self-identity, or the self-identity she has constructed since becoming ill: “*the illness strikes people who are great; if you weren’t great, he wouldn’t pick on you ... I think I’m greater than God in worth; God is greater in power, magical power...*” Both Tyler and Patricia and some consumers whose self-concepts will be discussed shortly, offer a challenge to Vonnegut’s (1976:preface cited in Estroff 1981:240) belief that, “most diseases can be separated from one’s self and seen as foreign

intruding entities. Schizophrenia is very poorly behaved in this respect. Colds, ulcers, flu, and cancer are things we get. Schizophrenic is something we are.”

Rebecca also made a clear distinction between her self and her mental disorder: *“since I’ve become a Christian I kind of have more self-worth; doesn’t matter so much that I have this mental illness – that’s not who I am, just something I have to struggle with. As a person, I’m separate from that.”* Perhaps this distinction arose from experiences that Rebecca had when she was ill. For example, a former employer offered Rebecca another job – as a stripper: *“even when I’m in the funny world that I’m in, I’m still me; still know, there’s no way I’d do that. Weird, because I wasn’t really in my right mind, yet knew I wouldn’t do it.”* On the other hand, this occurrence may not be so “weird;” perhaps it can be explained by the, “dual nature of sickness – the way it can make us different persons while we remain the same person” (Brody 1987:x). Like others, Rebecca also accepted the designation of “disability” in regard to her mental disorder, as she receives AISH, and plans to go to Champions of Workplace Diversity: *“they help people with disabilities find employment that’s suitable.”* Later Rebecca reflected on her dream of having a career: *“you can get funding if you have a disability, but I feel so old. I feel like it’s too late to start going back to school ...”*

Lam also felt the need to sever his condition from his sense of self. While he initially denied having a mental disorder, now he is able to, *“accept myself as it is. I separate myself from the illness. One thing is the illness and other one is myself – like somebody who’s got diabetes, so what?”* Lam repeated this understanding later during the interview after he explained that he had inherited the illness: *“I came to the point which I had to separate the illness from myself – this is the illness and this is the person.*

Like a person who has cancer; cancer is not the person, it's only a condition. I learned this through therapy and support groups."

Lam's struggles with his self-identity began long before he was diagnosed with a mental disorder. He remembered questioning different facets of his self from the age of five or six. In Nigeria, where he grew up, not only was there the witchcraft that he underwent, but Lam's father was verbally abusive and his mother could see things that he could not, leading him to wonder if there was something wrong with him. Eventually, Lam turned to alcohol, which helped him experience, *"the thrill, the pleasure of being drunk and high, and feeling I was somebody else; like trying to escape from something that reality wanted me to grab and say this is who you are."* Similarly, Dianne struggled with issues of self-identity from an early age. Growing up in a religious cult, she recalled, *"I'm a homosexual, but I had to keep that hidden, which I did very well."* She, too, turned to alcohol, and for a long time denied that she had a psychiatric disorder. Finally Dianne accepted that she has a mental disorder, with the belief that it was the suppression and oppression of her religious upbringing, and primarily the fact that she was not allowed to express herself, that resulted in her mental disorder.

Jenny also had a religious upbringing, not in a cult, but in the Lutheran Church. Later in life, Jenny said that like her other family members, she was *"driven to achieve something – comes from being the lowest of the low, and German."* She waged a number of *"David and Goliath battles,"* which she feels led to her mental disorder. Counseling has enabled Jenny to re-think her self-identity: *"I've let this mental illness take over my life – there's more to me than this bloody disorder and I've been ... acting as if the disorder took me over completely."* Jenny's comment on how her condition has affected

her can be understood as “the unmaking of the world” (Scarry 1985:23); she is now in the process of trying to reconstitute her lifeworld. Like Jenny, Ethan struggled with issues of self-identity early in life. As a child, he felt alone in the world, and did not relate to children until five years of age. A recurrent childhood dream was of a huge grey screen with a tiny dot that represented himself; in adulthood, this dream came to represent a “*sense of isolation and insignificance.*”

Alexander also faced questions of self-identity from an early age. Growing up in Brazil, he remembers, “*I was different from other kids – I was really smart and classmates are just kids and I’m thinking more difficult things ... bored ‘til grade four.*” As a teenager, he read a book about “*Outsiders,*” people who see visions that give them the truth of the world, a class of people to whom he felt he belonged. Alexander continues to feel different, but is trying not to think that he is “special” or better than others. It is not surprising that Alexander does not perceive his mental disorder as a disability, because he believes that this condition has given him a great advantage in the creative arena: “*I got something from something, so I have to use this ability. So I think this is ability. It’s a good thing.*” Rather than viewing his illness as disabling, Alexander insists that it enables him to create. As for the negative side to the disorder, Alexander made a conviction that was partly a result of seeing members of his support group: “*I feel sorry for people who really serious – they can’t enjoy their life, they’re always worrying about getting sick. I’m trying to not be like that – always thinking about this disease ... I’m trying to think this disease is only a small part of my life.*”

The above comment by Alexander can be compared to the following statement that Stacey makes regarding her disorder:

I'm trying to be a productive member of society despite what I'm dealing with. It is a debilitating disease, but a lot of people aren't working, being social, productive, participating in social life; for me, that's way too important – supporting myself, knowing I can do things and get there. My life doesn't revolve around my disease, it revolves around life.

Stacey had a broader understanding of “disability” than other consumers: “*everybody's created with some form of a disability; none of us are perfect people who don't have things to deal with or accommodate for to operate as members of society.*” One of the things Stacey is dealing with is the abuse she experienced as a child. Along with other forms of abuse, Stacey's mother had Munchausen syndrome by proxy, a condition where the parent intentionally makes the children sick or feign symptoms to get them medical treatment. For Stacey, this abuse seems to have affected her self-identity to a greater extent than her mental disorder. Like Rebecca, religion has had a positive impact on her self-identity: “*religion has given me a much greater acceptance of who I am.*” Like others, Stacey made a clear distinction between her self and her illness:

*I am **not** the illness; that is not the definition of who I am as a person. Who I am as a person is so many things greater and better than what the illness signifies. Just something I have to live with, happens to affect my brain, like heart conditions affects my life, not the definition of who I am, it's just a part of how I live.*

Rachel refers to her self-identity when she discusses the onset of her mental disorder: “*I wasn't myself. It was almost like I was out of my mind, like I wasn't myself. I didn't feel safe, felt like video cameras all around me, watching me.*” If, following Merleau-Ponty (1969:369) we define the “self,” as an embodied orientation to the world, or a focal point for perception, we can see how serious illnesses like bipolar affective disorders and schizophrenia cause a change in the embodied experience of the world (Good 1990:118). Rachel's statement, along with her conviction that she was under

attack by the devil, reflects such a change in her embodied experience of the world. Like William Styron, who describes his experiences with mental illness in Darkness Visible (1990), Rachel found what changed first was the world around her: “the body as physical object and as agent of experience did not belong to separate worlds. The illness was present in the lived body. It was experienced as a change in the lifeworld” (Good 1990:117). The same can be said for the majority of consumers with whom I spoke.

Once Rachel began taking medication, she found that her pre-illness self was intact: *“my family doesn’t necessarily believe that I have it and if I do have it, it doesn’t put a damper too much on who I am.”* Rachel accepts both the presence of disability and an intact self-identity, in her explanation of her condition: *“I don’t see it as majorly affecting my life, skills and abilities, although it does present a bit of a disability in my life, but it doesn’t take away from who I am.”* For Rachel, the disability that mental illness has given her is not life-altering, but is merely, *“weighing me back a little bit,”* as she is able to work and maintain relationships. Like Rachel, Jeff is high-functioning as he is able to work and he rated himself as being *“in the top one per cent of people with this disease.”* Still, like Rachel, he perceives his illness as a disability. Speaking of how his family had no desire to talk to him about his “crazy” symptoms, he empathized, *“who wants to talk to a raving madman – I wouldn’t either if I didn’t have this disability.”* Like many of his peers, Jeff makes no attempt to incorporate his condition into his self; rather, one of his life goals is *“being free of this disease.”*

Sarah also made use of the term “disability” when discussing her mental disorder. When she was very ill, she could not leave her house to go anywhere on her own, and she was granted an attendant’s card so that she could have a friend accompany her on the bus.

On one occasion, a bus driver refused to honour the attendant's card, saying to Sarah, "But you're not handicapped," referring to the absence of wheelchair or walking aids. Sarah replied, *"that's not the only kind of handicap there is."* Sarah was ambivalent about whether her condition was a disability: *"I don't believe it's a 'handicap' because I believe it's here to help me teach other people. It is a disability that I have problems doing things, but it's also – through this disability I can teach people about it."*

For some consumers, the disability imposed by serious mental illness was experienced as much more disabling. As Patricia put it, referring to her mental disorder, *"I feel crippled – hard for me to walk and my mind doesn't work properly."* In Patricia's case, the disability led to the need for dependence: *"Life's too hard for me living on my own. I need someone to help me with my life – it's too much on my own."* At the other end of the spectrum, some consumers contested the idea that mental illnesses are disabilities. One member of the support group for individuals with bipolar affective disorders felt that not all "bipolars" were sick enough to be on AISH all the time.

Gary recalled with relief when he was, *"finally accepted on AISH, which is Assured Income for Severely Handicapped, that does now apply to people with schizophrenia and bipolar disorder."* Many consumers relied on AISH to some degree, suggesting that at some level they accepted their status as disabled or "handicapped." Lisa recalled that, *"for a long time, I looked at myself as disabled, I looked at myself as weak or inferior or less than a person."* She remembered that in a college course she had once taken, they were taught: *"to say it's a person with a disability, and it's always the person first. But it's sometimes hard to look at ourselves that way; we always see the disability first, we always see the mental illness first and we get consumed by that."*

Lisa had incorporated her mental disorder into her self-identity to a greater extent than many of the consumers discussed thus far. Explaining how she perceived her condition partly as a “gift,” Lisa said that it, “*made me who I am today.*” Similarly, Brendan, Frank and Andrew accepted that their disorders were part of their self-identities. Gary also incorporated his condition into his self-identity to a greater extent than others, and explained that when he found out his diagnosis, it was almost a relief: “*I used to ask, ‘why me?’ when things went wrong; almost like an equation was solved when I found out about the illness and different symptoms.*” His current philosophy also demonstrates his acceptance of his mental disorder as part of his selfhood: “*with the renewal I had with spirituality and programs, I feel if I’m meant to have this condition, then I can deal with it ... I don’t have to dig within myself to find out what’s wrong with me.*”

Perhaps because of her understanding of mental illness as an unrealized sixth sense, Dee did not speak of her illness as a disability. The following comment about her self-identity points to both internal and external reasons for Dee’s difficulties:

I’ve always had too much empathy, more consciousness, awareness; for people with that kind of sensitivity and empathy, the world gets to be too much. They don’t balance things enough in the interests of society and people. There’s as much good news happening, but we don’t hear about the good things.

Like Dee, another consumer did not view his mental illness as a disability. In fact, he had incorporated his condition into his self-identity to the point where he felt “*deprived*” when he was put on medication to dispel the mania resulting from his mental disorder: “*I was really feeling more like myself; other people might not have liked that, but I was feeling more like myself – more creative, more free ...*” This statement resembles one

made by Murphy (1997:5443): "...perhaps the psychosis of schizophrenia may bring about a fundamental reorganization of the self."

On a more somber note, while this consumer initially explained how his belief in God had helped him to resist giving up, he has been suicidal, and noted that this option, *"may sound like taking the easy way out, but it's like I've had a fulfilling enough life and I'm causing myself and others so much concern and anguish. I don't know if I want to do this anymore – if I can't be well, I don't want to do this at all."* Hahn (1995:26) would likely classify this description as "rational suicide," where a person decides to end his life after weighing his life and its future. This type of suicide should not be called sickness, as "suicide may be the best means of fulfilling an integral life. ... It is inappropriate to refer to acts that complete the self as self-harm" (Hahn 1995:26). Whether or not his suicidal tendencies came about because of a reorganization or completion of the self, Hahn's understanding is particularly striking in this consumer's situation as he was hospitalized against his will by relatives who perceived him as "sick," as they thought he was suicidal.

Mystics or Madmen? ... Challenging the Authority of Normalcy

In our society, normalcy is usually a standard to which people aspire. Being abnormal is a description few people would want applied to them. However, several of the consumers I interviewed challenged the authority of normalcy. Some of them would probably agree with R.D. Laing (1960:12), that our "normal," "adjusted" state often includes giving up ecstasy, betraying our full potentials and acquiring a false self to cope with false realities. R.D. Laing and other members of anti-psychiatry crusades accused

psychiatry of labeling the psychotic as diseased and therefore inferior to “normal” people.

In contrast, Laing (1989:53-54, cited in Shorto 1999:14) insists that:

a schizophrenic may indeed be *mad*, ... but he is not *ill*. The mind as a whole ... is like an ocean, of which the ego remains mostly ignorant. But a psychotic is in touch with it: he is swimming (one might say drowning) in it. He is not out of his mind but, in fact, *in* his mind; we, the sane, are the ones who are out of our minds, or rather out of touch with most of our minds, in that we can't access them.

Estroff (1981:215) states that we need to avoid ethnocentricity in assuming that “normalcy” is equally attractive to people, particularly to people who receive signs that they are different. This point was made by Alexander:

for someone like me, someone who is thinking I'm an artist, that's kind of, I don't know, maybe it sounds strange, but it's kind of good, because it's special. Only 1% of the population have this disease. And lots of writers and composers have same disease. That means maybe I could be...I don't think ordinary people can feel this colour and this light and these crazy things in my brain. It could be really good for creative work.

Later Alexander repeated this understanding of his condition, when he reflected on how his understanding differs from that of most people who view the disorder as strange and crazy: “*I have this disease and I can see things more than ordinary people ... so I have to use this ability ... it feels really good when I get high*” Alexander challenges the authority of “normalcy” again, when he values part of his illness over his normalized state of being: “*when I get high I can make more things and it's better than when I'm normal, ... so that makes me believe this disease is good to create.*” Similarly, in an earlier chapter, other consumers linked creativity to their mental disorders. In contrast, another consumer said that it is a myth that his mental disorder heightens creativity and explained that he has met many people who only *think* they are creative:

If I was in a normal state, I'd be productive. I know painters who are so-called “normal” and they consistently paint every day, 8 hours a day ... when you're

depressed, you can't do that. I wonder what van Gogh would be like if he was not bipolar ... if he was normal maybe he would have cranked out twice as much and maybe it would have been just as good.

Still, the link between creativity and mental illness persists, and the list of poets with probable bipolar disorder or major depression is staggering: Dylan Thomas, Tennyson, Percy Bysshe Shelley, Dante Rossetti, Ezra Pound, Edgar Allan Poe, Sylvia Plath, John Milton, Ralph Waldo Emerson, Emily Dickinson, Coleridge, William Blake, T. S. Eliot, to name only some of them (Jamison 1993:267-268). Sandblom (1998:83) discusses the poetry of German romantic poet Friedrich Holderlin, who developed schizophrenia:

The bizarre style and the schizophrenic visions, bordering upon psychosis, heighten the expressiveness of the great works and give them their unique strength. It is truly remarkable that a mental derangement in the work of a great poet should be an initial influence in the universal lyrical development towards greater linguistic richness and freedom, keener images, metaphors untrammelled by conventional logic.

Sandblom discusses other poets, stressing that their mental illnesses greatly influenced what they wrote and how they wrote it. In contrast, a 1995 study compared the poetic output of what the researchers termed "psychotics" and "normals." Their findings should jolt us into a rethinking of our conceptions of "normalcy:" few differences were found between the poetry written by people with schizophrenia and the poetry written by "normals." The findings were interpreted to mean "that 'normal' poetry has strong 'psychotic' features" (Rhodes et al. 1995:318), meaning that the language and content of poetry is similar to the language and content of "schizotypal" thinking. An alternative interpretation put forth was that "poetry by psychotics is basically 'normal'" (Rhodes et

al. 1995:318). In either case, normalcy is inverted and we are forced to recognize that “normalcy” is but an empty construct.

While Frank was not as critical of normalcy as Alexander, his comments reflect a questioning of the value of normalcy, which goes unquestioned by most of us. During his description of his condition, Frank explained that you have expectations that are unreasonable, and you are not functioning so that you fit into “*so-called normal living ... you don't have normal associations that most people have.*” He also recalled being hyperactive in high school and enjoying this state of being, but explained how others react to the projects he undertakes:

they say they're difficult or they can't be done; maybe a different way of doing things. Routine sometimes drives me crazy. If you've done something three or four times, I can see a better way of doing things ... I'd say 'let's do it this way.' They say, 'why do you want to change – we've done it this way for years.'

Thinking of his career, Frank recalled that the amount of work he accomplished was much appreciated. He suggested that some companies would allow for “*irregularities*” or “*abnormalities*” because they benefit in the productivity of “*bipolars*” in comparison to “*normals*.” A consumer who works in a very different field, also found that employers made room for people like himself:

I've worked in the creative arena. I would suggest that those professions give an allowance for people to be a little – not quite to the societal norm. A lot of people enter those fields who suffer from mental illness ... not ostracized ... strange allowance to act strange in those professions ... other fields a little more stigmatized ... maybe there's an acceptance of people having mental illness and being creative – it's popular. K.R. Jamison wrote a book about poets, artists, composers – you're not gonna write a book about construction workers and typists, engineers; doesn't have the bang for the buck.

Another consumer had a different outlook on normalcy: “*I think I'm a pretty normal person, mental health wise, as long as I don't get too hyper; on the other hand,*

my mind works better when I'm a little hyper." She told me about her friend who is a dumpster-diver and scavenges dumpsters for useful items, including food. She spoke with disgust about how some of us can let good food rot in the garbage when others are starving: *"it's a crazy society we live in; so naturally, anybody that doesn't conform to society is got to be crazy. If the society's crazy, maybe we're the only two sane ones around."* While this consumer had the label of a mental disorder, she believed that the society in which she lived was more disordered.

This reading of "normalcy," where one sees oneself as normal and the rest of the world is crazy, echoes the words of R.D. Laing (1960:11-12):

in the context of our present pervasive madness that we call normality, sanity, freedom, all our frames of reference are ambiguous and equivocal. A man who prefers to be dead rather than Red is normal. A man who says he has lost his soul is mad. A man who says that men are machines may be a great scientist. A man who says he *is* a machine is 'depersonalized' in psychiatric jargon.

During the group interview, which took place two days after the September 11th tragedy, the same interviewee brought up this understanding: *"if you have a disorder and the norm is the other kind of people ... I personally believe that the society is just as crazy as I am, and the last couple days has been proof of that!"* Speaking of how his religious beliefs have helped him to cope with his mental disorder, Brendan reflects this idea of where the craziness lies: *"in this crazy world, you need somebody; it's very lonely sometimes, a lot of lonely people – if they don't have something to hold onto they get sucked into other religions or whatever and get really screwed up. And I know that, meeting the people that live in my building."*

Jenny, unappreciative of a psychiatrist who tried to give her medication, and only medication, repeated Frankl's (1959:105) warning about tranquilizing existential despair

with medication. Jenny believed that she had created existential despair for herself, which she saw as part of a search for meaning. While she is aware that the doctors explain mental illness as a biochemical imbalance, Jenny says *"I'm too stubborn to settle for burying the stuff under the pile of drugs."* Dee would agree with Jenny and Victor Frankl; she spoke about her amazement when she started sculpting because the beauty seemed to originate beyond the illness, in which case, it should be nurtured and controlled, instead of suffocated with drugs.

The use of pharmaceutical medications was a contested issue in regards to the normalcy question. One consumer insisted that, *"the 'medications work; I would say I'm almost back to my normal self.'"* Similarly, at a support group meeting, when a consumer reported that she felt very "weird" because she has become very quiet, which is very unlike her, another member stated matter-of-factly, *"maybe this is your bio-chemical 'normal'."* In contrast, one of the consumers addressed the age-old question of what constitutes normal in the following way:

Most of us forget what the hell normal is. I think it's all contextual based on the day ... the problem for a lot of people is that you get put on mood stabilizers and that definitely does not put you to normal. If you're not on it you're not normal, if you're over-medicated you're not normal, if you're under-medicated you're not normal, if you're having a shitty month you're not normal. It's hard to determine what a normal state of being is. What was normal for me when I was twenty-five years old is not normal now. What's normal now changes all the time.

Another consumer confided that, *"I still haven't figured out what normal is."* During the group interview he said, *"today I went to see my therapist and he said, 'things are pretty normal in your life.' I said, 'how can you say that? Last month you wanted to talk to my psychiatrist. How can you detect when things are normal?' And he couldn't answer that ... normal is iffy."*

One of the reasons that “normal” is so “iffy,” according to Boisen (1936:165), is that what constitutes normative, or “normal” depends on one’s point of view:

If we are merely detached observers or are content to take things as they are, we use the term normal in the sense of average. But just as soon as we become interested in accomplishing something, as soon as we cease to be mere observers and become participants in some enterprise, then our objective becomes for us the normative and we introduce the value-judgement...the ‘good-bad antithesis.’

And once this value-judgement is introduced, it is a short step to arrive at the conclusion of a 1935 physician, that, “the abnormal prevent the development of the normal. This fact must be squarely faced. Why should society not dispose of the criminals and insane in a more economical manner? ...” (cited in Whitaker 2002:66).

The contextual nature of normalcy was highlighted by a number of consumers who explained that they initially existed in the world with a different concept of normalcy. Brendan, who had grown up in a dysfunctional home, described his experience living in one of Alberta Mental Health’s approved homes for people with mental illnesses: *“you come to a home that’s more functional and it’s weird; I felt like, what am I doing here, it’s too strange. I felt like it was too temporary, wasn’t gonna last forever.”* The normal felt abnormal for Brendan, just as Dee described how normalcy was inverted: *“treatment has segregated me ... it’s very hard to find a place in society. At Self Help and my apartment, everybody has mental illness. It’s like the norm is not normal. Not too many places you can be with normal people; it’s hard fitting in – the illness kind of follows you around.”*

Marilyn noted the following about hearing voices: *“I just assumed everybody had that – I didn’t know it was the exception as opposed to the norm.”* Lisa had a parallel experience, which was highlighted when she went to see a psychiatrist: *“first guy to*

finally explain to me that it's not normal to hear voices – a relief, I thought everybody had that.” During a group interview one consumer explained that he initially rejected medication: *“I thought everybody suffered depression, like me, everybody was high, like me, they just hide it, don't tell you; they think the same way – we're all humans...”* Dianne continued to believe this, evident in her comment that all around there are, *“people struggling behind vanilla boxes, living in various states of insanity.”*

Anthropologists have for a long time recognized that “normalcy” is culturally constructed. What is normal in our society may be very abnormal among small-scale societies, and vice-versa. In “Shamans and Acute Schizophrenia,” Silverman (1967) explains how the behaviors of shamans in other cultures and those of people with acute schizophrenia are very similar. However, while the shaman is accorded prestige for his activities, “similar kinds of ritualistic behavior when performed by a person in a schizophrenic state lead to absolutely nothing at all that has cultural significance, other than as verification of his insanity” (Silverman 1967:29). The reactions of society's members to the experiences of the shaman and the person with schizophrenia differ greatly, leading to the pathologization of the one and the validation of the other. Similarly, in her argument that social situations are replicated symbolically by drawing on bodily symbols, Douglas (1982:74) explains that trance states are perceived as dangerous where the social situation is greatly structured, but welcomed and even induced in groups that lack such structure: “the inarticulateness of the social organisation in itself gains symbolic expression in bodily dissociation.”

Dee noted that among native groups, *“people like me would become medicine men.”* Instead, she says, *“the white man's still torturing their spiritual leaders.”* Dee

went on to say the following about the way mental illnesses are approached in our society, or rather, the way they are not approached: *"...there's a lot more happening than it being just an illness ... may be part of a sixth sense that's not developed in a nurturing environment...it will come to light that it's a very valuable part of the evolution of humankind."* While mental disorders may not be "normal," then, they are not something to be devalued as "illnesses" and stigmatized as they are today. Dee's words and her later comment that her mental disorder has made her more aware of the fact that all of us are connected, reflect the beliefs of proponents of the psyche-spirit movement and consciousness studies, who reject traditional understandings of what human beings are, how we know and what knowledge is composed of; along with Dee, they "assume that individual consciousness is broader, weirder, fuzzier than we normally allow, that it somehow or other extends beyond the skin of the individual person" (Shorto 1999:225).

Dee had dreams that had significance in the waking world when she followed up on them, causing her to wonder, *"how come psychics aren't labeled crazy?... somewhere along the way they got introduced to the right people or believe enough in themselves, or balanced themselves enough to do that kind of thing."* Dee's perspective could lead to the suggestion that mental illness is a myth, as Pallone (1986:10) says, "a socially relativistic construct invented to denote merely that which the rest of us find odd or offensive." Another experience occurred after a grade ten class, when Dee started conversing with a voice whose origins she did not know. An older girl who heard her said, "you sound like you've lived for a hundred years," and the math teacher drew a diagram on the blackboard including universal minds, individual minds and the unconscious. The idea was that we all carry this structure with us and not all of us are

connected, but at different times the Universal Mind wants to say something to certain people. Reflecting on the situation, Dee noted, *"the mathematician saw the whole episode as something different, where if I had been sitting there with a psychiatrist, he would have been diagnosing."* As Goffman (1963:138) put it, "the normal and the stigmatized are not persons but rather perspectives."

Shorto (1999:15) suggests that there is an increase in spiritually-oriented psychiatrists who believe a broader view of "abnormal" states must be adopted. Indeed, one consumer noted that a psychiatrist told her that the symptoms of mental illness are similar to what happens when the kundalini opens too quickly: *"it's different for a psychiatrist to notice that, but I think some psychiatrists are waking up to there being different reasons that different things are happening."* Rather than labeling religious delusions as signs of illness needing suppression, they encourage patients to identify the spiritually valuable parts of their experience, thus finding meaning in their madness. Unfortunately, these psychiatrists are in the minority, and as Dee put it, *"I don't feel too natural about talking about those things, [religion/spirituality] you may be put on more medication!"*

If a religious person experiences Christ's body entering her own, or hears God's voice or the voice of a deceased family member, the following question is asked: when do experiences like these become pathological, and when are they culturally acceptable (Whitaker 2002:168)? A 1973 experiment by psychology professor David Rosenhan (1973:251) addressed the issue of defining this line. He and seven other "normal" people went to twelve different mental hospitals, complaining of voices that said, "thud," "empty," or "hollow," these being the only false symptoms they reported. Although they

acted calmly and described their relationships truthfully, of the twelve admissions, eleven were diagnosed as schizophrenic and one as manic-depressive psychosis (Rosenhan 1973:252). The conclusion arrived at from these results, was that, “we now know that we cannot distinguish insanity from sanity” (Rosenhan 1973:257).

Tom shared Dee’s belief that if people with mental illnesses were raised in other cultures, they would be trained to be shamans or medicine men. Tom was perplexed by the notion of normalcy: *“I don’t really know what is normal. I looked in the dictionary or something and only sixty percent of people are normal – that’s not normal!”* Speaking of his condition, Tom said, *“there’s a fine line between a spiritual and chemical imbalance.”* In a related vein, psychiatrist Tony Stern believes that there is a fine line between mysticism and psychosis, and that the process at work may be the same (Shorto 1999:98). In fact, a 1993 study comparing mystical experiences reported by psychotics and mystical experiences reported by religious contemplatives, found these experiences to be basically the same, with small differences because of cultural expectation and interpretation (Shorto 1999:172-173). This study supports the following notion:

if the mystic’s experience is to be called religious then so too should the psychotic’s. Perhaps the real differences are exterior to the persons involved: we prefer to think of one as religion and the other as mental illness; we prefer the idea that religion brings well-being and control. We prefer to think of real religion as something that we choose to engage in, not something that forces itself upon us. So we make an arbitrary determination: *this* is religion, *that* is mental illness masquerading as faith (Shorto 1999:173).

Tom and a number of other consumers believed that some of their “experiences” were spiritual rather than psychotic. In fact, the majority of consumers identified value of some sort in their illnesses, often including the notion that their spiritual beliefs had deepened.

While Tom challenges the authority of normalcy, he also realizes that to function well in our society, one has to achieve a certain level of normalcy: *"hopefully, a few generations down the line, we can teach them how to grow up to make em feel more normal or train them differently so they can excel more better."* Sarah explicitly challenged the existence of normalcy: *"I don't believe anyone is actually normal. There is no normalcy out there...everyone has some aspect of stress ...Maybe a Buddhist priest, or a Zen master, where they're totally calm, one with the universe, maybe they don't have stress, they're normal."* The following dialogue during the group interview also constitutes a challenge to the authority of normalcy:

Interviewee #1: *"There's no such thing as normal."*

Interviewee #2: *"What is normal anyway? The reverse of nuts?"*

Interviewee #3: *"How well you conform to society. That's what I think the nurses and doctors think normal is. They think if you can do housework, et cetera, you're normal. They thought my mother was normal because she could do all the housework."*

Interviewee #1: *"Then I'm normal!"*

While this discussion was wrapped in humour, the following statement that some of these consumers would agree with is not: "medicalization can stigmatize as well as protect; it can institute a misguided search for magic bullets for complex social problems ... No other therapeutic system can exercise this degree of power, because no other has become so powerful a part of the state's mechanisms of social control" (Kleinman 1995:38).

Lyle would also likely agree with the above statement; however, when I first interviewed him, he spoke of coping with his mental disorder, insisting that *"the emphasis has to be on staying in the middle, having a normal mood..."* Towards the end of the interview, Lyle had identified value in his illness: *"I probably learned a lot from it ... if I was more normal – there are situations I wouldn't have had to deal with. Put me*

on a learning quest, supporting other people that have had depression, difficulties ..."

Later, Lyle had moved to the far end of the spectrum in his belief that no one is normal. Lyle would probably agree with Whitaker (2002:290) who insists that telling consumers that they have a biochemical imbalance in the brain is deceptive because there are numerous factors, biological and environmental, that can lead to mental disorders: "it is also possible that the capacity to go mad, as it were, is in all of us." As Erich Fromm (1963:122) put it, "while psychiatry is concerned with the question of why *some* people become insane, the real question is why *most* people do *not* become insane."

During a group interview, one consumer explained the essence of psychiatry: "*your mind's gone wrong, or something, in somebody's eyes.*" His challenge to the authority of normalcy is strikingly evident in his description of how individuals with mental illness are treated:

I believe I have been enriched by my illness because I think I've had a wider expression of emotion because of it ... but people around me don't necessarily want that or allow that so they medicate you or hospitalize you because they can't cope, it isn't within their realm. And so, in order for you to fit the norm of what everybody else wants, you're hospitalized and it's taken away from you and then the medication makes you like a zombie. How can that be better? So in a way, I feel it's very progressive, it's very creative, it's very advanced and I think you can relate in a different way to things because of it ... you could say it's a gift ...

During the next group interview, he repeats this understanding, reflecting Alexander's belief that illness is better than one's normalized condition: "*I like what I experienced when I was high and creative and doing things I might not normally do – that's why I mean **deprived** when they take the high away.*" This consumer felt that his condition had given him an expanded view of the universe. Similarly, Boisen (1936:192) had experienced serious mental illness, and concluded that the majority of people having

these experiences, “feel that their eyes have been opened to unsuspected meanings and possibilities in their lives. The so-called ‘normal’ range of vision becomes for them inadequate and superficial.” As one consumer put it, *“it’s a big drop, when you come down and realize you’re not an angel!”* On the other hand, another consumer responded that, *“it was a relief for me. I was glad to see some normalcy.”* Similarly, another consumer explained that she went through a period during her illness when she realized, *“my life was never going to be normal again. Now, thank God to newer medications, I’m back circulating in what I consider normalcy ... but it took, like, thirteen years.”*

Normalcy, evidently, is not always challenged. During the group interview, one interviewee told the group that he, *“would rather be on a steady line, making work, being happy as a normal person, having little peaks and dives – rather than high three months, then feeling like shit. What is the amount that comes out of that? I’m losing in the end.”* Tyler also explained that he’s *“trying to stay as sane as I possibly can, which is what everyone’s trying to do.”* He described it as *“walking the edge of this table – I don’t know whether I’ll fall off it or go over here and be really sane or normal, whatever normal or sane is.”* Later he defined normal as *“trying to be perfect but not being perfect.”* Normalcy was also reached toward by Carolyn, who explained that she is *“really working towards having as normal of a brain as possible and making the illness as small of a problem as possible.”* She also commented on how her striving for “normalcy” has been received by her family: *“now that I am treated and going to school and working and leading a normal life, they are very happy and relieved.”*

In her ethnography, Sue Estroff suggests that consumers, staff, and the larger community, construct a paradoxical, contradictory, or crazy world. So people diagnosed

with mental illnesses participate in “making it crazy” because the advantages of accepting the crazy identity outweigh the disadvantages (Estroff 1981:214). Patricia insisted, *“life’s too hard for me living on my own. I need someone to help me with my life. It’s too much on my own.”* Brendan, while discussing his experience with mental illness, noted, *“I’m unique, but I’m not normal,”* and his feelings of abnormality led him to the following decision: *“In 1999 I decided to have an operation so I can’t have children because of my illness and because of my dysfunctional family...”* He, too, reflected Estroff’s idea about clinging to the “crazy” identity, when he wondered about the future with apprehension, not knowing how consumers who rely on AISH will cope if there ever is a cure for mental disorders. Brendan insisted that there still needs to be financial support for consumers even if a cure is found.

Normalcy is not only a socially and culturally relativistic construct, invented to denote that with most of us deem acceptable and inoffensive, but also one that is accepted and contested to varying degrees. Estroff (1981:15) believed that people have a right to be different and even crazy and examined how they did this in American society; unfortunately, the rest of society is not nearly as accommodating, and allows little room for dreamers. The attempt to make someone who has schizophrenia “normal,” may be a misguided mission: “what right does the DSM task force have to rule that someone who cannot spend eight to ten hours a day in productive activity does not have a genuine role to play in society – as dreamer, lover, artist, visionary?” (Shorto 1999:60). The answer, of course, is that it has no right, but as Foucault (1965) has shown, each time period throughout history had its own view of madness, which reflected the social and logical concerns of that time.

Rubenstein (1980:12) insists that because "madness" is often a question of "cultural incongruence," there needs to be limits on how far we allow psychiatrists to evaluate the way reality is comprehended. Many consumers have created or are in the process of creating postscripts that challenge the authority of "reality" and "normalcy" with regard to their conditions. While these postscripts have not yet become newly authoritative narratives in their own right, the rise of consciousness studies and the psyche-spiritual movement lend support and authority to these postscripts. However, we must be cautious in making this suggestion, for the following reason:

the intersubjective experience of suffering is so various, so multileveled, so open to original inventions that interpreting it solely as an existential quest for meaning, or as *disguised popular critique of dominant ideology*, notwithstanding all the moral resonance of those foci, is inadequate. It may distort and eventually transmogrify this most deeply human of experiences (Kleinman 1992:190, emphasis added).

CHAPTER SIX: OF THE BRAIN, FROM BEYOND OR BOTH: MODELS AND METAPHORS OF MENTAL ILLNESS

As Herzlich (1995:159) found regarding physical illness, there may be a unique system of mental illness conceptions independent of medically constructed categories. Indeed, not all of my informants subscribed to the medical model that locates the cause of mental illness in biochemical imbalances in the brain, usually with a genetic component. While seven informants did subscribe to this model, seven others had very alternative understandings of their conditions. The other ten informants combined both the medical model and various alternative understandings of mental illness in their descriptions of the nature and causes of schizophrenia and bipolar affective disorder. That many rejected or supplemented the medical model is particularly striking since all of the informants were members of support groups run by agencies that subscribe to this model of mental illness, and for the most part, the support group facilitators also had this understanding of mental illness. These findings remind us that people generally live their lives independently of the intellectual frameworks created by academics, and that the arena of knowledge cannot be separated from the local world in which people act (Jackson 1996:4).

Medical Models

Andrew restates the medical model of mental illness followed by the majority of psychiatrists, in simple terms:

Like they say, a disorder of the brain – problem with some of the chemicals in the brain which affect your thinking ... a physical thing – there's something wrong with my brain – the chemicals don't quite work right ... don't know what caused it ... have to take medication to keep it under control. It could have happened to anybody ... try to do the best I can.

Carolyn's understanding of her condition contains more detail, but it is also in agreement with the medical model:

It's caused by a brain chemical – dopamine – not going along the path it would in a normal brain; it misses the receptor ... therefore the thought is not completed, so you have scattered thoughts, problems with concentrating, problems thinking in-depth, in advanced stages, delusions and hallucinations ... corrected by the doctors giving you more dopamine to give you a complete thought and rational thought. I don't think it was something I created or brought on by outside influences ... just one of those people who have a problem with their brain ... just happen to have it, it's that simple.

Similarly, Gary described his condition as “a mental health condition where all five of the senses can be affected ... it's a chemical imbalance in my brain – dopamine is overabundant and it's treated with medication.”

Tina seemed a little more hesitant in accepting the medical model:

it's mainly a bio-chemical disorder of the brain with periods of mania – times where the brain is speeded up, times of depression with periods of stability in between ... it can be triggered by environmental factors – sleep deprivation, stress, so it combines both environmental factors and an inherent biochemical predisposition. It's genetic as well, my grandmother had it, my mother had a mild form, my brother and I have it.

During a group interview, Tina reflected on her experiences with mental illness, saying that she was able to handle the extreme emotions that accompanied her illness and even enjoyed aspects of it. While Tina accepts the medical model of mental illness, she seems to be questioning the way disorders such as hers are viewed by society. Similarly, while Lam subscribed to the medical model of mental illness, he expressed the idea that there could be something more involved in his condition. He spoke of attending various different churches and Bible study groups and explained how spirituality became an addiction:

I try to be really aware of how far I go because when I've gone too far on the spiritual aspect, I get into trouble, get really depressed or converted easily, more vulnerable ... I try to keep it even – on even keel, because I've heard people say this is an evil thing – a thing of the devil – this illness; this is more, how you say, genetically, than anything else.

This connection between spiritual imbalance and mental illness is a theme that has come up in a number of other consumers' narratives. One consumer remembered, "*when I wasn't on medication, depression could get quite intense ... I think I felt more connected with something like a soul ... spirit that is universal; when my emotions were more intense, I felt more connected that way.*" She also spoke of Biblical figures such as Jesus Christ, John the Baptist, Mary's sister, as well as many of the saints, who would be classified as mentally ill by the standards of modern psychiatry. During a group interview, another consumer expressed an alternative understanding of religious delusions:

traditionally, it's always been a spiritual issue. It's just modern psychiatry that's coming into play; industrial society wants to control the inhabitants. Before, people would have these delusions, these religious experiences, and they would come out of the episodes and be integrated back into society. In our society, we institutionalize them, put them on drugs. Some people don't have to be on drugs but they are on drugs, some people have mild little episodes – depends on how society views the individual ... in other cultures people would have experiences in villages, et cetera and people would just accept them as having religious ideation.

Frank gave the following explanation of his condition:

a state of living where ... you have highs or unreasonable expectations, ... you have lows and where, in most cases, you're not functioning well enough that you fit into so-called normal living ... in the brain, where the messages don't find paths through the brain to the proper area; lack of transmitters, serotonin doesn't make a proper connection, you don't have normal associations that most people have.

Earlier in the interview, Frank noted that it was his wife who recognized the beginning of his illness episodes, while he "*wasn't that aware of these episodes - some of the things*

she considered manic, to me, weren't that manic, just certain ways of doing things she didn't agree with." While he clearly subscribes to the medical model of mental illness, Frank's comments raise interesting questions about normalcy.

Combining the Medical Model with Alternative Understandings

Moving a little farther along the spectrum, we find a number of people who combine the medical model with an alternative understanding to create what for them is a workable version of the nature of schizophrenia or bipolar affective disorder. On one level, Ethan subscribes to the medical model of mental illness and stresses the element of chance involved as well as the lack of personal responsibility for having the disorder:

I see it as a bio-chemical disorder ... genetics caused it. My father was cyclothymic and my grandmother had depression. My great grandfather had this disorder – he gambled away the family farm. It's on both sides – my great, great grandmother killed a guy, she was not normal! My uncle has it, he's self-medicated; my grandmother has acute anxiety disorder ... I wasn't responsible for this, it was passed down; they weren't responsible either ... just the circumstances of how it's happened.

When I asked Ethan whether there was any deeper meaning to his condition, he said, *"nothing deeper,"* and with a note of irony in his voice, *"it's deeply bio-chemical in nature ... basic neuroscience."* However, he later spoke of mental disorders in such a way that undermined this strictly biomedical understanding of mental illness. For example, he agreed with others who viewed "mental illness" as a recent phenomenon that was in the past a spiritual issue, where those with religious experiences were simply accepted.

William explained how he developed his condition as a result of illegal drug usage. He recalled being at a party where his drink was spiked with L.S.D, after which

he really noticed he had tendencies of his mental disorder. He also noted that, *"I don't smoke marijuana or take anything to get more dopamine because I believe the L.S.D. made the dopamine receptors in my brain grow; therefore, I have to be very careful."* However, more salient in William's understanding of his mental illness were the circumstances of his birth. He commented, *"I had possibilities of this mental disorder all my life,"* and in his view, the cause of the disorder was *"the way I was born – birth trauma."* William described his birth as follows:

It was a difficult birth. The nurses and aides were busy...down canning fruit, and my mother tried to have me on her own. I was born blue and had to be resuscitated. I was put in an incubator that had pure oxygen but no moisture! I don't know whether it was from the viral infection that she had or being in an incubator with no moisture, ... it probably had some effect on my brain.

There is slight evidence that William's condition can be caused by birth trauma, so it can be said that William combined this aspect of the medical model with the alternative understanding regarding drug usage. It is also interesting that he did not discuss the possibility of a genetic component when I asked about the causes of his disorder; later in the interview he spoke of his *"grandfather's brother's daughter – she likely has it ... I think it runs in the family."*

Marilyn believed that her mental disorder was primarily a *"biological, physiological disease of the brain."* However, she went on to say,

I think they're gonna find out hormones play a role. Causes can be environmental ... brain trauma, certain chemicals can trigger it, can carry the gene, the insult usually takes place invitro in the third to fifth month when the brain is developing ... abnormality in the structuring of the brain; there's also the viral infection theory – my mom had the Hong Kong flu during the third to fifth month of pregnancy...my relationship broke up, I was heart-broken, I starved myself and I was getting anorexic...starving the brain contributed to me getting sick – what came first, the eating disorder or the mental illness?

While Marilyn subscribes to the medical model at some level, she seems open to the possibility of a number of other factors being involved. If she fully subscribed to the medical model of mental illness as a biochemical imbalance requiring treatment with pharmaceuticals, it is unlikely that she would have made the following comment: *"we should be able to tell our doctors – if we're in control, why do we need the medication? ... if we get out of control, then we need medication."* In a comment reminiscent of another consumer's explanation of why she was put on medication, Marilyn states, *"I don't think there's people available to support us because they're so used to medicating us to the point where we can't move – it's for their comfort, not ours."*

The alternative understanding was further highlighted when I asked Marilyn if her religious beliefs affected how she understands her condition:

I think so ... because I think that with religion, it's usually a component of this disorder. A lot of people who have it believe they're Jesus Christ or a prophet or have a closer relationship with God. And maybe their awareness is just a reflection of what people should have towards God ... you know, I thought we reflect the consciousness of the times ... a reflection of the priority society should put on it.

This "awareness" is a theme that will be explored more fully in the section that follows on alternative understandings of mental illness. For now, it is sufficient to compare Marilyn's statement to one made by R.D. Laing, a psychiatrist who takes an existential-phenomenological approach to understanding psychosis:

I am aware that the man who is said to be deluded may be in his delusion telling me the truth, and this in no equivocal or metaphorical sense, but quite literally, and that the cracked mind of the schizophrenic may let in light which does not enter the intact minds of many sane people whose minds are closed. Ezekiel, in Jaspers's opinion, was a schizophrenic (Laing 1969:27).

While Marilyn no longer believes that she is God's chosen daughter, she continues to believe that people with mental illnesses are closer to God:

God protects them, because you're more vulnerable, like street people ... every person I know who has this condition has become so obsessed with God – that they have direct communication from God, they're the chosen one, have a role to do ... I don't know why ... I'm thinking there's got to be. [a closeness to God]

Recently diagnosed with a mental disorder, Stacey gave an explanation of her condition that would fit within the medical model:

it's a mental condition where the brain chemicals don't function properly. I can't stabilize my mood on my own without the help of medication ... I flip back and forth very quickly – I can go from in the morning being hypomanic to after lunch, being suicidally depressed. ... There's a hereditary issue involved; my mother has mental illness, multiple alcoholics and people who are depressed, on medication for depression, in my family. And your own brain chemistry, how it's set up, whether you're going to end up with the illness.

However, when I asked Stacey whether she believed that her religious beliefs affected how she understood her condition, she replied, *"it's how God made me and somehow part of His plan for me, that I'm going to deal with this ... God loves all of the people He creates and He created me with this illness so there's obviously some sort of purpose for me dealing with this illness ... there's something to it."* This notion of a deeper meaning or purpose for struggling with the disorder was also brought up earlier by Stacey when she discussed her religious beliefs: *"I believe there's a purpose and plan for us...because if there really wasn't, why would any of us bother to go through the suffering we go through, and get up the next day? ... if there wasn't some reason to be doing it."*

Rachel, who has also been recently diagnosed, worked through her beliefs about her condition, to arrive at a holistic understanding. I asked whether her religious beliefs affected her understanding of her condition, and she gave the following response:

Yeah, because I first thought from the religious or spiritual point of view, that it was an attack from the devil and demonic. The more I understand it and especially the point that it is a chemical imbalance, I understand, no, it isn't demonic, spiritual; but the experience of it, experiencing it, the only way you can understand it would be in spiritual terms because it seems like it's something beyond this world, beyond the physical – hearing voices talk to you and things happening you don't understand, it seems like it's beyond the corporeal realm.

What Rachel is learning about the disorder from outside sources clashes with her interior, experiential understanding of her condition. Her statement also reminds us of the insistence of Husserl, the founder of phenomenology, that we must not reduce lived experiences to causal principles of which the individual is not aware (cited in Jackson 1996:16).

When I asked about the nature of the disorder and why it affected her, Rachel returned to the medical model, saying that it is a,

chemical imbalance in the brain and relates to dopamine and serotonin – I don't know if it's an excess or depletion – it affects the connection between the neurotransmitters; as a result, voices, hallucinations, almost like this voice directing me back in time ... whole experience was like a flashback, very odd ... videocameras, I thought I was in trouble, the police were after me ... I'm the unlucky one out of one hundred, I guess, it affects a certain amount of people and I guess it got me.

She also remembers, however, that during her hospitalization, she was certain that the “whole problem was spiritual.” I asked Rachel if she still believes there is a spiritual component to her condition, and she pondered, “there must be, in some way, shape or form; otherwise, I don't feel I would have had such a spiritual hunger at the time ... I think there is.” Like Stacey, Rachel believes that there may be a deeper meaning or purpose to her condition, which she explains when she returns to the etiology of her mental disorder, adding to the medical model she used earlier:

If there is a deeper meaning, it's making me more spiritual – more of a spiritual person, being a better Christian, and making me more dependent on going to church. ... I think that when I got sick there was a combination of things that were wrong in my life: the spiritual dimension to who I was, also the medical dimension, and getting sick made me think, Rachel, you're not very healthy. So spiritually I looked after what needed to be looked after and medically, I looked after what needed to be looked after.

This statement demonstrates that she understands her condition through a combination of the medical model and an alternative framework that centres on spirituality. Her comments also bear an affinity to the conclusion Boisen (1936:209) arrived at, “that right relationship with that which is represented by the idea of God is essential to mental or spiritual health.” Rachel's final statement reiterates that there is a gap between her intellectual understanding of the mental disorder and her experiential knowledge:

from what I've learned, spirituality and this illness don't really have anything to do with each other, but I feel that people are, like, whole – body, mind and there is a spiritual component as well. So when something happens to your body, you have to cope somehow spiritually, as well as with your mind ... spirit has to come to terms with changes in the body; the two are interrelated ... holistic idea.

Like Rachel, Brendan understands his mental disorder in both medical and spiritual terms. Initially, he said the following:

I think of mental illness in terms of Bible times when they had leprosy and plague and now they have AIDS and mental and physical illnesses ... Paul asked God to take away his thorn in the flesh, God said no, through your weakness you are stronger. So for me, my illness is a thorn in the flesh...

When I asked if God had given him this illness, Brendan said, “unfortunately, yes,” and explained that the thorn is given to you because “if you have everything given to you on a silver platter, if they're rich and healthy ... then why do you need God, like, they don't feel the need for Him because everything's going so well.” At one point Brendan made use of the medical model to explain his condition. When I asked him to explain the

nature and causes of his mental disorder, he said, “...*I should have brought a pamphlet ... a chemical imbalance in the brain, there’s a lack of dopamine or too much dopamine, I can’t remember....*” Later, however, Brendan makes a statement that succinctly captures his ability to combine the medical model and the spiritual model without difficulty: “*why I got it in the scientific world? – hereditary, but for the spiritual world - the thorn in the flesh. So that’s probably why God gave it to me – so I would always want to be close to Him.*”

Lisa described her mental disorder, as “*caused by a chemical imbalance in the brain. I believe it’s genetic – my mother has it, her sister has it, my aunts, my grandmother was believed to have had it; she was an alcoholic and I think that’s what she did to self-medicate.*” While this is all in accordance with the medical model, Lisa goes on to say, “*I’ve come to understand it as a chemical imbalance, but I also feel there’s probably factors like childhood environment played a factor in this illness ... more balanced view.*” While Lisa experienced a very difficult childhood, including numerous forms of abuse, the majority of psychiatrists would not agree that such an environment would lead to the development of a mental disorder. They may agree that such events could be stressors that uncover the condition in a person with an inherent predisposition. Lisa also agreed with Marilyn’s belief that hormones play an important role, and that hormonal imbalances exacerbate mental disorders. Lisa admits that she was angry with God for allowing her to become ill; now, however, she realizes that there, “*could be bigger purposes. Maybe in the future I could help others because of what I’ve gone through ... I believe it opens up doors to see the world in a whole new way.*” Again, the idea of a deeper purpose in mental illness is expressed.

Initially Rebecca explained the cause of her mental disorder with the following alternative understanding: *"it's a fallen world – that's why there's sickness, that's why there's mental illness, because sin came into the world when people rebelled against God ... so it's not my fault that I have it."* During one of the group interviews, another consumer expressed a strikingly similar understanding. Disagreeing with someone's belief that *"it's biochemistry that just plays havoc,"* this consumer insisted on the following interpretation of why mental illness exists:

I think it's because Adam and Eve fell and sinned and brought whatever in the world that came into the world ... people get sick, diabetes, it's just life, part of the fact we're not living in the Garden of Eden right now. I wish people would get ... it doesn't have to be from God or the Devil. Why does it all have to be black and white?

Rebecca also reflected on her beer drinking and *"pill-popping"* of prescription drugs. A doctor later told her this behavior could have been lethal, since she should not have been drinking alcohol at all with her medication: *"I think, well, maybe there's a reason for me to be alive now and that's why I didn't die. God gives you your life and it's up to Him to decide when you die; if you're down here there's a reason for it."* Later in the interview, Rebecca used the medical model to explain the nature of mental illness: *"I guess that it's a physical illness because it's a chemical imbalance in the brain."* She also discussed a book she had recently read that described the characteristics of children who later develop her condition; *"thirty percent were shy, withdrawn, passive, sensitive ... likely to be teased, but they didn't write that ... that helped me to come to grips that it's just my make-up, body chemistry."* Towards the end of the interview, however, Rebecca returns to an alternative understanding of her condition, and the voices in particular:

I used to worry they were demons and I had to tell them to go away in the name of Jesus Christ. Now I know once you say that, it's up to God, it's not up to me to make them go away. Whether there is some sort of demonic influence or whether it's just my brain acting up ... I know Satan and fallen angels are real but I don't have to think about it. I think there is some component of that in cancer, or car accidents ... all the bad things in the world aren't caused by God. I don't care if it's actually a demon saying something to me or whether God has allowed me to have a sickness that makes me hear things. I don't care what that voice is and I don't even listen to it – I leave it up to God.

Speaking of the disorder in general, Rebecca says, *"I think of it as an illness that is caused by – if we're not totally in the presence of God, bad things can be there. If you say to God, I don't choose You, then there's gonna be some bad stuff in the world, like, it's not my fault. It's sad but there is sickness in the world."* Clearly, mental illness cannot be reduced to a biochemical imbalance.

The differences between the understandings of Tina, Marilyn, Stacey, Rachel, Brendan, Lisa and Rebecca, as well as some that follow, underline the importance of the phenomenological approach, where the emphasis is moved from what beliefs *mean* to what they are *made* to mean by those who hold them. For while many of my informants have similar religious beliefs and profess themselves to be Christian, often of the same denomination, such as Catholicism or the United Church, what these beliefs are made to mean, particularly in relation to their disorders, can vary widely. As William James (1978:97) put it, "the truth of an idea is not a stagnant property inherent in it. Truth *happens* to an idea. It *becomes* true; is *made* true by events. Its verity *is* in fact an event, a process." We need to study lifeworlds (Lebenswelten) rather than worldviews (Weltanschauungen) (Jackson 1996:6). This privileging of lived experience over theoretical knowledge calls into question the division in Western discourse between the knowledge of "scientists" and the knowledge of ordinary people. In this case, as will be

shown with the next informant's understanding, the privileging of lived experience calls into question the division between the knowledge of psychiatrists and the knowledge of consumers.

Referring to a number of job losses, Jenny answered my question about the causes of her condition in this way: *"what caused it? That's a difficult question. I think probably what caused it, I put myself through so much in my life that a normal human being couldn't stand it ... major crises."* When I asked her if she believed there were any other factors such as genetics involved in her being affected by the condition, she agreed that *"that's got something to do with it, my older brother has it."* But she also felt that it was definitely caused by what she had done in her life: *"I keep looking for these Goliaths that I want to be David to ... I think I've created for myself existential despair or existential problems."* Jenny spoke of how existential despair is part of a search for meaning, and when I asked her whether her disorder was part of a search for meaning, she referred to a book she had recently read: *"I would think so, very much so if I think of that book, with the seven chakras and all that stuff ... spiritual life is very big part of you and you can't be in good mental health without the spiritual side of you...my whole life has been a search for meaning."* Jenny would likely agree with the point made by Shorto (1999:15) that, "by looking at psychosis as a mere illness ... psychiatry misses the whole point of the affliction: that it is ultimately an attempt to find deeper meaning." I also asked Jenny how the medical professionals had explained the disorder, and she said, *"the doctors explained ... nerves in the brain and all that jazz – I'm too stubborn to settle for burying the stuff under the pile of drugs. Maybe it's just not possible to sort out your existential despair – you'd have to change the world too much."*

Near the end of our interview Jenny repeated her alternative understanding:

Is it the mental disorder that's fucked up my life or is it my own wanting to always fight Goliath? ... probably that's more basic because that's probably what brought on the disorder. Just sort of reaping what I sowed; being Luther to the Lutherans, being a genuine person who wanted to get rid of some bullshit in the education system ...

Clearly her Lutheran upbringing had an impact on how Jenny understands her mental disorder, and when I asked whether she thought her religious beliefs had helped or hindered her in dealing with the illness, she answered with a question of her own: *"did being spiritual or religious help or hinder Jesus Christ? – quite a bit of both!"* Jenny believes that her religious beliefs have, in part, led to the disorder, as well as helping her cope. When I used terms like "ill" and "illness," Jenny said, *"I don't like [pause] I don't think I'm mentally ill, thinkin' more about this lately; 'disorder,' that I can stomach ... it is a disorder, it's not an illness..."* Jenny initially locates the cause of her disorder in her tendency to *"wage revolutions,"* but later she shifts the locus of disorder outside of herself: *"I'm rebellious enough to think that this society is more disordered than I am ... I'd like to think that if all the people in the world were more like me, we'd have a better world, or it would be getting better a lot quicker..."*

Alexander first expresses an alternative understanding of his condition:

when I think about my mental disorder, I don't think it's only chemical in my brain. I think there's something else ... when I'm high I can write very strange things. I don't know how I get these ideas. I can't explain ... I feel like somebody is telling me the story – I want to say God, but I don't know any God. I don't know what is God. I don't have strong desire to find out – I don't want to say yes or no, black or white, right or wrong

Later Alexander switches to the medical model of mental illness to make sense of his disorder: *"I basically believe it is just chemical in the brain, so we have something*

wrong with our brains – sometimes have too much ... I read that book, it says, dopamine. I think it's genetic." Commenting on his earlier explanation, Alexander said *"it's a really big contradiction. It's just chemical, basically, but because I believe there's something more than material in this world, it should be something else. This is just chemical, but when we get more dopamine, we can see different worlds other than this one."*

Alexander told me about his childhood and the difficult time he had around thirteen years of age when he was reading many books to try to find answers to why humans exist and other philosophical questions. It was during this time that he read a book about "Outsiders:" *"it's about this, your study - some people see visions...writers, that give them the truth of the world. That book was my Bible from thirteen 'til twenty-one. I saw visions maybe once or twice when I was really high ... I thought I understand everything in this world."* When I asked him about the nature of the answers he received, Alexander said, *"it's feelings, not logical ... Zen kind of thing, like Buddhists, they don't eat for few months to get high and get the answers. I think it's similar to that but we don't have to do what they do – we can get high."*

Alexander's experience would likely qualify as a mystical one: "although so similar to states of feeling, mystical states seem to those who experience them to be also states of knowledge" (James 1958:293). The fact that Alexander's understanding of his mental disorder lies much closer to the alternative end of the spectrum is exemplified in his words, *"in this book, Outsiders can see something more than five senses – we can say it's all a chemical thing in our brain, but I don't believe that."* Similarly, another consumer commented that the *"doctors say it's chemical ... my previous doctor says we*

don't really do psychotherapy ... from the neck up, it's brain chemistry." However, he also put a different twist on the idea of chemistry as the basis for mental illness:

I personally think everybody has bipolar illness: some are in the middle with their chemistry, some definitely get blue, short term, some get happier than others. But in our case, we're more bipolar 1s or 2s or 3s, which is just a different range of it. But I think we're just a bag of water and chemistry, eh ... that's what we are – chemicals, and I think it's within the human range. And I think we've been given labels to all these things ...

This perspective of the medical model of mental illness contains an implicit challenge to the notion of normalcy.

Sarah described her condition as a *"chemical imbalance, like a lamp with an electrical cord and you have a short in it, the power's not getting from the plug-in to the lamp ... endorphins, chemicals, I can't remember the exact word, does not reach from one side to the other, it sort of bounces."* Sarah later expanded on this medical model, saying that *"nobody knows what causes it ... could be chemical imbalance, could be something in the genes, some say it could be from hard drugs; it is a chemical imbalance in the brain, that's all the doctors say. I think it's partly due to genes, I believe the illness is in my ancestry."* Sarah's alternative understanding emerged when she reflected on the experience of having this mental disorder: *"at times I hate it and say why did it ever happen to me, but I figure God or the spirits have endowed me with this so I can help other people with it."* Her alternative understanding is hinted at when Sarah examines the treatment of those with mental illnesses throughout history:

at one time persons with mental illness saw visions – they were medicine men or medicine women, then they were deemed witches and burned at the stake. It goes from one extreme to another. In the 20s and 30s they shoved 'em into institutions and gave 'em lobotomies – what good is that?

The reference to medicine women is relevant, in that Sarah later told me that “*people say I’m a mystic, like a medium ... and a shaman has told me that not all of what I see is delusions – some of it’s real.*” When she relates such things to her psychiatrist, however, he says, ‘are you sure?!’ Sarah believes that some of her experiences are spiritual, and now that she is medicated, she can distinguish which are psychotic and which are real. For example, she has vision quests when meditating and animals tell her about protecting the earth; this would constitute a real vision as opposed to a psychotic one.

Sarah is considering whether there is meaning in the “madness” of her mental disorder. Murphy (1997:542) states this idea in more certain terms:

the psychiatric community has been reluctant to acknowledge anything of value in psychotic phenomena, but I know in an experiential way that meaning can sometimes be found in them. I do not discount the validity of the medical model of psychiatric disorders. I am only saying that, in conjunction with the biochemical disarray of schizophrenia, there can be something else – something discernible amidst the chaos.

Similarly, during a group interview, one consumer revealed her openness to alternative understandings of mental illness:

I had this rather interesting conversation with a guy – he has the belief that everyone with schizophrenia, it is our past lives subconsciously coming forward. The more severe the schizophrenia is, the more voices you hear, and the higher up you are on evolution. I’m sittin’ there thinking, you never know ... he talked about reincarnation and past lives. I think you can remember things and feel things from past lives. It could have some inkling of cause and effect ... something that has happened in a past life, and built up to the point that it’s causing schizophrenia.

She also wondered about the possible meanings in the voices she hears:

that’s one thing I’ve always worried about. I take this medication to control the voices, but what if they’re actually there to tell me something pertinent, something important. Because I’ve been told by different people I have a spirituality ... if I take this medication, it’s going to block whatever ...

Boisen, (1936:56) who had also experienced a severe mental disorder, believed that “voices” and other hallucinations signal a “stirring of the deeper levels of the mental life ... which in itself may be helpful as well as destructive. Their chief significance lies in what they may reveal as to the inner trends and attitudes. What the voices say is always the important question, not the mere fact of hearing voices.”

Another consumer also had an alternative understanding about the voices she hears, evident in her reflections on what is going on in her mental illness:

I came across a book, Developing My Psychic Abilities ... I would have been better off if I'd discovered this book a few decades ago. The energies, maybe these voices are us picking up from other peoples' voices ... I've talked to other people about this and the voices are more prevalent in crowds. I'm sensing a lot more energy ... voices are other peoples' subconscious and part of your own ...

She also shared some experiences that led her to her alternative understanding. Once she met a woman and repeatedly saw a knife going into her stomach. The woman noticed that she was disturbed and asked what was wrong, and when she heard the vision, “*she said, 'you wouldn't believe how many stomach surgeries I've had!'*” After that, the images stopped appearing: “*most of the time,*” this consumer said, “*these things just come out of the blue and you don't go and ask people because they sound so absurd. I've heard of others with mental illnesses who have dreams and in the next couple of weeks, the things happen.*” Reflecting on the experience of seeing the images, she told the group, “*that was the first time I started thinking about these things ... I write down my dreams and I've noticed there's links with my dreams – I'll dream something and it'll happen.*”

The previous three consumers' explanations of mental illness were discussed under the combination of medical model and alternative understanding category; however, their explanations were so close to alternative understandings, with only a brief mention of genetics or chemistry, that conceivably they could also be included in this final category. When I first asked Lyle about the nature and causes of his condition, he said *"it's supposed to be chemistry, but I don't know if pills can really do one hundred percent of your recovery."* Months after our interview, when I visited Lyle in the hospital, he repeated his skepticism about the efficacy of medications: *"why else would people be on five different medications and still be depressed for a year ... I think the illness just needs to run it's course."*

The other comments Lyle makes regarding the medical model consist of what psychiatrists have told him. For example, at one point Lyle stopped taking his medication and tried such things as Chinese medicine, herbs, and acupuncture, with the belief that he would stay well. Recalling the response of his psychiatrist when he got ill, Lyle said, *"my doctor said 'I could have told you, you were going to get ill, that that wouldn't work,' meaning it was a chemical thing and you need to take medication."* After discussing the feelings and events that led to his suicide attempts, Lyle expressed an alternative understanding of why he has a mental disorder: *"you think there has to be a reason for why you're going through this, cause you don't know why ... in God's plan there's a reason why you're going through this."* This belief was reinforced by the fact that although Lyle has attempted suicide several times, he has not harmed himself:

...my body physically has not suffered from overdose, my organs have not been damaged ... so close but they could revive me. I'm fortunate I still have my liver, kidneys, heart – I survived all that, there must be a reason why I'm still here in terms of God's plan. He's not finished with me yet, I'm still here. What is my real purpose for being here – there must be a reason I don't know about. People will say, 'life is a gift' ... that is very true...

Dee gave me a psychiatrist's explanation, which included the idea that mental illness is a "physical imbalance – people have shields around their heads that protect them from outside influences. For the average person, static doesn't get in, but with the illness it does ... neurons not firing correctly in the brain, part of the brain is way more active." She then expressed her criticism of the medical model in the following way:

I don't know whether they're so right in taking mental illness and sort of chopping it all up and puttin' it in these categories and labels. And I wonder if there's a lot more there that they don't understand; that really we're going backward in time when we should be going forward ...

Dee's alternative understanding of mental illness makes reference to how people like herself would be treated in other cultures, as well as questioning the very nature of mental disorders:

Native people, or people in different cultures, people like me, and similar people with this diagnosis would become medicine men and be trained and when going through visions ... taken care of afterward ... like they say, 'the white man's still torturing their spiritual leaders.' It sounds kind of grandiose but I think there's more to it, having to do with a sixth sense, than they realize ... most people have a wash on their brains and the mentally ill don't - why? What are we hearing? Why do we have difficulty in crowds; are we picking up voices from minds?

Later Dee repeated this understanding, and reflected Jenny's beliefs about the cause of his disorder being partially rooted outside of herself, in the society:

from my own personal point of view, a lot that contributes to the unbalance is stress in the society ... perpetuates the illness; my sister says if I had been born centuries earlier, I would be taken away and cloistered and taught all these things - some kind of truth in that through different religions, Native, Mexican, Australian - they end up being the medicine men of the group.

Dee's alternative understanding consistently stresses the progressive nature of the condition, rather than anything pathological. From this perspective, the tragedy is not that they suffer from mental illnesses, but that their unique abilities have not been realized. Dee stated with confidence the following about her religious beliefs:

I just have faith that it's going to come to light that there's a lot more happening in mental illness than it just being an illness. Really, it could be part of a sixth sense that's not developed in a nurturing environment or an understanding environment, and some day it will come to light that it's a very valuable part of the evolution of humankind.

Tom had an understanding of mental illness quite similar to Dee's understanding in some respects. For example, he explained how his mind races:

if I get into a crowd of people, seems like it picks up voices all over the place. I gotta count in my own mind to drown out the other part of my mind, or other peoples' minds. I still sometimes think I can hear other peoples' thoughts or they can hear mine ... it's just so strange.

A number of times during the interview Tom asserted that the medication helps: "*I know medication does help, that is true. Without it I'd be jumpin' from one lily pad to another screamin' my head off.*" However, when I asked him whether he thought there was more to his mental disorder than a chemical imbalance, Tom said,

sometimes I wonder about that ... because of the different things I see, sometimes I think, young men will see visions and old men will dream dreams. That's how I used to think before I was medicated ... still believe it to a certain degree but I don't share it with everybody or I'd be locked up still, you know.

However, Tom felt comfortable sharing his understanding of his condition with me and seemed very excited by having the opportunity to discuss his belief that it could be a "spiritual imbalance or maybe it could be a gift that's just not nurtured because of our culture ... few hundred years ago it could have been."

Later, Tom expanded on his idea, which is reminiscent of Dee's alternative understanding:

if I was in an Indian tribe or something, the old medicine men would teach me because they knew I had something there. ... I've heard people say prophets, missionaries – they're mentally ill ... I'm thinkin' is this just something that's not taught or balanced or what?

One of Tom's only references to the medical model was stated in the following way, reinforcing the idea that his condition is something progressive rather than pathological:

"I don't know if you're born with it or not, and if you are, I think it's just an unnurtured gift that's out of control ... like maybe we do produce too much of one chemical but maybe that's meant to be for things to come to pass what are supposed to in certain peoples' lives."

Like other consumers, Tom also felt that there was a significant spiritual component in his condition, which he described as a *"fine line between a chemical and a spiritual imbalance."* Later he repeated this belief, adding, *"I don't know which one weighs more, but they both intertwine."* Tom recounted some of the experiences that led to this understanding:

the medication keeps me balanced so I don't go one extreme or the other but at the same time, I'll see a tree with no trunk and it's as if it's hanging from Heaven and I'll think that's the Tree of Life. Why wouldn't a person with child-like beliefs or faith think that? ... that's the only thing that keeps me sane sometimes.

Another significant experience occurred at a religious event for youth, where there was a *"guy with ulcers, taking medication for it, but at the same time he got prayed for and I seen a spider leap from his stomach; after a month or two the ulcer was gone, gone through medication ... at the same time, like you know, there's got to be a little bit of belief in..."* When I asked him if his religious beliefs affected how he understands mental

illness, Tom said, *"I still sometimes think there's more to it than just what meets the eye as far as chemical imbalance goes, but we need people to teach ... nurture them from childhood up and say, this is the only way you can do it because if you try it the other way you're gonna hurt yourself."* Tom experienced the need to distance himself from spiritual pursuits, just as Lam did, to avoid a spiritual imbalance, evident in his earlier statement that he avoids becoming engrossed in prophetic books.

Dianne also believed religion was a factor in her illness. She described her condition as a *"dysfunction ... whether it's genetic ... a product of your environment, this is all a true reflection of the environment."* The environment Dianne is speaking of is the religious cult in which she was brought up, that she described as follows: *"religious addictions and cults – it's a drug. When you're not having contact with the right spirit, it's destroying you and it's all negative programming ... it's all mind control."* The results of such an upbringing, in Dianne's view, included her mental disorder and the fact that *"my spirituality – it's so sick."* Later, Dianne said the doctors explained the condition as *"a chemical imbalance and a lot of it was genetic ... all the Westons were heavy, heavy alcoholics, and the Westons that didn't drink also had mood disorders...I've had psychiatric illnesses they don't have the alphabet ready to give it a label."* Her own understanding, however, was clear when I asked her whether he meant, by her earlier comments, that her religious upbringing and the accompanying oppression had led to her mental disorder: *"oh yes, primarily because we weren't allowed to express ourselves."*

Commenting on his mental disorder, Jeff noted: *"I used to think it was demonic ... I dismissed that in recent years."* His current explanation of the cause of his condition, while not involving spirituality, was still alternative to the medical model: *"I was into a*

lot of chemicals – I think it might have brought it on early or caused it totally ... I got it I think, probably, because I was so involved with drugs and alcoholism.” As I mentioned earlier, psychiatrists and researchers would not agree that using drugs and alcohol could cause mental illness.

Patricia initially stated that she *“always had the illness – since I was born,”* and mentioned the chemical imbalance explanation given to her by the doctors. However, she also told me about her Jewish faith, and how she keeps kosher only sometimes; when she doesn’t keep kosher, it is to escape prejudice. A short time later, Patricia explained that she believed the cause of her mental disorder was *“improper diet, prejudice by others against me ... bullying.”* She also added that *“the illness strikes people who are great – if you weren’t great he wouldn’t pick on you.”* This anthropomorphizing of mental illness also occurs when Patricia explains how the illness is a Nazi who tries to murder her by trying to put her in the oven, or trying to make her eat out of the toilet. The illness is a *“killer.”*

In a similar fashion, Tyler portrayed his disorder as an external being with human-like characteristics. As he knocked on the wooden table nearby, hoping to ward off the need for medication, Tyler said, *“it’s not worse enough that I can’t sort of channel it off or let it feed off itself yet.”* When I inquired as to how he does this, he replied that he just says, *“‘if you want to hear voices, go ahead hear voices’ ... if it’s hungry enough, it’ll just feed.”* I commented that it sounded like the illness is a separate entity from Tyler, and he agreed that he viewed things that way. Schutz (1962:216) asserts that in the world of everyday life, we experience the self as the “author” of its activities and the “originator” of actions; we experience and act upon the world through our bodies. In

contrast, both Patricia and Tyler note that their experiencing and acting selves have been invaded and it is the illness that now has agency; the mental disorder is a “killer,” an aversive “it.”

Tyler’s understanding of how he developed his condition was also interesting: *“seeing what it did to my mother, it sort of jumped to me ... mom had it and it sort of rubbed off on me. I don’t think I’ve ever heard of it rubbing off on another person this way.”* This explanation is particularly interesting because Tyler is not referring to a genetic component, as he was adopted. Again using the metaphor of the illness as agent, Tyler stated that there was *“nothing I could do to help ... it picks on everybody and there’s no specific person it doesn’t pick on.”* At the end of our interview I asked Tyler if he thought that his religious beliefs affected how he understands mental illness: *“sometimes yes, sometimes no ... try to understand the illness, but don’t let the illness understand you ... it’s a buffer that keeps me going down that thin line and road to wherever God wants me to do.”*

While I have divided the understandings of my informants into the categories of Medical Model, Combinations of Medical Model and Alternative Understandings, and Alternative Understandings, they are more accurately conceived of as lying at points along a continuum. Furthermore, it must be remembered that these understandings are not static: “experience is emergent, not preformed. It changes. It goes on and on. The ethnographer must be cautious about creating an end that is artificial, an illusion of a finality that is not to be found in intersubjective space...” (Kleinman 1992:190). Just as experience is continually changing, the explanatory models, metaphors and understandings that individuals develop to make sense of experience are fluid as well.

CHAPTER SEVEN: CONCLUSION

In taking a phenomenological perspective, I have tried to offer in-depth descriptions of how people diagnosed with schizophrenia and bipolar affective disorders immediately experience time and the world they inhabit (Jackson 19996:12). When exploring consumers' experiences with work, relationships and stigmatization, it becomes startlingly clear that loss and suffering are common, daily occurrences that must be endured, rather than brief episodes that may be avoided. Not only are loved ones lost, but expectations of having other relationships and children are given up. Work opportunities are lost, either through discrimination in the workplace or through work-related stress that results in illness episodes. In some cases, it is not stress, but the side effects of medications that make working difficult. Time, itself, is perceived as lost, since inner time is slowed through hospitalization and medication, while outer time speeds by. Feelings of loss were also expressed in terms of motivation, concentration, memory, will to work and sex drive. A few consumers even expressed loss in terms of loss of potential, such as creativity that comes with "highs" and the expanded range of behaviours and emotions, all of which are stifled with medications. There is so much loss that one wonders how consumers cope if they do not have a therapist to help them with grief work.

One difference that was found between consumers with schizophrenia and those with bipolar affective disorders was that the latter group was more "functional" in terms of work, as they were more likely to be working, sometimes full-time, or they had worked before retiring. In contrast, more consumers with schizophrenia relied on AISH partially or wholly for their income. The few individuals who recognized some value in

their inability to work as it excused them from the daily grind of work, were diagnosed with schizophrenia and schizo-affective disorders. In contrast, individuals with bipolar affective disorder were more likely to see work as a "haven from pain" in that it helped them cope with their disorders. A few of these consumers even believed that their conditions were beneficial to their ability to work, giving them drive, stamina and the ability to work hard without reward. This dialectical relationship in which work helps one to cope with a mental disorder, and that same illness increases one's capacity to work, brings up the idea of mental illness as a "gift."

Jackson (1989:20) states that a theory of culture or lifeworld must include the following:

...some account of those moments in social life when the customary, given, habitual, and normal is disrupted, flouted, suspended, and negated. At such moments, crisis transforms the world from an apparently fixed and finished set of rules into a repertoire of possibilities. To borrow Marx's vivid image, the frozen circumstances are forced to dance by us singing to them their own melody.

This passage is an apt description of what happens when consumers suspend the socially accepted view of mental disorders as entirely negative and pathological, and see possibilities, gifts, even "*ability*" in their conditions. The "gifts" include creativity, a sixth sense, becoming closer to God, friendships, reaching the understanding that everyone suffers, and the ability to empathize with and help others.

The meanings found in illness, including this notion of value in one's illness, are not usually explored because of the way social reality is organized; in the same way, we generally do not analyze the structure of our social world (Kleinman 1988:9). However, the phenomenological turn requires that such meanings are examined, an exploration that is not only valuable as a way to understand consumers' lifeworlds, but also has

repercussions for treatment. Some consumers responded to their diagnoses as Good (1990:128) suggested those facing chronic illness react: when chronic illness threatens to deconstruct the lifeworld, humans counter this threat by creating meaning, by reconstituting the world. Jenny, along with a number of other interviewees, believed that the meaning of the experience for the individual has been neglected, and understanding that meaning is a crucial part of the experience of, and recovery from, mental illness. (Sullivan 1998:30). For some consumers, part of the meaning in their condition involved the instigation of a spiritual search, something that is at odds with the focus of medicine: "because it eschews teleology, the very idea of a moral purpose to the illness experience is a biomedical impossibility. That serious illness involves a quest for ultimate meaning is disavowed" (Kleinman 1995:32).

Csordas (1983:364) also draws attention to a link between religion and illness: "... 'disease' and the 'holy' are categories on the same phenomenological level, pertaining to ultimate issues of life and death ... generating fields of interpretive discourse the intersection of which is discourse about illness." If a connection exists between religious/spiritual beliefs and models of mental illness, it may be beneficial to take such beliefs into account in the treatment of mental disorders, rather than following the psychological framework, which is grounded in the Western biomedical paradigm. The issue of how religion/spirituality inform individuals' understandings of their mental illnesses is an ambiguous one, as religious beliefs often help consumers to cope, but religious delusions are potentially harmful, and some consumers developed spiritual addictions or imbalances.

One member of the support group for people with bipolar affective disorders, insisted that one's beliefs *do* have an important role in how one understands and lives with an illness, and that the medical field is finally starting to understand this truth. However, a few consumers noted that their psychiatrists interpret their comments about God as delusional. In addition, judging by the responses I received from consumers regarding whether psychiatrists inquire about their belief systems, it appears that the addition of "religious or spiritual problem" to the DSM has had little impact on the transactions between patients and their physicians.

An interesting finding was that it was slightly more common for consumers with schizophrenia to have this religious or spiritual dimension in their understanding of their conditions. Moreover, for about one third of these consumers, the spiritual dimension was distinct from understandings offered by consumers with bipolar affective disorders. For example, three of the consumers who have schizophrenia believed that their conditions would be viewed as shamanistic in other cultures, and they all believed that there was either a psychic, mystic or prophetic element in schizophrenia. Similarly, another woman who has schizophrenia, shared the belief that people with mental illness have an "awareness" of their closeness to God, which can be interpreted as reflecting the priority society should put on relationship with the divine. The notion of a linkage between mental disorders, or chemical imbalances, and spiritual imbalances, or overdosing on religion was also unique to consumers with schizophrenia or schizoaffective disorders. Finally, religious delusions like thinking one was God's chosen son or daughter, and the belief that one was being attacked by demons, were far more common among those with schizophrenia and schizoaffective disorders. It is difficult to

draw conclusions from these findings because of the small sample size, but this area could be a fertile one for future research.

The treatment of schizophrenia and bipolar affective disorders was a much discussed topic, particularly during support group meetings. Beliefs that psychiatry is merely "*fishing in a hole*" were reinforced by the fact that many psychiatrists offer little or no explanation of diagnoses and medications, and by the complaint that the profession has failed to educate the public about mental illnesses. While over half of the consumers agreed with the medication-based approach to the treatment of mental disorders, others challenged not only the medical model, with its emphasis on pharmaceuticals, but also the very epistemological basis of this model. The authority of the knowledge of doctors over their own experiential knowledge was questioned, and a few consumers prioritized their lived experiences over the theoretical knowledge of psychiatrists. One consumer challenged the primacy that is given to the mind over the body when he disagreed with the current trend in psychiatry toward neurology: "*there is so much about the human body, and is the mind really in control of all that?*" Others had an even more holistic understanding of what constituted mental health that included spirituality.

It was not only individual psychiatrists who were the targets of complaint. Few consumers saw the hospital as a haven from their suffering, and some even felt that they were "criminalized" through the process of institutionalization when so many of their basic rights were taken away. A few consumers insisted that the criminals were the hospital staff who treated them in the above manner, and wondered if the primary reason for hospitalization is the inability of others to cope. Indeed, one could argue that hospitalization is the beginning of a rite of passage that transforms individuals into

"schizophrenics" or "bipolars" who believe they are "sick" through the following rituals: patients are made strange to themselves by being dressed in hospital clothing, tagged with an ID bracelet, forced to take psychiatric medication, by having their eating and sleeping regimented, and by being locked in the ward. Now trapped by their illnesses in a liminal state, consumers often stand outside society, watching others spend time with loved ones, travel to and from work, pursue hobbies, and more: "... *currently I don't fit in the world. I don't exist in the real world ... I'm on the edge, I'm on AISH, I'm marginalized.*"

Living as they do, on the threshold, many consumers have much time to ponder meaning-of-life questions; for people like Jenny, ultimate meaning was a constant rumination, rather than something to think about when the topic arises, or on Sunday mornings (Shorto 1999:131). While mental illness can push a person into a liminal state, outside roles that involve family, career, society, and outside concepts of space and time, Shorto (1999:167) reminds us that this is also the place of religious experience. However, while these liminal experiences were once viewed as sacred, with rationalism and the rise of the biomedical model, these experiences have, more often than not, been pathologized.

In many cases, side effects from psychiatric medications caused problems for consumers at work and in their relationships, and in some cases, even caused other disorders and diseases, such as obsessive compulsive disorder, polycystic ovarian disease, liver problems and potential brain damage. Reflecting on the seriousness and visibility of the side effects of psychiatric medications, Estroff (1981:114) wonders about the trade-off that consumers are asked to make: "it seems to me somewhat cruel to help them clarify and organize their thinking and perceptions, when part of what they will

accurately perceive is others' fear, disdain, and rejection because of stigmata that are now physical." "Stigmata" included weight gain and a dulling effect that resulted in the frustrating inability to feel and express emotions, that made people feel (and sometimes look) like "zombies." Other side effects included difficulties hearing and seeing, dry mouth, wet mouth, muscle tension, shaking, loss of concentration, memory, the ability to speak and sex drive, lockjaw, fatigue and Tardive dyskinesia (involuntary movements of the tongue and mouth). Whitaker (2002:291), examines the treatment of the mentally ill from the eighteenth century until the present, and ends his book with a sobering thought:

...if the past is any guide to the future, today we can be certain of only one thing: The day will come when people will look back at our current medicines for schizophrenia and the stories we tell to patients about their abnormal brain chemistry, and they will shake their heads in utter disbelief.

Toward the end of my second interview with Dee, she told me about a new medication for bipolar affective disorder; one of the side effects is, "*it could kill you – they wouldn't put other people on this stuff.*" This comment raises the issues of normalcy and stigmatization, suggesting to some that unlike "other people," or "normals," people with mental illnesses are considered less valuable, and ultimately expendable, because of their pathology. However, as Chapter Four makes clear, normalcy is a contested state of being. Some consumers strive toward "normalcy," understood as the ability to work, maintain relationships, and "fit" within society, and they believe that psychiatric medications help one get "back to normal." A few consumers inverted the notion of normalcy, insisting that they are normal, and the rest of the world has gone crazy. Others reject normalcy as a valid concept, and insist that it is socially constructed, or that it is contextual. Some consumers felt that their experiences when "ill," were preferable to

their "normalized" condition, and that "normalcy" was a form of social control. Some consumers eschew the medical model and view their conditions as given by God to draw one closer to the divinity, or having higher purposes such as helping others, a sixth sense, a shamanistic ability that is not nurtured in our society, a spiritual imbalance, or caused by existential despair. These understandings can be viewed as a serious challenge to the way mental disorders are viewed in our society: "at its best anthropology has always been subversive. By describing different social, cultural, and psychological arrangements, it challenges commonly accepted ways of perceiving, articulating and understanding the world" (Crapanzano 1990:145 cited in Hahn 1995:1).

In light of the side effects of medications, stigmatization, and struggles with work and relationships, one cannot help but marvel at this group of people. For consumers, most of what the rest of us take for granted, can be insurmountable obstacles. For example, going to college or university, living independently, working, developing and maintaining close relationships, getting married and having children are all stages of life that can be difficult or impossible for consumers to experience. Living free from stigmatism is something else that most people take for granted, but stigmatism is either experienced or feared by most consumers. In some cases, family members deny that a consumer is even "ill," preferring to believe that she is lazy.

From one perspective, consumers can be viewed as "unsung heroes," and the triumph of living an illness is evident in their very existence, as many commit suicide. From another standpoint, the way society views mental disorders as pathological "illnesses" devoid of value, bears reconsideration. What Kleinman (1988:247) says about the care of the chronically ill, can also be applied to the experience of mental

illness itself, which, "need not be overly solemn or gloomy: there is ample place for wit and humour, a sense of irony and paradox." All of these qualities emerged during interviews and support group meetings. For example, at a support group meeting for individuals with bipolar affective disorders, members referred to those on psychiatric wards as "loonies;" ironically, most of these consumers had also spent time on hospital psychiatric wards. Humour also arose, particularly in group interviews, and during support group meetings, humour was cited as a coping mechanism. Many witty remarks were made about psychiatrists; one support group member reminded the others that half of the psychiatrists graduated in the bottom fifty percent of their class.

Conditions like schizophrenia and bipolar affective disorders not only unmake the lifeworld, but are often an assault of an ontological nature, affecting the concept of self. While a number of consumers incorporated their mental disorders into their self-concepts, more commonly, consumers expressed a need to separate themselves from their conditions, insisting that the disorders are not who they are, just something they have to live with, like diabetes, cancer or heart disease. A few consumers with schizophrenia even saw their illnesses as entities with agency, completely separate from their selves, signaling an alienation from their conditions. For both groups of consumers, however, the self-identity is almost always a stigmatized one. Perhaps if alternative understandings of schizophrenia, bipolar affective disorders and other mental "illnesses" were expressed openly and validated, stigma and fear would be replaced with curiosity and acceptance. As Rosenhan (1973:257) wondered, in part referring to the hierarchical nature of psychiatric wards,

if patients were powerful rather than powerless, if they were viewed as interesting individuals rather than diagnostic entities, if they were socially significant rather than social lepers, if their anguish truly and wholly compelled our sympathies and concerns, would we not *seek* contact with them, despite the availability of medications? Perhaps for the pleasure of it all?

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INTERVIEW GUIDES

Life History Interview Guide

Tell me about yourself. How did you get to where you are today?

What experiences stand out in your mind from your childhood?

Where were you born?

What did your parents do?

Tell me about your education experience.

Did your family attend church?

As a child, what are your memories of religious or spiritual issues?

Can you tell me about your education and work experience?

What significant relationships have you had or do you have? (marriage, parenthood)

What were/are some of your life goals and dreams? What obstacles have you faced in trying to achieve your goals?

You mentioned "mental illness"/ "schizophrenia" / "being sick" / "bipolar disorder" etc.

(_____ - whatever terms he/she uses) Tell me what you mean by that. What has your experience with "_____" been like? (*) When did it begin and what did the treatment include? How has your experience changed?

How would you describe your religious/spiritual beliefs?

Have your attitudes towards life, toward life goals, toward your condition, and religious beliefs changed? If so, how and when did these change?

* this term (and the blanks in the following interview guide) has been purposely left out, so as to use the terms and concepts used by the informant rather than imposing my own terms.

Semi-Structured Interview Guide

What is your explanation of “_____,” and your own condition in particular? ie. the nature of the condition, what caused it, why did it affect you?

When did your symptoms occur? What was going on in your life when symptoms started? How did you first understand them? How serious did you think it was? What were your expectations about the course of your “_____”?

How did you come to understand your condition? Can you think of social situations that contributed to your creation of meaning with regards to “_____”?

How has it been treated and how do you think it *should* be treated?

How did your friends and family members understand “_____”? How did you feel about their reactions?

How do the medical professionals who have treated you explain “_____”?

Tell me more about your religious/spiritual beliefs? Are they in any way connected to how you understand your condition? Have you ever had religious/spiritual experiences when you were “_____”? ie. thinking you were God, communicating with God, etc.

What are your experiences with religious/spiritual people? ie. churches, pastors, etc.

How do medical professionals respond to your religious/spiritual beliefs?

What is the main way “_____” has affected your life? ...main way the treatment of your “_____” has affected your life?

What do you fear most about “_____”? ...fear most about the treatment?

Focus topic: How do your religious/spiritual beliefs affect how you explain schizophrenia/bipolar affective disorder?