

THE SOCIAL CONSTRUCTION OF BIPOLAR DISORDER:
THE INTERRELATIONSHIP BETWEEN SOCIETAL
AND INDIVIDUAL MEANINGS

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SUSAN G. GOLDBERG

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This dissertation has been accepted for
the faculty of Fielding Graduate University by:

Ruthellen Josselson, Ph.D.
Chair

Committee:

Kjell Erik Rudestam, Ph.D., Associate Dean
Sam Osherson, Ph.D., Faculty Reader
Annie G. Rogers, Ph.D., External Examiner
Marsha Perlmutter Kalina, MA, Student Reader

Abstract

The Social Construction of Bipolar Disorder: The Interrelationship Between Societal and Individual Meanings

by

Susan G. Goldberg

Viewed through the perspectives of individuals diagnosed with bipolar disorder, this qualitative study investigated how American society has constructed the diagnosis of bipolar disorder and what the implication may be for individuals labeled with this diagnosis. The study involved narrative interviews of five women and one man who were diagnosed with bipolar disorder. Participants were in their thirties to fifties and identified as European Americans. Hermeneutic, social constructionist, and Lacanian approaches influenced the analysis.

There were two main sets of findings. First, a mutual interaction between individual experience and societal labels was evident. Language, culture, and society limited the choice of labels for self and other. The participants' self-labels, such as how they moved from being "depressed" to "bipolar," reflected changing societal conceptions of mental disorder.

The second set of findings revealed the challenges to self and identity that the participants faced. It was difficult for participants to develop a cohesive sense of self in light of the particular way the psychiatric community defines bipolar disorder and society understands it. The participants also found it challenging to experience "selfsameness,"

an ongoing and continuous sense of self, especially because they experienced some affective states as foreign and “not-me.” Further, the biochemical imbalance explanation for bipolar disorder undermined participants’ sense of identity and personal control because this explanation suggests that their feelings and behavior are controlled by an external entity (biochemicals) rather than their conscious will.

There are four areas in which the findings may link to larger societal issues. The first involves a blurred and fluctuating boundary in American society between “normal” exuberance and “crazy” mania and how this societal confusion affected participants’ meaning-making. The second addresses the process by which society inducts people into the role of patient. The third implicates Western society’s difficulty in recognizing the limitations of volitional control. A related issue is the Western challenge in bridging mind-body dualism. Participants faced this issue when making sense of experiences that are labeled a mental illness, but which have somatic, affective, and cognitive components. The findings also suggest that negative societal projections about bipolar disorder may be shifting.

Key words: Bipolar disorder, depression, mania, hypomania, manic depression, social construction, Lacan, narrative research, projective identification, labeling theory, identity

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DEDICATION

This dissertation is dedicated to the generations of my ancestors, from an imagined time in the land of Israel through centuries of travels and travails. My more recent fore-parents lived in small towns in Russia, Lithuania, and Poland in the 19th century.

My great-grandparents in Eastern Europe experienced political and religious persecution, which compelled the decision to immigrate to America in the late 19th and early 20th centuries. Their dream was to create a better life for themselves and for their descendants. The immigrants endured poverty, difficult lives in the new country, prejudice, challenges in acculturating, and often early death. For these families, the better life they sought for their descendants was one involving scholarship, performing good deeds, family life, and political activism.

Most of my immigrant ancestors had only limited education. The prospect of starting an academic program in midlife would have been unimaginable for them. My opportunity to pursue graduate studies at Fielding was hopefully one result they were seeking when they made the courageous decision to immigrate.

I dedicate this dissertation to the memory of my ancestors, both known and unknown.

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CHAPTER ONE

INTRODUCTION

Much Madness is divinest Sense –
To a discerning Eye –
Much Sense – the starkest Madness –
'Tis the Majority
In this, as All, prevail –
Assent – and you are sane –
Demur – you're straightaway dangerous –
And handled with a Chain—
(1890/1960c, p. 571)

Emily Dickinson's poem about madness, written over a century ago, eloquently captures the socially constructed boundary between sanity and madness. She suggests that so long as a person behaves properly, as determined by the larger society, that person is deemed sane. But if one speaks or behaves in a way that is not socially acceptable, the person may cross the threshold and be placed in a locked ward. The question is whether the discerning "I" can locate the boundary. The goal of this study is to understand how the dominant American society has been constructing meanings about the label of bipolar disorder, filtered through the perspectives of individuals given that diagnosis.

Discussions in the Literature

Cultural Designations of Normal and Abnormal

From the cultural perspective of anthropology, each society develops its own ideas of the location of the threshold between mental health and "madness." It must also determine which behaviors to place on either side of the boundary line and how to categorize abnormal behaviors. By studying cultural manifestations of abnormal behavior

in different societies, anthropologists concluded that these categories are always culturally determined. This notion was voiced in anthropology as early as 1934 by Ruth Benedict (1934/1967). She presented extensive anthropological evidence that each culture develops its own analysis of which behaviors or experiences are deemed mentally healthy and which ones constitute mental illness in that culture. She provided examples of behaviors that are considered unmistakably abnormal in the United States, such as trances or paranoia, but which are highly valued in other cultures.

Benedict also pointed out that even though there is a large range of possible human behaviors, each culture selects from the possibilities a limited number to be designated as appropriate behavior for that culture:

No one civilization can possibly utilize in its mores the whole potential range of human behavior. ... Every society, beginning with some slight inclination in one direction or another, carries its preference farther and farther, integrating itself more and more completely upon its chosen basis, and discarding those types of behavior that are uncongenial. Most of those organizations of personality that seem to us most incontrovertibly abnormal have been used by different civilizations in the very foundation of their institutional life. Conversely the most valued traits of our normal individuals have been looked on in differently organized cultures as aberrant. Normality, in short, within a very wide range, is culturally defined. It is primarily a term for the socially elaborated segment of human behavior in any culture; and abnormality, a term for the segment that that particular civilization does not use. The very eyes with which we see the problem are conditioned by the long traditional habits of our own society.

(Benedict, 1934/1967, pp. 15-16)

Benedict points out how powerfully our individual views are colored by cultural ideas. Her premise was grounded in anthropological evidence of how other societies have organized the boundary between normality and psychopathology. Thus, the anthropological understanding is that each culture devises its own categories of normal

and abnormal, based on the particular emphases of that culture. The next question is how that process takes place in a particular culture.

Labeling of the Other

The process of designating some behaviors as deviant is addressed in sociological labeling theory. The key ideas are that when society classifies behaviors as abnormal, societal institutions like the media perpetuate the distinctions. Then behaviors that constitute deviance from the norm are taught to and imposed upon some individuals by society. Social institutions ensure that deviants remain in their assigned role (Scheff, 1999).

One aspect of labeling theory addresses how people placed in the role of deviants are viewed by society as all alike or homogenous (Schur, 1984). Schur suggests an explanation for society's difficulty in differentiating among people in a denigrated group: "One sees reflected in categorical devaluation an apparent urge to differentiate as much as possible between "them" and "us" (Schur, 1984, p. 28).

People who are labeled as "other" have several options, from accepting the label to rejecting it. Yet labeling theory posits that people are rewarded for remaining in the deviant or "ill" role and are punished if they attempt to return to mainstream roles. In the deviant role, the person has a certain status, that of being the deviant or ill person. If the individual accepts the role, he or she experiences "engulfment" into the "deviant" role. Sociological role theory has studied the process by which the person labeled as "denigrated other" encounters the deviant role.

Goffman (1961) utilized role theory as it applied to staff and patients in mental hospitals and other institutions. He described as dehumanizing the process a person encounters when entering into the role of mental patient or other institutionalized person. People in mental institutions become indoctrinated into the role. Their property, their bodies and their sense of self are taken away from them step by step, until they are demoralized enough that they comply with those in power in the institution and adopt the negative view of themselves as given by those in power.

When Goffman (1961) wrote in the 1960's, most institutionalized mental patients did not receive treatment by choice. The psychiatrist had the power to decide what rights and what property the mental patient would have. The psychiatrist also had the power to label the patient and designate the category of the patient's pathology. Goffman argued that survival for an institutionalized mental patient meant capitulation to the newly created social label:

Mental patients can find themselves in a special bind. To get out of the hospital, or to ease their life within it, they must show acceptance of their place accorded them, and the place accorded them is to accept the occupational role of those who appear to force this bargain. This self-alienating moral servitude, which perhaps helps to account for some inmates becoming mentally confused, is achieved by invoking the great tradition of the expert servicing relation, especially its medical variety. Mental patients can be crushed by the weight of a service ideal that eases life for the rest of us.

(Goffman, 1961, p. 386)

In Goffman's analysis, the expert, in the form of the psychiatrist, creates the label. The patient, in order to obtain privileges, acquiesces into the role of mental patient.

Lally (1989) applied labeling and role theories to the phenomenology of mental

patients as they are indoctrinated into the role of mentally ill person. He noted that much of the earlier research and theory on labeling and roles focused on the society, without paying attention to the experience of self-labeling by the person in the role of “other.” Lally’s study explored the mental patient’s experience of self-labeling and engulfment, rather than society’s imposition of the role. Based on qualitative data from interviews with 60 people hospitalized in a psychiatric facility, Lally proposed a three-stage developmental process whereby people become engulfed into the role of the “deviant.”

In the first stage, patients worked at avoiding engulfment in the role. They minimized their symptoms and emphasized distinctions between themselves and other patients. Lally suggests that patients needed to do this to avoid the negative connotations of hospitalization for a mental illness. But with re-hospitalizations, patients started to become “engulfed in the patient role” and started labeling themselves as mentally ill. In the second stage, patients accepted the label of mental illness. During this stage patients started identifying more with the other patients and separating themselves from those in the “outside” world. They sometimes claimed that hospitalized mental patients were more intelligent or special than people in the outside world. However, they did not fully endorse the mental patient role, since they did not know if their psychiatric problems were permanent or temporary. Young adults, for example, explained that they expected to return to the outside world and the developmental tasks of their phase in life, like marriage, school, and work. In the third stage, which Lally calls “the late stage of the process of engulfment in a mentally ill self-concept,” patients conceptualized themselves

as mentally ill “and see this as an all-encompassing, permanent view of self.” Lally (1989) found that patients in this stage were mourning their lost self, but also creating meaning for themselves in their new role.

Lally’s study expands the work of the labeling theorists by directing research to the experience of the person in the “deviant” role. His findings suggest that the process of engulfment is not a passive one, as contemplated by the labeling theorists, but an active one. Lally proposes that in each stage patients are trying to maintain a positive sense of self in relation to the negative stigma of mental illness.

Stigma and Prejudice

Labeling theory is premised upon the negative societal views of a denigrated “other.” This is often referred to as stigma. Goffman’s (1963) definition of stigma combines two facets: the societal prejudice towards deviant groups; and the “mark” on a person, or the internalization of the external negative perspectives. Goffman noted that a person who can manage the stigma has learned to handle both the public and relational elements as well as the internal distress and shame of being placed in a deviant role.

In recent years Patrick Corrigan and his colleagues have written extensively on the nature of mental illness stigma (Corrigan, 2005; Corrigan & Cooper, 2005; Corrigan, Markowitz, & Watson, 2004; Corrigan & Penn, 1999). Corrigan resolves the dilemma of the two aspects of Goffman’s concept of stigma by analyzing them as different constructs (Corrigan, 2004). Corrigan thinks of “public stigma” as socially endorsed stereotypes, prejudice, and discrimination. He views “self-stigma” as the internal acceptance and then

enactment of the societal stereotypes.

The anthropological and sociological theories discussed to this point posit that each culture creates its own boundaries between normal and abnormal psychological behavior and that societies have powerful methods for enforcing the distinctions, labeling outside groups as deviants, and perpetuating different kinds of stigma towards the groups. In each case the categories are so deeply incorporated into cultural knowledge that the categories are perceived as an unquestionable truth. Social constructionism challenges such notions of truth.

Social Constructionism

The philosophical ideas of social constructionism (sometimes called post-modernism) view the “modern” perspective on “truth” as only one narrative or story about how to understand human nature (Gergen, 2001; Richardson, Fowers, & Guignon, 1999). The social constructionists propose a different narrative, suggesting that there are many and changing truths. The goal of theory and research, from a constructionist perspective, is to have the reader resonate with understanding rather than learn the “truth.” The theory proposes that whatever we know as “true” and “real” is instead a set of co-created understandings that are embedded in a cultural context (Gergen, 1994, 2001).

There has been some research into the social construction of specific illnesses. Some recent examples of studies looking at illness from a social constructionist perspective include analyses of Gulf War Syndrome (Mahoney, 2001) and anorexia

nervosa (Hepworth, 1999; Toon, 2002). The social construction of illness is explained through the lens of medical sociology.

Medical sociology. The field of medical sociology focuses specifically on the social construction of such concepts as illness, disease, diagnosis, and treatment, Brown (1995) laid out a nuanced framework for studying the social construction of illness. He first distinguishes between two theoretical approaches to social construction, the “strict” one, most consistent with American psychological theorists (e.g., Cushman and Gergen), and the European view, initially articulated by Foucault. The “strict” version challenges the notion of any reality and assumes that a consensual reality is created through discourse. For that reason, the focus is mainly on the discourse. The European version of social constructionism, however, deconstructs all language and symbols to show how knowledge is created even without language. Both approaches to analysis, studying the discourse and analyzing symbols and language, are useful here.

Brown (1995) describes the elements that encompass the social construction of illness and diagnosis: the social construction of medical knowledge focuses on diagnosis and the medical perspective; the social construction of illness addresses the experience of people having the “illness.” In terms of diagnosis, Brown delineates two opposite impacts of the social construction of diagnosis. The creation of a health diagnosis sometimes pathologizes “normal” behavior. At other times it provides a relief to the sufferer by validating previously unlabelled painful experience. An example of a diagnosis that involves social control is “late luteal phase dysphoric disorder,” (i.e., pre-menstrual

syndrome). He argues that this diagnostic term pathologizes normal functioning. He cites chronic fatigue syndrome as an example of a diagnosis that provides “legitimization” and relief for people who experience the illness (p. 41).

This typology is useful for this dissertation because there has been no prior research about the social construction of bipolar disorder. Using Brown’s typology, this study involves the social construction of an *illness*, since the analysis emerges from the experiences of people with this diagnosis. Yet this study also involves the social construction of the *diagnosis*, since the research question investigates the meanings and understandings that society assigns to this diagnosis.

Language. One method for understanding how a construct is interpreted in a society is through the use of language. Allport (1954/1979) discussed how “linguistic labels” become filled with meaning. An example in English involves use of the verb “to be” when describing someone with a diagnosis of mental illness (e.g., “I *am* a bipolar”), rather than the “people first” language proposed by disability activists (e.g., “I am a *person* with a diagnosis of bipolar disorder”). Language is important in a post-modern analysis because the focus of study is changed from the “object of knowledge to its representation” (Gergen & Kaye, 1995, p. 173). Post-modern thinkers view language itself as creating or structuring experience (Gergen, 1994). Lakoff and Johnson (1980) address this issue by proposing that all thought is metaphorical and our choice of metaphors reflects our particular cultural construction of experience.

One likely set of (conscious and unconscious) meanings that American society

assigns to bipolar disorder center around notions of madness or craziness. In order to appreciate any research findings and analysis about the bipolar illness or the diagnosis, it is useful to review briefly some of Western society's attitudes towards people deemed insane.

History of Attitudes Towards "Madness"

Some history of the treatment of and attitudes towards people with mental illness is presented here in order to provide a context for the current American construction of mental illness. These ideas from Western history likely remain in what Jung (1993) would call the "collective unconscious" of American culture today.

Middle Ages through 16th century. In the Middle Ages, Christian ideas dominated European societies. From this perspective, madness (the terms used then) was seen as either a spiritual despair or a demonic possession (Porter, 2002). During the 15th to 16th centuries, witches and heretics were placed in the same category as the mad and both groups were usually viewed as demonically possessed. People in these groups were punished with what we would call torture, often to death. The explanations for these punishments involved spiritual goals, like ridding the madman of his demons.

Porter (2002) noted a decline in the 15th century of the belief that mad people are supernaturally possessed. As a result, mad people were no longer seen as evil. But this simply transferred the choice of reviled groups to other scapegoated groups, namely, "beggars, criminals, and vagrants" (p. 32).

The Renaissance period of the 15th and 16th centuries brought in significant cultural change, where art, poetry, and creativity were extolled. Among its products was the notion that in madness one could find true knowledge. As a result of this elevation of the notion of madness, poets and artists started claiming they were mad. Madness came to be understood as a message of wisdom.

By the late 16th century, attitudes towards witches and mad people had changed to a more medical model in many European countries. Both witches and mad people started to be viewed as ill, needing treatment, rather than as supernaturally possessed. But the supernatural possession perspective continued in some European countries until as late as 1700.

Ship of fools. Foucault (1965/1988) addressed the historical idea that during the Renaissance, mad people were sent away, separate from the rest of the populace. Foucault used the example of the “ship of fools,” a boat for mad people who were evicted from cities and towns. The boat was said to travel up and down rivers, with mad people perpetually kept aboard. Foucault claimed there were many ships of fools; these were mostly in Germany, but also in other European countries. Other historians, e.g., Torrey and Miller (2001), dispute this historical claim. Torrey and Miller asserted that there was never a “ship of fools” and the idea was simply one that existed in the popular imagination of that era.

Foucault’s goal in presenting this material appears to be to explain sociological and cultural trends in different eras and their significance in today’s culture. He explained

the metaphoric and symbolic power of the idea of a “ship of fools” wandering up and down the rivers. Foucault proposed that the story represents the symbolic placement of mad people at the threshold between the known and the unknown. In this symbol, the mad are located both outside of the known (outside of towns) and inside it (in rivers which are inside of land). Madness had moved from serving as evidence of demonic possession to representing “ambiguity, menace, and mockery” (Foucault, 1965/1988, p. 13).

Literary imagination. Throughout the 17th and 18th centuries, poets and artists elevated the idea of madness. The fantasy developed that mad people have a deeper knowledge of life (Porter, 2002). This attitude spawned the “madness is genius” cultural construct, which has not abated to this day. Ballads about Bedlam, a large institution in London for mad people, were very common in the 17th century. The artistic interest in mad people was also expressed in high literature, as Shakespeare reportedly addressed madness in at least 20 of his 38 plays and many of his sonnets (Torrey & Miller, 2001).

Foucault (1965/1988) viewed the literary emphasis on madness during that period as managing the anxiety of people about their own possible craziness. Foucault also interpreted the literary metaphors in the 16th and 17th centuries about mad people as evidence of a change in attitude. Foucault saw the cultural image in the Middle Ages of the ship of fools as involving the sending of the madman out into the wilderness, much like the scapegoat in the Bible. However, Foucault understood the 16th and 17th century stories of madmen and madness, from those of Cervantes to Shakespeare, as having a

more internal location. No longer are mad people “out there”; now they have moved “in here.” Foucault stated: “Behold it moored now, made fast among things and men. No longer a ship but a hospital” (Foucault, 1965/1988, p. 35). Foucault’s metaphoric analysis of the literary approach to mad people, and the changes in these views over the centuries, captures well the societal changes taking place during these centuries.

Attitudes in the United States. The idea that mad people should be treated with kindness and decency took hold in the United States in the early 19th century. During this period, a number of public and private asylums were built to provide “moral treatment” to insane people. The asylums were often based on Quaker ideals, but they were expensive, requiring extensive staff and services. A vast expansion of asylums took place in the U.S. in the second half of the 19th century. In 30 years, from the 1840’s to the 1880’s, the number of mental hospitals in the U.S. increased from 18 to 139. Almost one in 354 people was living in a mental institution by the end of the 19th century (Whitaker, 2002). Unfortunately, moral treatment became too expensive to maintain, so asylums reverted to institutions of control of mad people, situations alleged by many to be violent, punitive, and abusive.

Second Half of the 20th Century. In the 1950’s, attitudes in the United States towards people with mental illness started to change again (Porter, 2002). This coincided with the development of antipsychotic medications, starting with Thorazine. By the 1960’s, the general attitude was that neuroleptics provided a complete cure for people with schizophrenia and manic-depression. President Kennedy encouraged the discharge

from hospitals into the community of most people with mental illness. Through the rest of the 20th century, there was a mass deinstitutionalization of people from mental hospitals in the United States. These hospitals held 559,000 patients in 1955, which was reduced to 107,000 in 1988 (Shorter, 1997), and would be significantly less now. The mass deinstitutionalization resulted from the advent of psychotropic medications as well as the writings of the anti-psychiatry movement (discussed below). Shorter (1997) believes the role of antipsychotics is a more important factor than the anti-psychiatry movement, but other historians credit the anti-psychiatry movement with the change in cultural views about the institutionalization of people with mental illness.

Although historians of psychology viewed the introduction of antipsychotics as a major transformation in treatment in America of people with mental illness, Whittaker (2002), representing the perspective of patients, argued that little had changed. He asserted that the psychiatrists and family members had engaged in a “love affair” with Thorazine and other neuroleptics, but patients did not share the positive views. Whittaker argued that these original antipsychotics made people physically ill. He asserted that these medications essentially constituted a new kind of torture. He recounted how patients finally rebelled in the 1970’s, demanding the right to consent (or not) to treatment. From Whittaker’s perspective, the development of neuroleptics was simply a furthering of the various tortures of mental patients from earlier years, such as lobotomies.

Interestingly, during most of the 20th century, the popular fascination with the madness of creative artists diminished from the 19th century, when madness was a particular focus in literature (Torrey & Miller, 2001). The societal interest in creativity and madness re-emerged at the end of the 20th century.

The anti-psychiatry movement. There had been an anti-psychiatry movement throughout the 19th and 20th centuries, but it had a major rebirth in the 1960's, in large part due to the leadership of social scientists like Michel Foucault (1965/1988; 1976/1954), R.D. Laing (1961; 1969), Thomas Szasz (1974; 1997/1987), and Erving Goffman (1961; 1963), as well as mental health and patient activists. The social scientists generally argued that mental illness is only a metaphor for what society views as deviant behavior. From their perspectives, the categorization of people as mad, insane, crazy, or mentally ill is simply a result of social and economic processes.

Szasz' (1974) argument was as follows: the literal meaning of "illness" is a physical deficiency in the body. To include in the term "illness" that which causes emotional suffering is to expand the meaning of the word from its literal meaning to a metaphorical meaning. Thus, the term "mental illness" is only a metaphor. It is a term that pretends that a person's suffering or disability, or, even more, what other people—namely psychiatrists—deem to be a person's suffering is an illness, like a somatic illness. Psychiatrists seek to make this connection because of their status as medical experts. They use medical terms and act as if psychiatry involves medicine just like cardiac medicine. Because of this sleight of hand, a metaphor is being treated as a "real" illness.

There is no “real” mental illness, only behaviors that are deemed deviant and then labeled crazy. The only problems of people deemed mentally deviant involve interpersonal conflicts and social constraints. The problem is not in the patient but in the desire of those with power, e.g., psychiatrists, to label the patients and take away their rights, such as whether to take medications.

Szasz (1997/1987) argued that even though the current language of mental illness is that it is a “brain disease,” there is no evidence of a disease process in the brains of people with mental illness. Thus the claim of brain disease is just another euphemism. Using occasionally dramatic language, like “psychiatric imperialism” and the “paternalism” of psychiatry, Szasz challenged every aspect of the notion of mental illness. He argued simply that it is improper to place deviance in the category of disease. In his later work, Szasz (1997/1987) expressed concern that the metaphor of mental illness is so entrenched in our cultural understandings that psychiatrists, patients, and the general public cannot even imagine the metaphoric nature of the construct.

More current language would conceptualize Szasz as arguing that mental illness is a socially endorsed construct that people treat as if it is more than an abstract idea. In today’s discourse, Szasz would be saying that mental illness is reified as if it were something real, concrete, and tangible.

R. D. Laing (1969) was a British psychiatrist who developed the theme that mental illness, and particularly schizophrenia, were reasonable efforts of an individual to deal with a “crazy” family situation. He argued that the symptoms were logical when

examined from that perspective. He challenged the whole notion of the medical model and argued that the term “mental” disorder is problematic, as most mental health problems are simply problems involving social situations.

Criticisms of the Anti-Psychiatry Movement. Although Szasz and Laing and other writers had a profound effect on ideas about mental illness, the deinstitutionalization of mental patients, and a 20th century intellectual discourse, there has been a strong backlash against them. For example, Roth and Kroll (1986) responded in the 1980’s by asserting that symptoms of mental illness have remained stable over an extended period. More recent biological researchers have responded with an abundance of research supporting a biological etiology of mental illness.

This history is important because these ideas from history are still present in American belief systems, and are perhaps best evidenced in art and culture. For example, ideas of demonic possession continue to emerge in literature and the arts, like *Rosemary’s Baby*, *Devil’s Advocate*, and even *The Devil Wears Prada*. Also, romantic ideas about the madness of creative artists are still flourishing. In order to further contextualize society’s current views of mental illness, the various theories that seek to explain the nature or etiology of mental illness are now presented.

Theories of Mental Illness

From its emergence in the 18th and 19th centuries, the field of psychiatry was divided between theorists focusing on psychosocial variables and those emphasizing biological and neurological etiology and treatment (Shorter, 1997). Even though the

biological explanations available in the 18th and 19th centuries were different from the current biological understandings of mental illness, the distinct approaches became well defined during that period. Three approaches historically had the most impact on the understanding of bipolar disorder and other mental illnesses: psychoanalysis, biological psychology or psychiatry, and the anti-psychiatry movement.

Freud and psychoanalytic ideas. Szasz (1997/1987) noted that psychoanalytic thinking had two repercussions in terms of the construct of mental illness. One was to separate mental illness from medicine and body (or soma), tying it more directly to dreams and general human experience. This was useful in terms of depathologizing the insane. But the second and contradictory effect of Freud's ideas, according to Szasz, was to pathologize experiences of "normal" life. One of the consequences of this is the idea that social difficulties, like alcoholism, became labeled as disorders.

Many historians of psychiatry and psychology today view psychodynamic thinking as defunct. Shorter, for example, stated:

If there is one central intellectual reality at the end of the twentieth century, it is that the biological approach to psychiatry ... has been a smashing success. Freud's ideas, which dominated this history of psychiatry for the past half-century, are now vanishing like the last snows of winter.

(Shorter, 1997, p. vii)

Academic discourse in psychology and psychiatry today largely endorses this position.

Biological psychiatry. Biological psychiatry sought physical or physiological explanations and treatments for mental illnesses. It emerged powerfully in the 19th century in Europe. The discovery of lithium in 1949 as a treatment for what was then

called manic-depressive illness was the beginning of a transformation of attitudes towards mental illness, with an emphasis on biological processes.

Today the medical model of illness is based on the principle that there are distinct categories of disorder, each with clearly definable symptoms, etiology, and course of disease (Mundt & Backenstrass, 2005). The model only assumes physiologically-verifiable pathology, however. There are no physical diagnostic tests that separate “normal” from “abnormal people. This differs from physical illness, where diagnosis is usually based on biological tests that demonstrate pathology. Thus, in diagnosing mental illness, the biological substrate is assumed (from reported behaviors and feelings) rather than substantiated. The only form of confirmation of a diagnosis is if the expression of symptoms changes with medication. In psychology, the medical model perspective focuses on the biological aspects of a disorder and generally excludes social ones (McCulloch, Ryrie, Williamson, & St John, 2005).

With regard to mental illness, the biological approach has fairly completely replaced the psychodynamic approach, both in professional circles and popular culture. Peter Kramer (1993; 2005), a psychiatrist, has been a popularizer of the biological approach. Kramer’s book, *Listening to Prozac* (Kramer, 1993), was a best-seller for many years. He is now critical of any discourse that considers depression anything but a biological deficit (2005). Although trained as a depth psychiatrist, he now believes that the meaning of symptoms is irrelevant and the only appropriate treatment for depression and other mental disorders is medication. Thus, he recently criticized the burgeoning area

of memoirs of depression and the “romantic” notion that great art requires depression. He now argues against any investigation into personal causes, meaning, and experience around depression. He even advocates for a future time when a gene could be implanted into a fetus to ensure that the child would not experience depression, like an immunization against smallpox.

The movement from psychoanalysis to biology. The paradigm shift from psychoanalysis to biology was captured well by Luhrmann (2000), an anthropologist who studied the training and perspectives of psychiatrists who work with people with mental illness. Initially she followed the training experiences of psychiatrists starting internships in July 1992, when the range of psychotropic medications was relatively limited. She explained how the training of psychiatrists at that time consisted of two divergent approaches – medication, learned by trial and error with very little academic or theoretical foundations, and psychoanalysis, also learned experientially with little theoretical background. According to Luhrmann, psychiatrists were provided no training, and rarely had any knowledge, of other psychotherapies or even the debates in psychology around psychotherapeutic techniques. Luhrmann noted at that time that the inconsistencies between the two paradigms were difficult to bridge. Nonetheless, psychiatrists managed to integrate the two approaches, in part because a psychoanalytic approach was incorporated into their training.

By about 2000, however, Luhrmann documented how psychiatric training and work had become totally transformed, in large part due to the role of managed care. She

described how, by the end of the 1990's, psychiatrists rarely engaged in psychotherapy; the psychoanalytic training element was minimal, if at all. Luhrmann noted how both psychiatrists and patients lamented the change in psychiatric treatment to medication over relationship, but how completely that change had occurred.

Luhrmann discussed one of the repercussions of the transformation to a biomedical model of treatment, which is that the only acceptable explanation for mental illness is a chemical imbalance one. Luhrmann said a positive ramification of this perspective is that the patient or family may no longer feel “blamed” for the illness. On the other hand, from this perspective no therapy or support needs to be provided, since medications are supposedly all that is needed to correct the imbalance.

Interaction of biology and environment. New models of mental illness are starting to integrate biological and environmental understandings (Fonagy, Gergely, Jurist, & Target, 2002; Reiser & Thompson, 2005). For example, since the 1990's some psychiatrists (e.g., Whybrow, Akiskal, & McKinney, 1984) have been conceptualizing affective disorders as emerging from and involving a combination of various biological, psychological, and developmental processes. Another example is the so-called “kindling model” of mental disorder, which suggests that a mental disorder may emerge in someone with a genetic predisposition for a particular disorder, due to trauma or other aspects of lived experience. The theory then holds that once depression or another symptom is first experienced, it is much more difficult to change it, because neurological connections have been developed (Kramer, 2005). With regard to bipolar disorder, most

current epidemiological theories perceive a close biology-environment relationship in terms of both etiology and symptomatology (Reiser & Thompson, 2005). Other theorists have proposed theoretical integrations of various approaches (e.g., Drob, 1989, 2003). For purposes of this study, although many agree that there is a relationship between biological factors and social environment in the etiology and manifestation of mental illness, the rivalry between the more biological and the more psychological theories remains consequential in many discourse communities.

Mind-body dualism. The ongoing debates between biological and psychological explanations for the etiology and nature of mental illness is a reminder of how the mind-body dualism articulated by Rene Descartes in the 17th century is present in today's discourse. Noting the ongoing disagreements about the etiology of bipolar disorder, the psychiatrist Hagop Akiskal (1995) commented: "the schism ... is an instance of the mind-body dichotomy that has characterized the Western intellectual tradition since Descartes" (Akiskal, 1995, p. 1072). Even with the emerging integrations of biological and psychological processes today, the mind-body distinction continues to impact the different professional attitudes and conclusions about the etiology, manifestation, and treatment of mental illness in general and bipolar disorder in particular.

Regardless of one's theoretical orientation, however, the document that has the most authority and legal standing over psychiatric categories and diagnosis in the United States is the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text

Revision (DSM-IV-TR).(American Psychiatric Association, 2000). This is discussed in the next section.

Diagnostic Organization

In the United States the DSM-IV-TR is the codex that organizes, categorizes, and labels mental disorders. It claims to be atheoretical and symptom-based, in order to avoid the conflicts in description of disorders offered by different theoretical orientations. The DSM-I and DSM-II were more based on psychoanalytic theory (Spitzer & Williams, 1985). The DSM-IV-TR sets as its goal simply to identify and describe the symptoms of what it sees as each discrete mental disorder.

In the 1970's and 1980's, the anti-psychiatry movement challenged the DSM and its claim of describing "actual" disorders. In the 1990's, Kutchins and Kirk (1997) made the argument that the categories of mental illness laid out in the DSM-IV are purely political compromises and do not reflect any valid disorders. They claimed that the DSM simply pathologizes "those in our society who are undesirable and powerless ... because of unspoken cultural biases about what should be considered normal and what should be considered disease" (Kutchins & Kirk, 1997, p. 16). They argued that the DSM-IV's reliability is based on biased research that simply confirmed the beliefs of the psychiatrists polled (often an elite group). Kutchins and Kirk's conclusion about the DSM's claimed reliability is that "the DSM revolution in reliability has been a revolution in rhetoric, not in reality" (p. 53). They highlighted the role of Robert Spitzer, the psychiatrist who essentially masterminded the DSM, and his power to decide which

diagnoses would be included and which omitted from the manual.

Shorter (1997) is critical of the DSM for another reason. He expressed a concern that the expansion of discrete disorders in the DSM is dangerous for psychiatry. He claimed that psychiatry is most effective when doing “lumping” rather than “splitting” (i.e., combining groups of disorders into a few categories rather than creating many discrete disorders with similar sets of symptoms) (Shorter, 1997, p. 303). He noted how there are more mental disorders listed in the DSM-IV-TR than all of the other physical disorders combined that are listed in the catalog of physical disorders.

An apparently unintended consequence of the DSM-III and its successors, one that has been criticized by many, is the way the DSM has taken on biblical proportions. It has been “universally and uncritically accepted as the ultimate authority on psychopathology and diagnosis” (Andreasen, 2007). Yet some thinkers foresaw this consequence; it was being discussed as early as 1984. For example, in 1984 Himelhach, as quoted by Goodwin and Jamison (1990), warned about this consequence for the diagnosis of mood disorders:

The diagnosis of the affective disorders is in danger of becoming a formula. Descriptors of depression or mania are selected from one diagnostic system as if from a Chinese menu. . . . Diagnosis turns into simple description, and diagnostic categories into neo-platonic Procrustean beds into which heterogeneous affective syndromes are forced to fit regardless of their obvious differences from one another regarding premorbid development, course, and outcome.

(Goodwin & Jamison, 1990, p. 89)

In effect each iteration of the DSM has resulted in new criticisms and then efforts to correct the problems created by the changing perspectives of the consensus group.

From the social constructionist perspective, however, this process is not troubling. Diagnostic labels set out in any particular DSM are simply one way to organize and categorize experience. In American society, the DSM is one part of the packaging and construction of recognizable “illnesses” (Gaines, 1992; Gergen, 1994; Smart & Wegner, 1999). Thus, labels signifying mental illness may indicate as much about the society doing the labeling as about the properties of the people being labeled.

Several theories about the etiology and manifestation of mental illness have been summarized, as well as the diagnostic approach currently in vogue in American society. I now address theorists who provide hypotheses about unconscious factors that may influence and explain intrapsychic and interpersonal processes involved in the stigmatizing of people with mental illness.

Theories about Disowned Feelings

Psychodynamic theories of self. Various psychodynamic thinkers, starting with Freud, have proposed theories to understand how humans (in Western society), when constructing a sense of self, deal with uncomfortable, anxiety-arousing experiences. Melanie Klein and Harry Stack Sullivan are two psychodynamic theorists who studied the development of self. They were both interested in the process by which infants disown anxiety-laden aspects of their experience and how this disavowal affects adult life.

Melanie Klein viewed infancy as a time in which one feels love and comfort as well as terrifying emotions such as intense persecutory anxiety (Klein, 1959/1985). In

Klein's view, an infant experiences rage, sadness, and frustration, along with feelings of joy and love. One of Klein's unique contributions to psychoanalytic theory involves the notion of psychological "positions," *paranoid-schizoid* and *depressive*. In the *paranoid-schizoid position*, an individual has difficulty finding subjectivity and instead depends on defenses such as *splitting*, *projection*, and *projective identification* to make sense of the world, whereas in the *depressive position*, the individual can experience a continuous sense of self, across different affective experiences, including grief and loss

For Klein, *introjection* is the taking in as part of self an experience from the outside world. *Projection* involves attributing one's own feelings to other people. Both *projection* and *introjection* are experiences that are hypothesized to occur throughout our lives; thus, our sense of "reality" is continually modified by these experience (Klein, 1959/1985).

In Kleinian theory, each individual's inner sense of self, particularly in the *paranoid-schizoid position*, is "split" into "good" and "bad" parts. The separation occurs in infancy as a way of managing unbearable aggression and anger at the nurturing but withholding parent. The "bad" parts are split off from the good parts, allowing us to love our nurturing parent and ourselves. They are then projected outward, thus reducing the anxiety about our aggression, which the infant fears could cause disintegration of self.

Klein suggested that in the unconscious psychic process *projective identification*, an individual *projects* aspects of the self *into* other people as a way to control both the other person and the parts of self; this in turn reduces one's anxiety. Unlike projection

alone, the two people are connected in projective identification; the person projecting can experience his or her *bad* parts (or *good* parts) as alive in the other person.

Klein views this process as exhausting and draining; she focused on the depleting aspect of this process. The sense is that one is weakened, terrified of the power in the other person (Main, 1985). Main sees the process as “a variety of joint personality depletions and invasions and interpersonal disturbances” (Main, 1985, p. 50). Yet the process can also be viewed as a way of reaching greater integration and psychic health (e.g., Ogden, 1994).

The theory hypothesizes that the person projecting material into another has ambivalent feelings towards the projected material (and the other person holding it), as there is both desire for and fear of what is projected (Horwitz, 1985). Ogden (1994) suggested that the projective identification process of expelling into the other person serves two functions: protecting oneself from dangerous material or protecting the material from oneself. The person projecting is using the other person to hold these parts. In the process both parties have negated parts of themselves. The person taking in the projections is also changed as he or she incorporates and identifies with the projected parts (Horwitz, 1985).

Klein theorized that the emergence of the depressive position is when the infant starts to “pine” for the loss of the good object. Pining allows the infant to experience both the good and bad parts. But it is difficult to hold the *depressive position*:

In short – persecution (by “bad” objects) and the characteristic defenses against it, on the one hand, and pining for the loved (“good”) object, on the other constitute

the depressive position.

(Klein, 1940, p. 130)

Klein (1940) explored how mourning might be related to “manic-depressive states.” She proposed that so-called “manic-depressive experiences” serve as a defense against experiencing loss. She noted that all people experience fluctuations in moods. A person in mourning will feel restored when he or she “reinstates” intrapsychically both the dead person and the good parents. Interestingly, Klein suggested that part of the healing involves greater introjection of the good and bad parents as well as increased projection into others. She linked the process with the manic-depressive defenses:

When the depressive position arises, the ego is forced (in addition to earlier defenses) to develop methods of defense which are essentially directed against the ‘pining’ for the loved object. These are fundamental to the whole ego-organization. I formerly termed some of these methods *manic* defences, or the *manic* position, because of their relationship to the manic-depressive illness.

(Klein, 1940, p. 130)

Klein’s conceptualization of these processes is complex and can provide a framework for understanding troubling aspects of human subjectivity.

Sullivan. The American psychiatrist Harry Stack Sullivan presented another perspective on how the child manages the anxiety of inner and external experience. For Sullivan, anxiety “is responsible for a great part of the inadequate, inefficient, unduly rigid, or otherwise unfortunate performances of people” (Sullivan, 1953, p. 160). Sullivan conceptualized that the infant manages interpersonal anxiety by developing three aspects of experience of self, all of which are connected by “my body”: “good-me,” “bad-me,” and “not-me.” The “good-me” aspects of personhood are those that are reinforced by the

“mothering one” and by society and which essentially become known to us as “I.” The “bad-me” parts emerge in anxiety-provoking interactions with the “mothering one” and other people and constitute our known personal deficits. The *good-me* and *bad-me* are similar in that the child – and later the adult – is generally aware of them.

Sullivan’s notion is that the “not-me” aspect is one that is repressed, unconscious, and unknown. It is only accessible through symbolic communications such as dreams and nightmares. The *not-me* emerges from “intense anxiety” and “uncanny emotion” (Sullivan, 1953, p. 163). The original experience that developed into a *not-me* state was confusing and anxiety-provoking; the infant could not digest it at all; all the child could do is eject it from the world of the known. Although Sullivan’s conceptualization is not as complex as Klein’s, it sets forth a similar idea of how aspects of self can be pushed out of consciousness, and proposes that this process develops from the relationship with the person in a role of mother.

Group processes of scapegoating. Wilfred Bion took some of Melanie Klein’s ideas and applied them to relationships among groups. Yet ideas about group process are much more ancient. One is from the Hebrew bible. Each year at Yom Kippur services, on the holiest day of the Jewish year, Jews read aloud the origin story of the scapegoat:

And Adonoy* spoke to Moses: speak to your brother Aaron Aaron shall begin by presenting his own bullock for a sin-offering, and make atonement for himself and his household. He shall then take the two he-goats and stand them before Adonoy. ... And Adonoy shall place two lots on the two he-goats, one lot marked “for Adonoy” and one lot marked “for Azazel.”** And Aaron shall present the goat that has the lot “for Adonoy,” which he will later prepare as a sin-offering. And the goat that has the lot “for Azazel” shall remain alive before Adonoy, for Aaron to make atonement on it and send it to Azazel in the desert. ...

When he finishes making atonement of the inner Sanctuary, ... he shall present the live goat. And then Aaron shall lean both his hands on the head of the live goat, and he shall confess on it all the iniquities of the Children of Israel, and all their transgressions, all their sins; and he shall place them on the goat's head and send it to the desert with a man specially designated for this purpose. The goat will thus carry all their iniquities to a desolate area, and he shall let the goat go in the wilderness....

This will be an eternal statute for you; each day on the tenth day of the seventh month, you shall fast and not do any work. ... For on this day Adonoy will make atonement for you to cleanse you; from all your sins before Adonoy, you will be cleansed.

Leviticus 16:1-34
(Davis, 1983, pp. 439-442)

* Adonoy is a name for God

** Azazel is generally understood to be a place deep in the wilderness

In this ancient ritual, all the sins of the Israelites are symbolically placed on the goat, which is then sent into the wilderness, along with the sins, thereby leaving the Israelites free of those sins. The recitation goes into extensive detail on how Aaron and the man taking the goat to the wilderness must cleanse themselves, for any error in the process may result in death to Aaron and injury to all Israelites. This ritual seems to evoke powerfully the unconscious striving to rid both individuals and society of evil.

Bion proposed theories on the nature of that group process. He extended Kleinian ideas about individual *projection* and *projective identification* to group unconscious behavior (Bion, 1959). In Kleinian/Bion theory, when the infant projects difficult material into the mother and the mother can “contain” these feelings, the infant can then experience and metabolize the feelings safely. But if the mother cannot contain them, the child feels intense terror and unraveling. This process is then repeated, in a kind of

parallel process, with groups.

Hurwitz worked with Bion's ideas and proposed three group processes that involve projective identification: "role suction"; using a member as a spokesperson; and scapegoating (Horwitz, 1985, p. 29). Role suction involves the process by which a group places one of its members in a specific role and then deposits projections into that person. When a member is used as a spokesperson, particularly for a socially unacceptable cause, the member takes on all of the negative aspects of that particular position, leaving the other members to feel superior and benevolent. In the context of projective identification, scapegoating involves the displacement into the scapegoated person all of the "unwanted affects" and "desired but threatening impulses" (Horwitz, 1985, p. 30).

These processes then manifest in groups in society. With groups named and projections placed in them, members of the group become filled with the societal projections (Main, 1985).

Another way of thinking about how groups form "us" and "other" groups is to consider that any person, except mother, is an "other" to the developing infant (at 8 months) (Erlich, 1997). The stranger then becomes "the prototype of the internal psychic enemy that becomes a social reality" and all strangers or enemies hold a "boundary position" (Erlich, 1997, p. 133). In fact, "others" who are most like us are often our most hated enemies (Volkan, 1986). By maintaining ties to them through projective identification, we maintain an ongoing relationship and may even become obsessed with them.

As a result of these various group processes, groups create and maintain both a denigrated “other” and an idealized “other”; these are created individually and among groups (Green & Skolnick, 2002). Altman (1995) analogizes the psyche to neighborhoods: there are idealized good and denigrated bad neighborhoods. Bad people are in the bad neighborhoods and people from good neighborhoods avoid them for fear of what happens there. They prefer the “good” neighborhoods. Through group process, “the public sector becomes the repository, on the social level, for the “not-me,” for the disowned, the different, the degraded, the incomprehensible.” (Altman, 1995, p. 127)

From this perspective group healing can take place only when individuals – and the dominant group – reclaim their denigrating projections from the public sector and from the out-groups. In doing so, the dominant group can recognize that the evil and all that they fear is not just outside its members but also inside them.

Foucault (1976/1954) utilized related theories and applied them to societal attitudes towards people with mental illness. Referring to the Benedict (1934/1967) article discussed above, Foucault provided one explanation for why Western society defines people with mental illness as deviant and external: “... our society does not wish to recognize itself in the ill individual whom it rejects or locks up The analyses of our psychologists and sociologists, which turn the patient into a deviant and which seek the origin of the morbid in the abnormal, are, therefore, above all a projection of cultural themes” (Foucault, 1976/1954, p. 63).

The ideas of Klein, Bion, and others who write about disowned feelings are

important for thinking about how denigrated others come to be denigrated in society and what function they may serve for those doing the denigrating.

This review has examined social science theories of cultural, social, and group dynamics that create and maintain social hierarchies, with “mad” people being on the “other” side of the threshold between normal and abnormal. The history of the treatment of mad people has also been discussed, as well as the current theories that explain the nature of mental illness. The remainder of this review discusses these ideas in connection with bipolar disorder, the specific diagnosis at issue in this study.

The Construct of Bipolar Disorder

DSM definition. Bipolar disorder is defined in psychiatric terminology as a mood or affective disorder. In the DSM-IV-TR, (American Psychiatric Association, 2000). someone with bipolar disorder must have experienced “episodes” of elevated mood (hypomania, mania or mixed moods), sometimes with depressed mood (major depressive episode). A manic or hypomanic episode is defined as “persistently elevated, expansive, or irritable mood” for a period of time (one week for manic; four days for hypomanic) (American Psychiatric Association, 2000). The person must experience at least three symptoms from a list of seven, which include inflated self-esteem or grandiosity, decreased need for sleep, “flight of ideas,” and distractibility. Whereas a manic episode causes “marked impairment” in functioning, a hypomanic episode involves “an unequivocal change in functioning that is uncharacteristic of the person when not symptomatic” (American Psychiatric Association, 2000). Symptoms of major depression

include depressed mood, markedly diminished interest or pleasure in all or almost all activities, fatigue or loss of energy, feelings of worthlessness or guilt, and recurrent thoughts of death and suicidal ideation (American Psychiatric Association, 2000).

Although symptoms of mania or depression qualify on their own for an affective disorder diagnosis, hypomania is considered to have crossed the line into abnormality only if the person also experiences symptoms of mania or a major depressive disorder. (

The lifetime prevalence of bipolar disorder in the United States has been described as about 1% to 2% (Kessler, Stang, Wittchen, Stein, & Walters, 1999), but some clinical prevalence estimates are as high as 5% (Benazzi, 2005; Faravelli, 2005; Patten, 2006) or 7.8% (Reiser & Thompson, 2005). A recent study found that the diagnosis of adults with bipolar disorder nearly doubled during the period of 1994-2003 and the diagnosis of young people with bipolar disorder had an approximately forty-fold increase (Moreno et al., 2007). Worldwide, bipolar disorder is the sixth leading cause of disability (Murray & Lopez, 1996). There is a high rate of mortality in people whose bipolar disorder is untreated (Keck, McElroy, & Stakowski, 1998), and bipolar disorder is considered one of the most incapacitating of disabilities in the United States (LaPlante, 2002). Research has found that those who have experienced multiple episodes of elevated or depressed mood lose functioning during and between episodes; this deterioration can cause significant impairment to their psychosocial functioning and quality of life (Arnold, Witzeman, Swank, McElroy, & Keck, 2000). It is estimated that approximately 25% of persons with bipolar disorder have attempted suicide (Dilsaver, Chen, Swann, Shoaib, &

Krajewski, 1994).

The medical and psychiatric studies involving bipolar disorder address issues of medication, treatment, discrete diagnosis, and prevention of suicide, generally reflecting the perspective of the medical or biological model of mental illness (e.g., Rapaport & Bosetti, 2002; Rucci et al., 2002; Simpson et al., 2002; Sobo, 1999). Many studies by psychologists also approach treatment from that framework, viewing the disorder as one for which interventions and treatments must be applied and administered (McClure, Kubiszyn, & Kaslow, 2002; Rivas-Vazquez, Johnson, Rey, & Blais, 2002). Thus, factors such as symptoms, prevalence, and treatment are the questions generally addressed in the psychiatric and psychology literatures. These approaches are more concrete and applied than the conceptualizing in other social science theoretical literatures, as discussed above.

Conceptualizations of mood disorders. The notion of a diagnostic relationship between depression (then called melancholia) and mania developed in the mid-19th century (Goodwin & Jamison, 1990). Diagnostic understandings of what are now called mood disorders have been in flux since that time, however, as different theoretical perspectives gained ascendancy and then waned. The first clinically detailed explanatory framework for “manic-depressive illness” was developed by Emil Kraepelin in 1899 (Akiskal, 1995). Kraepelin initially differentiated between manic-depressive disorder and melancholia, but by 1913, he considered all kinds of melancholia to be subsumed within the category of manic-depressive disorder (Goodwin & Jamison, 1990).

In the early part of the 20th century, there were multiple competing perspectives

on manic-depressive disorders, depending on one's theoretical orientation (Akiskal, 1995). The first DSM had one category for manic-depressive illness and one for "manic-depressive reaction" (Goodwin & Jamison, 1990). This was based on a theoretical approach proposed by Adolf Meyer that focused on the relationship between stress and societal influences. Many in the United States endorsed this perspective, which hypothesized that the etiology of manic and depressive symptoms for some people was because their biological systems were vulnerable and succumbed to stressful psychological and social influences (Goodwin & Jamison, 1990).

Eugen Bleuler developed another diagnostic conceptualization in the 1920's, proposing that manic-depressive illness and *dementia praecox* (similar to our construct today of schizophrenia) were located on two ends of a continuum and that the problems of most patients fell somewhere along that continuum (Goodwin & Jamison, 1990). Bleuler changed the title of the "affective" side of the diagnostic pole to "affective disorders," a label that was adopted in both the DSM and DSM-II (Goodwin & Jamison, 1990).

The drafters of DSM-III felt that DSM-II created diagnostic confusion because each diagnostic category of affective disorders was premised upon a different theoretical understanding.(Goodwin & Jamison, 1990). Theoretical conceptualizations, supported by research, started to differentiate again between bipolar illness and "pure" depression. This distinction was adopted in the DSM-III, distinguishing between "bipolar" and "unipolar" disorders (Spitzer & Williams, 1985).

Yet the bipolar-unipolar distinction also proved to be problematic. For example, in 1990 Goodwin and Jamison were already arguing that the distinction between bipolar disorder and major depression in the DSM-III-R (continued into the DSM-IV-TR), was problematic and that a more nuanced nosology was required.

Current directions. Many clinicians today are arguing for a more complex framework for diagnosing mood disorders. Many psychiatrists claim that there should be several new categories of bipolar disorder, including a bipolar spectrum disorder. They argue that there are several patterns of symptoms, some similar to cyclothymia, that are not as serious as Bipolar I or II but are still worth treating with medication and should be labeled as bipolar disorder (Phelps, 2006a). They are arguing that the next DSM include additional bipolar diagnoses such as Bipolar II ½, Bipolar III, and Bipolar III ½..

There have been many studies about the biological etiology of bipolar disorder, its prevalence, medication treatments, and psychological treatments (Reiser & Thompson, 2005). Yet there has not been an in-depth study of the social construction of bipolar disorder. It is worth investigating how this relatively new construct was and continues to be created in American culture.

The emphases from the medical model have been on discrete diagnosis, specific medical treatments, and empirically supported therapies. That area of analysis is concrete and practical and is intended to provide answers to specific questions, like which pharmacological agent works best with which symptoms. Yet the social construction of bipolar disorder seeks understanding beyond these discrete areas. Someone diagnosed

with bipolar disorder must also grapple with the societal views of the disorder. Although societal ideas may be impacted by medically-oriented research, changes in medical knowledge may not immediately change societal ideas.. Thus, is it also important to contextualize this information in terms of societal attitudes.

Whether Bipolar Disorder is Still Associated with Crazy

Seeing as bipolar disorder is a fairly new construct in American society, it is useful to know bipolar disorder is considered a “crazy” diagnosis in American society, as “manic-depressive disorder” used to be considered. One part of the answer to this question can be found in memoirs of people with that diagnosis.

Memoirs of people with bipolar disorder often describe complex inner lives with varied emotional experiences, ranging from severe depression and suicidality to expansive “manic” or “hypomanic” moments. It seems to be a lifelong task of making “sense” of the meaning of the label and of the symptoms for oneself. For example, a doctoral student who had a psychotic episode that resulted in receiving a bipolar disorder diagnosis wrote about crossing that threshold:

I had never been “crazy” before. I was a normal person. I had excelled as an undergraduate. ... [But now] I was on the other side of the wall between “normal” people and “crazy” people. I had left society and had become a “mental patient.” The locked doors of the psych ward separating us from “normal” people became my dominant metaphor.... Me as “crazy” now replaced every other image I had formed about myself – scholar, musician, and poet. ...

(Fekete, 2004, pp. 190-192)

Part of Fekete’s process of digesting the diagnosis was initially to adopt the “medical” explanation for his “disorder,” namely a disorder of chemical neurotransmitters.

One of the early concepts that liberated me from the metaphor of the mental hospital was the medical model for my condition.... As I grew to understand the medical model of bipolar disorder, I was able to overcome the stigma associated with my illness and to redefine my person as it relates to my illness. I found that the chemicals that shoot forth from my neurotransmitters are imbalanced. This means that my illness isn't mental at all – it is physical. It is like a broken arm. I am not mentally ill. My illness is not some scary mental thing. It is a physical thing, like every other normal, non-scary physical illness. ...

(Fekete, 2004, pp. 190-192)

Then Fekete discusses how and to what extent having the diagnosis affected his sense of his identity:

And as a physical illness, I distinguish between bipolar disorder and what I mean by me, or my identity. My illness is a separate, alien thing from my identity. There is me, and then there is my illness. I am a whole, functioning person with defective neurotransmitters. I am not defined by my illness.

(Fekete, 2004, pp. 190-192)

Fekete touches upon themes that will be explored in this dissertation. These involve how much a person with a diagnosis of bipolar disorder will treat the diagnosis as meaning he or she is mentally ill. Another is how one explains to oneself and others the etiology of the “disorder.” The third theme is how much the label of bipolar disorder enters into one's sense of identity.

A more famous example is the actress Patty Duke, who experienced significant emotional distress prior to receiving a bipolar disorder diagnosis. When she was finally diagnosed, she felt such relief at no longer feeling like a “monster”:

When I started my Lithium therapy, it didn't mean I ended my fruitful psychiatric work with Dr. Arlen, it meant it could begin. I could face life as a garden-variety neurotic, not a green, squirrely monster.

(Duke & Turan, 1987, p. 290)

Duke felt that she could fully engage in psychotherapy only after she had a diagnosis and

a medication. Yet even with the diagnosis, she had difficulty explaining the nature of her disorder. Years later, after living with the diagnosis for some time, she wrote:

My mental illness is a genetic, chemical imbalance of the brain. I know that. But I also had a life that was, to put it mildly, out of the ordinary. I went through a lot of loss, and a lot of things that happened to me would have been enough to make anyone go crazy. So it sometimes gets a bit fuzzy trying to decide which of my manias and depressions came specifically from my illness and which may have had to do more with what was going on in my life.

(Duke & Hochman, 1992, p. 63)

Like Fekete, Duke embraces the chemical imbalance account of bipolar disorder but finds that it does not fully explain her emotional life experience.

Similarly, Dr. Kay Redfield Jamison, the well-respected psychologist and researcher on bipolar disorder, came out publicly about a decade ago with memoirs of her own life living with bipolar disorder. In her memoirs, Jamison described a brief but exhilarating experience, one that she now attributes to bipolar psychosis and which she labels as “madness”:

People go mad in idiosyncratic ways. ... I found myself, in that glorious illusion of high summer days, gliding, flying, now and again lurching through cloud banks and ethers, past stars, and across fields of ice crystals. ... I remember singing “Fly Me to the Moons” as I swept past those of Saturn

Was it real? Well, of course not, not in any meaningful sense of the word “real.” But did it stay with me? Absolutely. Long after my psychosis cleared and the medications took hold, it became part of what one remembers forever The intensity, glory, and absolute assuredness of my mind’s flight made it very difficult to believe, once I was better, that the illness was one I should willingly give up. ... My family and friends thought I would welcome being “normal” ... [but] I miss Saturn very much.

(Jamison, 1995, pp. 90 - 92)

What Jamison struggled with is the philosophical question of the nature of reality. One

could make the argument that the experience was “real” in that she lived it, remembered it vividly years later, and still misses those moments of euphoria. Yet Jamison has chosen the scientific path of attributing those exuberant moments to a psychotic mania that falsely imagined that those exhilarating moments were “real.” She states how she made sense of the experience:

Some of my reluctance, no doubt, stemmed from a fundamental denial that what I had was a real disease. ... Moods are such an essential part of the substance of life, of one’s notion of oneself, that even psychotic extremes in mood and behavior can somehow be seen as temporary, even understandable reactions to what life has dealt. In my case, I had a horrible sense of loss for who I had been and where I had been.

(Jamison, 1995, pp. 90 - 92)

Like Fekete and Duke, Jamison recognizes that her life experience had some role in her mania; it could not simply be attributed to a chemical imbalance in her brain.¹

Based on these anecdotal memoirs, it would appear that bipolar disorder is still associated in American society with “craziness”; that getting the diagnosis of bipolar disorder impacts upon a person’s identity; and that the available societal explanations for the etiology and meaning of the disorder are not fully satisfying to the person with such a diagnosis. An in-depth study that investigates these questions more systematically would therefore provide useful knowledge.

¹It is interesting to note that in the 17th century it was believed that Saturn, through its astrological aspects, had an influence on melancholy (Akiskal, 1995; Whybrow, Akiskal,

Question Investigated

Each culture constructs a line between what is considered psychologically normal and what is considered abnormal, a boundary that changes over time. The society organizes feelings and behaviors into categories that belong on either side of that line, but the threshold and the categories are often in flux. In any particular society, there are only a limited number of categories of feelings and behaviors. Consequently, there is a narrow set of options for people to make sense of and explain their feelings and behaviors. Language is the means by which we as humans learn the options and then choose among them.

This study investigates the construct of bipolar disorder in the United States today. The research explores how the construct has been developed to represent a particular set of feelings and behaviors. The various ways the construct is explained by society are to be studied, as well as changes in those explanations over time. These questions are examined as seen through the perspectives of individuals labeled as having bipolar disorder.

Relevance of the Study

This study is relevant today because of the prevalence of bipolar disorder as a diagnosis and an ongoing debate about whether the prevalence is increasing (Benazzi, 2005; Faravelli, 2005; Patten, 2006). It is relevant to those who have the diagnosis and to those who work with and are in relationship with people with this diagnosis.

& McKinney, 1984). Thus, during that era, Jamison's ideas about Saturn might have been

The questions in this study are also relevant for public policy and social theory. Large amounts of federal and state funds are directed to the care and treatment of people with diagnoses of mental illness, especially bipolar disorder. In terms of social theory, there is a spotlight today in the United States on the notions of mania and depression. Bipolar disorder, mania, hypomania, and depression are all vivid ideas in the dominant American culture. For example, American society prizes high energy and exuberance. At the same time, the culture maintains terrifying images of “crazy,” “mad,” and “manic” people. Through these images, the society both idealizes high energy yet disowns and denigrates those individuals whose mania or depression is “too” intense. The thresholds between healthy hypomania or creative depression and “crazy” mania or depression are the same ones noted by Emily Dickinson in the opening poem. In this study, I seek to provide a deeper understanding of the meaning and nature of those thresholds in American society.

Personal Engagement with the Question

I have always been interested in how societal and cultural phenomena meet and interact with individual lived experience. My focus has moved back and forth from micro- to macro-level processes. One intellectual interest has involved anthropology, which addresses the person-society relationship from the perspective of culture. I applied those ideas to individual experience when living in Senegal in 1975. I saw how some of what had been my solidly basic truths about “normal” and “abnormal” behavior were not

considered reasonable ideas consistent with her history of melancholy.

shared in that culture. I also studied the field of law, which grapples with the question of how far society can proceed in legislating behavior before infringing on individual rights. As an attorney for many years, I saw how the legal system constructs and enforces boundaries between appropriate and inappropriate behaviors in society. In psychology I have engaged with psychodynamic clinical theory, which tries to understand intrapsychic and relational experience. I have come to understand the unconscious behaviors of groups from group relations theory. By pursuing each of these paths, I have been seeking to understand how societies and groups create categories of in-group and out-group, and how individuals make sense of those boundaries.

My personal investment in these questions arises from the narratives I heard throughout childhood and adolescence from my Russian Jewish immigrant relatives. A century ago, they experienced the humiliation of having labels (Jewish, Russian, immigrant) of groups considered “denigrated others.” Yet they also claimed a privilege of intellectual, artistic, and political specialness. They were certain that their social movement in Russia would bring about a new world of justice and equality, even as the entire family was incarcerated in Siberia for their political beliefs. These idealistic beliefs and claims to specialness continued through many episodes of discrimination, poverty, and the challenges of immigration. It became evident to me that the term, “Jew” was a complex one with layers of meaning. This lifelong interest in the nature of “otherness” is part of what led me to seek the societal understandings of labels like “crazy” and “bipolar.”

I discovered some unconscious motives for this subject matter only when in the midst of writing this dissertation. I came to recognize how my own affective style and occasional emotional dysregulation influence my life and social interactions. While writing the dissertation, my moods ranged from hypomania to dysthymia, reminding me regularly of my own internal turmoil and inviting an experiential connection with my participants.

Structure of the Dissertation

This dissertation has seven chapters. The second chapter describes the mode of inquiry and my experience in conducting this study. The third through sixth chapters present and discuss the findings. A more complete discussion is in the seventh chapter. In the conclusion, I address the implications of the findings, their limitations, and recommendations for future research.

CHAPTER TWO

MODE AND EXPERIENCE OF INQUIRY

This dissertation is an in-depth study of the experiences of six individuals who were diagnosed as adults with bipolar disorder. The interviews produced exceptionally rich and complex data. I have analyzed the data from various perspectives. The presentation and analyses of the findings should provide a vivid sense of the participants' lives and a nuanced understanding of some of the social processes present. This chapter describes the process of recruiting participants, conducting interviews, analyzing data, and writing up the findings. It also addresses my experience in conducting the interviews and engaging in the study.

Choice of Diagnosis

The diagnosis of bipolar disorder was chosen for this study in the hope that that label would be particularly evocative in terms of societal associations. Many lay people, as well as mental health and psychiatric rehabilitation professionals, view bipolar disorder and schizophrenia as the two “serious” psychiatric diagnoses. The understanding in the psychiatric community is generally that these two diagnoses result in “severe and persistent” symptoms (Furlong, McCoy, Clay, McClory, & Pavick, 2002). Participants might present both negative projections about bipolar disorder as well as positive ones, like how people with bipolar disorder are creative, energetic geniuses (Andreasen, 1987; Andreasen & Glick, 1988).

Recruitment

The stated criterion for participating in the study was simply that an adult have a diagnosis of bipolar disorder. I also had informal criteria. I sought participants who had given a great deal of thought to the meaning of the diagnosis in their lives. I wanted to interview people who were articulate, insightful, and thoughtful. I was even hoping for participants who had been in psychotherapy. Although I developed a flyer and contemplated active recruitment through bipolar disorder support networks, I realized that it would be difficult to screen unknown people for these informal criteria.

Accordingly, I decided to recruit through a very small group of people that I know and trust, current and former local Fielding Graduate University classmates. I explained to a few classmates both my formal and informal criteria. I believed these classmates understood my recruitment criteria and would refer appropriate people as potential participants.

I received seven referrals from this group of people. The referrals were all of individuals currently or previously in some kind of relationship with my contact person. Four people referred one person each; one person referred three people. The referrals were of current or former therapy clients, friends, professional colleagues, and one former clinical supervisor. Six of the referrals became participants. The seventh indicated she was willing to participate, but did not return telephone calls when it came time to schedule the interview. Of the six participants, two were pilot participants who had been interviewed a few years earlier.

I was very cautious about the process of recruitment, for several reasons. First, I would be asking about topics that might at times be uncomfortable for participants to discuss. Second, I wanted to avoid any possibility of implicit coercion since some of the potential participants were current or former therapy clients of a classmate. Third, there was no direct benefit to participants to spend several hours in an intense interview. Fourth, I wanted to exclude anyone with whom there was the possibility of a future dual relationship.

Thus, I had one or two telephone conversations with all of the participants before the interview. I explained the nature of the interview, the interview process, and how I received their name. I discussed with them their level of comfort in proceeding. I tried to ensure that they were truly willing to volunteer for this task. All of the participants expressed a willingness to be interviewed. Several sounded very eager.

Participants

Specially selected group. Demographic information about the six participants is provided in the next chapter and in Table One. I should note, however, that I found this group of participants to be a remarkable group in terms of their depth, eloquence, and thoughtfulness. This might say something about bipolar disorder. More likely, it indicates that my classmates who referred these people chose to refer individuals who would satisfy my desire to interview people who were deep, eloquent, and thoughtful. Thus, these qualities are likely a function of the recruitment process rather than the phenomenon being studied.

Sample size. There has been extensive discussion in the qualitative research literature about how large a “sample” is an appropriate size for a qualitative study. This study is similar to the methodology called “grounded theory,” a method in which new theory is generated from the qualitative study. When utilizing a grounded theory methodology, one would choose participants based on a “theoretical sampling” process (Charmaz, 2000; Glaser & Strauss, 1967; Silverman, 2005). In theoretical sampling, interviews are used to gather information in order to further theory. My theoretical perspective concerns the social construction of bipolar disorder. After interviewing the six participants in depth, I felt that I had sufficient material to address the theoretical questions to be addressed in the study.

In other qualitative methodologies, evaluating the number of participants is determined by what is known as “saturation.” This occurs when new interview data fit within the categories created for the prior data (Charmaz, 2000). In other words, no further interviewing would be required because the themes from the later interviews were consistent with the themes emerging from the earlier interviews. I found that to be the case with the interviews for this study. In that sense I had reached saturation.

However, this study is mainly based in the narrative research theory of inquiry, which views the notion of saturation differently. From this perspective, research never arrives at a point of completion, since each individual is unique and has a particular story to tell. In this mode of inquiry, the researcher takes in the material and holds in her or his thinking all of the conflicting and ambiguous findings and meanings. One way to look at

saturation in narrative research is to see that a point comes when the researcher cannot hold or contain any more information, data, contradictions or themes (Josselson & Lieblich, 2003). In other words, as a narrative researcher, I am the instrument that takes the data and creates new stories and analyses from other people's stories. Since the six interviews were very rich with material, I felt quite "filled up" with the participants' personal stories and with my reflections about the many possible interpretations and analyses of these stories.

In sum, I felt that I had reached saturation in both ways the term is used in qualitative research. With six interviews, each of the themes that emerged was addressed by several participants. And because of the eloquence and expressiveness of the participants, I obtained very "thick" research data (Geertz, 1973).

Interview Process

My goal in the interviews was to have open-ended interviews in which participants would respond to the research question in a stream-of-consciousness style. This was done to permit unconscious material to emerge through such processes as metaphors, slips of the tongue, and disruptions in thought.

The two pilot interviews took place in the summer of 2003. The four remaining interviews occurred in the first six months of 2006. The interviews were all about two hours long, although the interview of "Sarah" totaled about four hours. The first two interviews, which were pilot interviews, were divided into two shorter sessions about a week apart. The four later interviews were all one-interview meetings. All but one

interview were conducted in person; one was done by telephone.

In terms of location, I interviewed two people in a public library; one in a private room in her church; one in his professional office; one in her home; and one by telephone. The locations were all familiar ones to the participants and confidentiality could be assured.

My interactions with participants involved some negotiation of logistics. I was travelling out of town to interview four of the participants. Due to my visual disability, I do not drive, so someone would drive me to and from each interview. This aspect of negotiation was awkward for me because of some embarrassment I have about my disability. It is possible this impacted the interviews, as these participants likely noticed I was not driving due to a disability. Since another person (the driver) was involved in the process, it occasionally made the initial greeting somewhat more complicated.

One interview was conducted entirely by telephone. This was the interview of “Sarah,” a psychologist who was willing to participate but did not want to disclose her identity. She was concerned that knowledge of her identity by me and members of my committee could imperil her license as a psychologist because of her diagnosis of bipolar disorder. Fielding’s Institutional Review Board granted permission for the interview to proceed, so long as “Sarah” signed the informed consent form as “Sarah” (her chosen pseudonym) and delivered it to my classmate who referred her. This choice of method for conducting the interview impacted my relationship with Sarah. It also provided important data about presentation of self with bipolar disorder, one of the topics in the study.

While meeting with participants, I reviewed the informed consent form with each person, after which each participant signed the form. The Informed Consent Form is in Appendix A. Each interview took about two hours and was audiotaped. I used an informal interview format in which I asked two main questions. The first was: “I am interested in hearing the story of your being diagnosed as having bipolar disorder and what that diagnosis has meant to you since then.” The second was: “I am also interested in hearing about the circumstances when you have told people something about your having a diagnosis of bipolar disorder and what that experience was like.” I had several prompting questions. The Interview Guide is in Appendix B. Since I was also interested in unconscious processes that might emerge through verbal and nonverbal communications during the interview, I paid particular attention during the interviews to evidence of disruptions in sense of self, such as “nightmares, failed acts (begun but not completed or acts with unintended consequences), and the disturbing sense of inexplicable repetition that crosses generations” (Rogers, 2006a, p. 3). I also listened for breakdowns, metaphors, and slips of the tongue.

During about the last ten minutes of each interview, I asked the participants what questions they thought I had omitted (and then I asked those questions). I asked about their experience being interviewed. Most described it as very rewarding because it provided them an opportunity to reflect in a new way upon their experience. Some participants indicated that aspects of the interview were more difficult than they had

expected. Sarah in particular found the first interview difficult. In the second interview with Sarah, she reflected on why the first one was difficult:

It was embarrassing. It was like, um, I talked to my husband and I was really upset. . . . I hadn't realized that it was going to be so awful. And then, he was like, "Why?" [laughs]. And I said, "Oh, I guess you're right. I guess—, well I kinda thought that I would be able to sort of tell her this story, and, that would be it." And he said, "Well, but you're telling her about your life, which was a bad life. So of course it's going to upset you" [laughs].

It seems that what was hard for Sarah was reliving some difficult experiences while recounting them in the interview. Sarah indicated that the second interview was easier for her. At the end of the interviews, I invited Sarah and the other participants to contact me with further feelings, reactions, or thoughts. The only participant who contacted me was one of the pilot participants from 2003 who contacted me in 2006 asking about the status of my dissertation. I explained that the results should be available in 2007.

During the debriefing I also discussed with each participant her or his preference regarding my discussing that participant's interview with the Fielding classmate who made the referral. This is because the referring people were part of my collaboration group. If a participant did not want me to discuss her or his interview with the referring person, I would have to protect that interview in any discussions with the collaboration group. All of the participants indicated they were comfortable with my discussing their interview with the referring person. The only limitation is that "Sarah" did not want anyone to listen to the audiotape, in case they might identify her voice. I usually left the tape recorder on during the process of debriefing, since I found that important information was conveyed during this process.

At the end of the interview, I asked participants for most of the demographic information listed in Appendix C. Their responses are set out in Table One. None of the participants had a clear recall of all of the information requested. For example, some could not remember specifically the year when they were first diagnosed with bipolar disorder or the names and dates of their prior mental health diagnoses. Thus, the demographic material should be viewed as a general reference, rather than exact information about each participant.

Data Analysis

Before transcribing the interviews, I created pseudonyms for the participants (except Sarah, who had chosen hers). I then transcribed the interviews in detail, trying to capture fully the participants' speech patterns, including every sigh, stutter, interruption, or slip of the tongue. The specificity of capturing participants' speech qualities was useful for some of the analyses I performed. The interview transcripts were all more than 30 single-spaced pages long; the transcript of the interview of Sarah was 60 pages long. I read each transcript multiple times in different ways. Each time I read them, I focused on different aspects of the interview. For example, I looked for themes, speech patterns, societal associations, laughter, use of words like "nuts" and "crazy," and metaphors.

Philosophical stance towards the inquiry. My analysis of the findings is premised upon a number of different and potentially competing theories of human nature. One of these is the epistemological approach of hermeneutics, as articulated by Gadamer (1976/1992) and Taylor (1989). This stance asserts that interpretation occurs in a cultural

context. From this perspective, it is not possible for the interpreter to step away from her or his perceptions and biases to develop an objective account of the facts, especially in a social science investigation that seeks to understand people's meaning-making. In fact, our individual knowledge and reaction is necessary in order to understand and interpret a phenomenon. This perspective understands that there are multiple interpretations of a phenomenon, and none of them is a "correct" one (Janesick, 2000; Schwandt, 2000).

The hermeneutic approach can be seen from two perspectives, the "hermeneutics of faith" and the "hermeneutics of suspicion" (Josselson, 2004). My approach is to dance between these two positions. One side involves representing the voices of the participants as richly as possible. I sought to bring to the reader the subjectivity of experience of being labeled with a mental disorder. This process of expressing the subjectivities and voices of those often unheard in the culture can be called the "hermeneutics of faith" or of "restoration" (Josselson, 2004). The other side is to interpret that which is out of consciousness for the participants, the "hermeneutics of suspicion" or of "demystification" (Josselson, 2004). My interpretations address affect, themes, and the meaning of societal metaphors, which are all aspects that may be outside of participants' awareness.

Yet I am also grounded in the theories of social constructionism, which posit an more ephemeral truth. These two approaches can be contrasted in this way:

"philosophical hermeneutics trusts in the potential of language (conversation, dialogue) to disclose meaning and truth," but in social constructionism, "there is no truth to the

matter of interpretation” (Schwandt, 2000, p. 198) because all meaning is created solely through relationship (Gergen, 1994). In other words, to perform a social constructionist analysis, societal and cultural beliefs, norms, ideologies and politics are requisite for interpreting any individual experience. I have tried to do that in my analysis, by bringing into the discussion cultural and societal material. *Approaches to analysis*. Qualitative research is an inductive approach that moves from narrative to understanding. With these philosophical premises in mind, I followed themes that emerged from the interview data. I found that the data could be organized into four overarching categories; these became the findings chapters. These address participants’ explanatory frameworks before the diagnosis; their initial reactions to receiving the label; how they made meaning of their experience, including questions about self and identity; and their explanatory frameworks after the diagnosis. Although this organization of the findings emerged inductively, it also happens to be a chronological presentation. The participants’ narratives were not organized in a chronological way; however, this seemed a logical way to present the findings. Yet as Cushman (1991) has pointed out, research findings are so culturally enmeshed that it is almost impossible to step outside of culture. “New” findings only reinterpret known cultural beliefs. I therefore recognize that my inductively emerging structure reflects the Western, chronological approach to the world.

In any event, for each of the chapters, I immersed myself in the interview data, finding themes addressed in one way or another by multiple participants. I present these themes in the four findings chapters. I also performed other analyses and interpretations.

For example, I interpreted some of the dreams and metaphors of participants. In the discussion chapter, I analyzed how the findings make sense in the context of American society and culture.

I also utilized in the findings some material from published memoirs of people diagnosed as having bipolar disorder. I read the memoirs to see if the experiences of these more public figures reverberated with the themes the study participants had discussed. I included some of the writers' thoughts on common themes.

These analyses essentially follow the principles of narrative inquiry from hermeneutic and social constructionist philosophical orientations. In addition to relying on diverse philosophical epistemologies, I used different analytical approaches. For example, some of the analysis is based on the ideas of Melanie Klein (1959/1985) whereas other aspects are based on principles of identity theory (e.g., Gregg, 1991). Using different philosophical and analytical approaches need not be problematic, however, because the effort to think through each approach yields increased breadth and depth of knowledge and understanding (Smith, 2007).

Data. In order to perform the various interpretations, particularly those based on the “hermeneutics of suspicion” and social constructionism, I used several layers of research material or data. The words of the participants represent one level. Other levels are the participants' style of discourse; their nonverbal communications; my reactions; my notes, journals, and memos about the interviews and the findings; my ongoing readings in professional publications as well as popular culture; the memoirs of other

people diagnosed with bipolar disorder, and the reactions and feedback from members of my committee and collaboration group. During the process of this study, I kept an ongoing journal (now over 150 pages) of readings, thoughts, reactions, ideas, interpretations, confusions, and feelings about the study, the interviews, my findings, and my interpretations. I consulted frequently with two of my collaboration colleagues, and occasionally with other colleagues. All of these ideas consolidated into the written interpretations.

Collaboration group. While preparing the proposal, I was part of a four-person collaboration group, members of which provided feedback as the initial ideas for the dissertation emerged and took form. While developing the dissertation I worked with six current Fielding students or Fielding graduates familiar with narrative research. They read and provided feedback on the interviews, my interpretations, and the writing. They shared their personal and societal associations to dreams, metaphors, and other communications of the participants.

From the social constructionist perspective, there is no correct interpretation of research data. There are shared cultural understandings, however. I found reactions to my interpretations by my committee and collaboration group colleagues very helpful in providing context and grounding. Their associations are part of the language and culture that we share with the participants, so their reactions helped round out the interpretations.

Evaluating my interpretations. A pure social constructionist perspective might claim that it is impossible for a reader to evaluate the quality of the interpretations in this

document. I do not agree. Narrative and other qualitative researchers generally do not employ terms like “validity” and “reliability” for evaluating the analysis, as those terms are grounded in the paradigm of quantitative methodologies. Elliot Mishler (2000) suggests that the term “trustworthiness” is a more appropriate term for evaluating a narrative analysis, as it is based on induction rather than deduction. He suggests that the questions a narrative researcher should ask her- or himself, and be asked, are the following:

What are the warrants for my claims? Could other investigators make a reasonable judgment of their adequacy? Would they be able to determine how my findings and interpretations were “produced” and, on that basis, decide whether they were trustworthy enough to be relied on for their own work?

(Mishler, 2000, p. 130)

In other words, the reader determines the quality of the work based on the reasonableness of the writer’s arguments, the transparency of the writer about her process, and the persuasiveness of the written argument.

Another way of thinking about evaluation is to consider that in the post-modern perspective the only “reality” that is left is a socially constructed one (Kvale, 1996). Thus, the only claims to validity would be to evaluate not the findings as valid or not but the “*quality of craftsmanship in research*” [emphasis in original] (p. 240). To do good quality work, he suggests that a researcher check the interpretations and question, and discuss the findings and theories with others. The community of discourse would include participants, members of the public, and the scholarly community.

I have tried in this chapter to provide an explicit discussion of my process of

interviewing and of thinking about the data, including the areas where I felt uncomfortable. I engaged with a small community of discourse, my committee members and collaboration group, to test my interpretations. The subsequent chapters reflect my effort to persuade the readers of the reasonableness of the interpretations.

Ethical Concerns involving Power and Vulnerability

Narrative researchers have wrestled with a myriad of ethical issues inherent in the narrative interview process. These include questions of ownership of participants' stories, power, equality, and culture (Scheper-Hughes, 2001). Narrative researchers have cautioned researchers to pay continual attention to the cultural construction of the story, the researcher's "interpretive horizon," relationship concerns, and power dynamics (Frank, 2000, p. 161). If the researcher is thoughtful about these questions, the balance of power can be improved and the researcher can provide a better cultural context for the reader (Apter, 1996; Estroff, 1981, 1995; Josselson, 2005; Lieblich, 1996).

Before conducting this study, I reflected on the power inequalities that are necessarily present in narrative interviewing. I thought they might be particularly present in a study such as this one, which investigated aspects of the experience of being labeled a "denigrated other." As a researcher, I tried to be sensitive to these considerations. I was very aware both of my own power as the researcher and my dependence on the participants. I could not have written this dissertation without six people choosing to share voluntarily a wealth of experiences from their lives, some quite difficult to discuss, without any direct benefit to themselves. I found it difficult to be as clear in discussing

these concerns with participants as I would have liked, due to time constraints and my reactions to the material (as discussed below).

My goal in this study is to analyze the findings from a variety of perspectives and to place them into some societal contexts. I anticipated that these larger analyses might not necessarily be consistent with the views of the participants. I concluded that the best way to honor both the participants' narratives and my own analytic stance would be to claim my "interpretive authority" (Chase, 1996), while also recognizing that the participants are experts on their self-narrative (Frank, 2000). I have tried to be clear in my writing to differentiate when I am presenting participants' perspectives and when I am presenting my interpretation and analyses of the findings.

Another ethical consideration with which I grappled was the extent to which I would become a "vulnerable observer" (Behar, 1996), claiming my own feelings and reactions in my relationship with my participants. According to Behar, a vulnerable observer is someone who recognizes and owns her or his own reactions and feelings to the material being presented. She noted, "writing vulnerably takes as much skill, nuance, and willingness to follow through on all of the ramifications of a complicated idea as does writing invulnerably and distantly" (Behar, 1996, p. 13). I try to honor this approach by describing my experience in doing this study in the following section.

My Experience of the Inquiry

Before engaging in this study, I had interviewed many people in qualitative interviews. However, I found these interviews both unusually exciting and unexpectedly

difficult (in a kind of bipolar experience). I was thrilled as different, interesting, and stimulating themes emerged across interviews. I was also excited by the conscious and unconscious communications around disruptions in sense of self. On the other hand, I became overwhelmed both by the content and affect. I will now try to give a sense of what felt overwhelming.

The participants were all very articulate and eloquent, as I had hoped. However, they also had fractured speech patterns. They would jump from one idea to the next; they would start one thought and interrupt themselves; they would start several thoughts at once and stutter while trying to express all of these ideas; they often would not finish a thought. Their thinking was unusually complex. This manifested in a pattern of modifying, correcting, and explaining each phrase while talking, making it difficult to follow their train of thoughts.

It appeared that all of the participants have inner lives that are rich with ideas, yet they have difficulty slowing down their thinking enough to present the ideas in an organized fashion. In order to provide a sense of this style of communications, a few long excerpts of the interviews are provided in the findings chapters. Here is one example of this process, from Kevin's interview.

The loss of meaning, the loss of, um—, and, and then on another level it just—, is and just comes—, to say OK this is, this is how it is. And I still—, if I were to look at, if you were to say to me, how much of your daily experience do you think—, your emotional life, sense of self, is related to the disorder versus related to all these other experiences, I would probably still weight it very heavily in favor, not in favor of the illness itself. That wouldn't be where I would—, although I tend to think of it a lot in those terms. I think—, because—, um, let me

just back up and finish one train of thought so I can, um,...[then started new thought]

Kevin recognized this pattern when he acknowledged that he had to finish one thought before starting another. Yet even while doing so, he did not finish that thought.

I made notes about the apparent moods and speech styles of the participants. My comments are simply impressionistic, since my role as researcher was not to make a clinical diagnosis. The participants seemed to have a range of moods and energy levels. Three of the participants talked extremely quickly and had high energy (what might be considered hypomanic). Another two participants seemed depressed and made frequent self-disparaging comments. The affect and energy of another participant appeared slowed down, but this seemed to be due to medication rather than depression. Of course other aspects of the setting could have influenced their mood states, such as anxiety about being interviewed, apprehension about sharing painful aspects of their history, and concerns about their privacy.

Whether speaking quickly or slowly, all of the participants had a great deal to say, rarely leaving openings for me to comment. I felt a little dizzy trying to follow the participants' ideas, as the participants flew or galloped (both metaphors felt appropriate) through the interviews. I marveled at and was touched by the participants' narratives. Yet their speech processes left me feeling that there was little space for me to think about what they were saying, take it in fully, and respond thoughtfully.

I also felt overwhelmed by the narratives of trauma and pain. As discussed in the findings chapters, all of the participants shared stories of difficult childhoods, some with

traumatic losses, and also some difficult adult experiences. Only one participant cried during the interview. I felt exhausted after each interview and wondered if I was “taking on” or “taking in” the painful affect that participants were not expressing, in a kind of Kleinian projective identification. While typing up the transcripts of the interviews, I once again felt exhausted and overwhelmed by the power of the narratives and the intense affect implicit in many of them.

The participants and I had set time boundaries for each interview. It was not easy for me to manage these boundaries, in part because of the richness of the participants’ narratives. I wanted to allow a stream of consciousness narrative, while also covering certain topics. Therefore, the interviews started out more open-ended; as the boundary approached, I interrupted the narrative flow to ask specific questions. The transition felt awkward to me, as did the greeting and parting process. Several of the participants acknowledged the difficulty in limiting their narratives, commenting that this is one of the stereotypes about people with bipolar disorder (saying a lot, with many words).

Relational Considerations

Kenneth Gergen (1994), when exploring the meaning of interaction from a social constructionist perspective, discussed how there is no meaning without relationship (p. 264). Although we may make utterances, it is only the relationship and the context that give meaning to these sounds or movements. He suggested that relationship is a kind of honor we grant one to another. “To communicate is thus to be granted the privilege of meaning by others” (Gergen, 1994, p. 265). He questioned the nature of experience as

something we experience “inside,” rather than something created through discourse. From this perspective, the narrative that emerges in the narrative interview is something new and, in a sense, is created out of the relationship.

I feel transformed by my interactions with the participants, both from the short time we spent in person together and from the many months I have lived with their thoughts and experiences while writing this dissertation. I experienced the participants as being in relationship with me or with projections about me. I will describe aspects of interactions with Darlene and Sarah, as these felt the most compelling to me. It is interesting that these are the two participants whose mood seemed most depressed and whose affect seemed sad and self-critical.

Darlene first explained how she had become very nervous before leaving for the interview. She made sense of her anxiety by noting that she had become very depressed a few weeks earlier and was concerned that her depression was related to my telephone call to discuss the possibility of being interviewed. She said,

It may be three weeks or something. That wa—, I had that after I talked to you. And so, before I talked. When I talked to you, I had been like happy-go-lucky for a year almost. And then that incident happened and it has pulled me down this month. I might have been more negative today than usual. [laughs]. But having had that experience coupled three weeks ago made me more apprehensive about today.

Darlene’s concern was that our initial discussion of her possible participation in the study might have triggered her subsequent depression. She believes that is why she became anxious right before starting the interview. This suggests that just thinking about being interviewed about her bipolar disorder could bring about a depressive episode.

During the interview, Darlene shared some assumptions about me. When she was discussing disclosure during the interview, she indicated she did not have concerns about disclosure, “and especially with somebody like you who knows everything there is to know about it.” Her assumption was that I was an “expert” on bipolar disorder and would not carry stereotypes of my own. At another point, she emphasized how she wishes she were “normal” again, like in being able to stay out late at night: “It was normal. I would love to be—. That would be so great. Yeah. ... I was, you know, like normal people. Like YOU. You just, you know, you just stay awake.” In this case her assumption was that I do not have a diagnosis of bipolar disorder and can stay out late at night, like “normal” people. It probably would have been best for me to recognize the projection and see how it played out in the rest of the interview. However, I felt the need to respond, in part from a desire to adjust the balance of power in this relationship. So I responded to Darlene’s last comment with, “I take a lot of pills. I’m not that normal.”

With Sarah I was also acutely aware of the nature of my relationship with her. As I noted above, she was very concerned about disclosing her identity to me. During the interview, she explained in detail her concerns that if I or a committee member knew her name, she might lose her license. She discussed questions she has had to answer to become a therapy “provider.” The insurance company will ask “whether you have any kind of physical or mental condition that would compromise your ability to do therapy. And they ask you if you’re taking any medications.” Sarah gave a hypothetical about this question:

And I think that—. OK, here's another hypothetical. What if one day you got a job on an insurance board. Then you'd be put in a whole different position. You would be st—, you would be stuck, and you knew my name. And suddenly you had to evaluate an application or something, and I had answered that question [laughs] that I told you about. And you'd be like, ah, wait a minute now [laughs].

For Sarah in this hypothetical, I, as a future psychologist, would be “stuck” and have to deny her application, simply because I knew that she has a diagnosis of bipolar disorder and experiences fluctuating moods.

In both cases, the views of me as expressed by the participants are projections about a “normal other,” someone who is an expert and who would see bipolar disorder as so serious as to disallow someone provider status. These feel like important aspects of the findings, and are part of how participants often experience themselves as the “denigrated other” (Green & Skolnick, 2002). It was interesting for me that the projections were of me as an “expert” and as “normal,” labels with which I am not particularly comfortable.

The research findings and analysis were richer from the attention paid to the nature of my interactions with the participants. The relational perspective impacted both my approach to the interviews and the analysis of the data.

CHAPTER THREE

INTRODUCTION TO THE FINDINGS AND EXPLANATORY FRAMEWORK BEFORE THE BIPOLAR DIAGNOSIS

And Something's Odd— Within—
That person that I was—
And this One— do not feel the same—
Could it be Madness?— This?
(Dickinson, 1862/1960)

There are four findings chapters. This first chapter introduces the participants. I then discuss the explanations that the participants and their families employed to organize and make sense of unsettling experiences and behaviors before participants were diagnosed with bipolar disorder. Since all of the participants were diagnosed in adulthood, they had names and explanations for feelings and behaviors that later might be attributed to bipolar disorder. The explanations used by participants are specific to the particular individuals and their families, but they are also culturally derived and defined. Both aspects are addressed below.

It is hoped that the reader can enter into the phenomenological experience of the participants and feel that the questions with which they are grappling are part of the human condition. Perhaps readers can identify with the verse from the Emily Dickinson poem at the beginning of this chapter. Otherwise, it will be easy to designate the participants and their experience as “other,” and view those experiences as pertaining only to people who receive a diagnosis of bipolar disorder, rather than recognizing them as aspects of human existence that we may all approach from time to time.

All six participants were diagnosed with bipolar disorder as adults, and some very recently, so they all had a lifetime to make sense of their experiences, feelings, and understandings of their family members and of their own lives, without benefit of the bipolar label.

Demographics

This section presents the “external” characteristics of the six participants. I must first note a few caveats. In order to protect the participants’ confidentiality, I intentionally changed or obscured some of the details of their lives. Further, although I use the present tense to describe the participants, the information is current as of the time of the interviews, which occurred a year or more earlier. Also, the adjectives I use to describe the participants, like “thoughtful” or “lively” are obviously my own impressions or projections. Some of these demographic categories are set out in Table One.

Rose is a lively and energetic woman in her mid-50’s. She married when young and now has adult children and grandchildren. Rose has held a number of high-level jobs, but is not working at present, in part due to her bipolar disorder diagnosis. Her husband has held high-level government jobs for many years. Ten years before being interviewed, Rose was diagnosed with clinical depression after a possible suicide attempt. A year before the interview, a psychiatrist changed her diagnosis to bipolar disorder.

TABLE ONE

BASIC DEMOGRAPHIC INFORMATION ABOUT PARTICIPANTS

NAME	AGE WHEN INTERVIEWED	DATE OF BIPOLAR DISORDER DIAGNOSIS	PREVIOUS DIAGNOSES	AGE WHEN RECEIVED PREVIOUS DIAGNOSIS (IF RECALLED)	ETHNIC IDENTITY	OCCUPATION
Darlene	48	40	Anxiety and depression, Borderline Personality Disorder, Co-dependency	Anxiety and depression, about 34	European American identity (ethnicity identified as Caucasian and half-Arabic)	Nurse-practitioner (not currently working, mostly due to bipolar disorder diagnosis)
Jodi	45	40	Depression	38	European American	Physician - internist
Kevin	39	30 or 31	Depression	Could not recall age	European American	Clinical psychologist
Natalie	46	44	Alcoholism	Since childhood; no formal diagnosis in adulthood	European American (ethnicity identified as German, Scotch-Irish, and 1/64 African American)	Government worker (currently unemployed)

Rose	55	54	Depression	44 or 45	European American (ethnicity identified as Irish-Welsh)	Manager and administrator, government and private sector (currently not working, mostly due to bipolar disorder diagnosis)
Sarah	40	25 or 26	Depression	15	European American	Clinical psychologist

Natalie is a woman in her mid-40's who projects a strong, confident presence. She has held high-level government jobs, but left her last job without notice. At that time she was experiencing depression and exhaustion that she believes were adverse reactions to a bipolar disorder medication; as a result, she felt unable to continue in the job. She is looking for a new government job, but is worried that the way she left her last job might make it more difficult to get hired again.

Sarah is an articulate and expressive 40-year-old clinical psychologist. She works as a therapist in a busy suburban practice. Sarah recounted that she had been depressed and angry as a teenager and attempted suicide at age 15, after which she received therapy for depression. When she was in her mid-20's, she received a formal diagnosis of bipolar

disorder, although she had self-diagnosed a few years earlier. She is married and does not have children.

Jodi is a physician in her mid-40's, who has been working as an internist at a community health center. She appears as highly intelligent and sensitive. She is divorced and has three children. When Jodi was in her late 30's, she had a period of depression, which she attributed to stress. Six months later she attempted suicide. Shortly after that, she experienced a number of significant life changes, all occurring during a six-month period. These included getting divorced and being diagnosed as having bipolar disorder. She is now living alone and dating a woman.

Kevin is a thoughtful and intellectual man in his late 30's. He is a clinical psychologist about to start a full-time private practice after several years of part-time private practice and part-time government work. He had been diagnosed with depression in his 20's and took medication for depression. About seven or eight years ago, Kevin was diagnosed with bipolar disorder. When interviewed, Kevin was dating a woman whom he subsequently married. Kevin is the only male participant.

Darlene is married, in her late 40's, with college-age children. Her presentation is both competent and vulnerable. She worked as a nurse-practitioner in a large, well-respected medical center for 20 years. She was diagnosed as having an anxiety disorder in her early 30's and received other mental health diagnoses over time. About ten years ago she was diagnosed as having bipolar disorder. She has not worked since getting the

bipolar diagnosis, mainly because of her concerns about her symptoms of bipolar disorder.

This is a group of educated, professionally successful people. Two are clinical psychologists, one is an internist, one is a nurse-practitioner, and two held responsible government or nonprofit business positions. Three were not working when interviewed. Two of them had chosen not to work due to the bipolar disorder diagnosis. The third had left her last job for reasons associated with her bipolar disorder medications. The other three (two psychologists and an internist) were both working in their professions.

In terms of demographics, five participants were women; one was a man. Four are married; one married after the interview was conducted; one woman is divorced; she is now dating another woman. At the time of the interviews, four of the participants were in their 40's, one was in her 50's (Rose), and one in his late 30's (Kevin). The participants identified as European American. Some identified another ethnic heritage in addition. Darlene indicated her ethnic background is half-Arabic; Natalie reported having one African American ancestor.

All of the participants were diagnosed as adults with bipolar disorder, ranging from age 25 or 26 to 54. They had also received other diagnoses during their lives, such as depression and borderline personality disorder. All were on one or more psychiatric medications for symptoms of bipolar disorder. Medications included Depakote, Risperidol, and Effexor. Of the six participants, one (Darlene) had been hospitalized three times for symptoms associated with bipolar disorder; one (Rose) had a brief

hospitalization after a suicide attempt; and two others were taken to the emergency room after suicide attempts (Jodi and Sarah).

This is a purposive sample, not a representative one. There is little demographic diversity among the participants: all identify as European American; all are middle-class and professionally successful. There is limited gender and sexual orientation diversity, as five of the six are women and five of the six are heterosexual (one identifies as a lesbian). It is also not a representative sample in terms of people with bipolar disorder. In the language of psychiatric treatment, all of the participants are considered “high functioning.”

It is significant to note the similarities among the participants for purposes of the analyses. Whatever understandings about the social construction of bipolar disorder that emerge from this study reflect the experience of a small number of middle-class, educated people, mostly women, who identify as European Americans. These participants are minorities in American culture in one way, which is that they all have a diagnosis of a mental illness, namely, bipolar disorder.

Childhood Narratives

In this section I introduce the participants in more detail and describe their explanations for troubling experiences.

Natalie

Natalie is in her mid-40's. She was the 4th of 5 children. When she was four or five, her nine-month old brother died:

I had a nine-month old baby brother who suffocated with a, um, cleaners' bag when he was sleeping. And my dad blamed my mom for it. And my mom blamed my mom for it. ... Nobody was to blame but you know that thing happens. You know, blame happens. It's not rational but it happens. And, uh, she didn't find any need to live after that. ... I was four. And I remember. I saw him, all blue and, um, icky

Natalie indicates that “nobody was to blame” but her father assigned blame, which her mother accepted.

Natalie believes that her mother drank herself to death during the next five years.

Natalie's mother died when Natalie was 10. As her mother was dying, Natalie said:

I felt sorry for her. ... I felt that she needed me. I just felt sorry for her. I wanted her to be happy and she go—. I couldn't make her happy. ... Every kid wants to make their parents happy. I think, I think I knew that there was no way she was gonna be happy. And I think I kinda was angry that I wasn't enough to make her happy. Being the next y—, the youngest now. You know, that I wasn't “good enough” to keep her alive.

Neither of Natalie's parents seemed to be very involved in her life during those first ten years and no one took over the parenting role after her mother's death. Instead, Natalie's older sisters introduced her to alcohol and drugs when she was 12:

Well, my mom died when I was 10. And as soon as she died, my Dad started dating. So us kids were basically non-supervised. I had three older siblings. And they just thought it would be cool if their little sister ... [got] drunk and got high. And when I got drunk and high, I said, “Yeah, it is cool, isn't it.” And then I just never stopped. It was like as soon as I started it wasn't one of those things that I dabbled with. I went wholeheartedly. And I could—. In 6th grade, I was playing chess for shots. ... Um ... I did LSD in my graduation ... from high school. I was unable to go to college because of my drinking. Um, I chose not to have children because of my drinking. ... I, I would be considered quote unquote a functional alcoholic

Natalie drank from age 12 to age 44, when she chose to become sober. She received the diagnosis of bipolar disorder immediately after “detox and rehab” from alcohol. Her main explanation of herself for all those years was as an alcoholic:

Didn't really into—, know life until I quit drinking. It's like I was driving around, let's say, with—, everything was in black and white. And then I quit drinking and all of a sudden colors are here, you know. And, and I can feel things. And I could. Cause you know I was so dead, I didn't care about anything. Myself included. You know. Could have cared less. Um. ...

For most of Natalie's adulthood, she felt emotionally “dead” and “didn't care about anything,” in part because of being an alcoholic. Yet it is interesting to note that Natalie's alcoholism started shortly after she experienced two real deaths.

Natalie does not have much recollection of how she felt as a child or ever, until she became sober: When asked about her experience of emotional pain when she was 12, Natalie said:

I don't know because I was numb. I don't know. And I—, and one of the problems I'm experiencing now is I don't—, I have lots of huge gaps in my memory. Huge, huge gaps. Because I'm working with my therapist on doing a, you know, kind of personal chronology, to try and fill in some of those gaps. Where I was. Because it all—. Alcohol abuse counselors say that you're emotionally at the age where you started drinking. So I'm basically 12.

What was clear to Natalie, from age 10 on, is that it was not acceptable to feel grief about the deaths or to talk about it:

It was kinda like, mom died, we moved, and ... for some reason everybody went their separate ways ... in the family. I mean of course we were all living under the same house, but ... there was no communication. In fact, I, one of my s—, when I went out to see my sister in [different city], we were talking about this. ... I said, “Was there some unwritten code that said we weren't gonna talk about all of this?” She says, “No, but we didn't, did we.” And I said, “No, we sure didn't.”

Until receiving the diagnosis of bipolar disorder, Natalie felt that something was wrong, but the only way to label it was that she was an alcoholic:

I've always suspected there's something different about me. Different mentally. That I don't process the same way people. And all alcoholics feel that way. They never fit in. That's one of the reasons they drink. ... It's normally the beginning. It's normally they don't fit in and then they drink and then they get the confidence to fit in. ... If I drank, I talked. If I drank, I'd ea—, I'd get along with people. If I drank, I'd—, hid all my insecurities.

And then I drank and lost friends. ... Cause I could outdrink them. And they were no fun anymore. So I could keep moving with people who drank as much as I did. Then it got ugly [laughs]. ... Well, other people who could drink as much as I did were pretty nasty people. Most alcoholics aren't happy people. Only a few, only a few happy drunks.

Natalie was aware during all those years that she was using drinking to avoid experiencing her feelings:

But I mean emotionally I wasn't feeling anything. And that was absolutely deliberate. ...

Interviewer: Can you think now what kinds of affect, what kinds of feeling, what kinds of emotional life you were avoiding?

... [long pause, then deep sigh]. I guess I really was avoiding the feeling that I really was abandoned. That I really was lonely. That I really didn't fit in. That I really was average. That I really was sad. [said with disgust]. ... I meant sad in kinda like the sad sack kind of personality. Oh, "woe is me" kind of thing. You know, I'm a believer that you're only as woe as you let yourself be. You know, you can take a lot of woe away, just by trying to change your mental image of things. I really believe that. You can really have some serious setbacks. You can have some serious depression. And you can have some serious downfalls. But you can also still have some outlook on life that is positive.

On the one hand Natalie is recognizing that she became an alcoholic in a deliberate effort to be numb and avoid feeling abandoned, lonely, and sad. Yet as soon as she says that, she condemns sadness and launches into a kind of positive thinking affirmation.

In the recent meeting with her sister, Natalie was able to fill in some of the blanks in her memory:

I didn't remember my Dad for twelve years. Um, still don't, but at least she told me what was going on in the family. ... That he was dating. And that he was just working and taking care of mom, I guess. ... But you know, she said, "You'd had no reason to know him. I mean, you know, he worked and came home and drank. And you know it wasn't like he said, 'Come over and sit on my knee,' or anything like that." So she goes, "You'd have no interaction with him." ... It was just, you know, didn't have a memory, you know. There wasn't anything to remember. And that felt good.

And it felt good that she affirmed many memories I DID have. That they were not made up in my mind. ... Oh, about my seeing my baby brother dead. And stuff like that. And things my mom did, and things like that. Because, I had been lied to by my Dad most of my life about things. Like, you know, my baby brother died of crib death. And my mother died of hepatitis. And, you know—, crap. You know. ... He basically told me, "To hell with you" on his deathbed. So I said, "Okaayyy. See you later, Dad." He did. Those were his words.

Natalie sees how her memory blanks might have served her, in hiding from her conscious mind how much she was abandoned by both of her parents.

Natalie's Explanations

Natalie's family avoided talking about any painful experiences and mourning the deaths of their baby brother and mother. But more than that, Natalie's father created new – arguably less painful – explanations of what happened (crib death and hepatitis). The message seemed to be that mourning was unacceptable, lies were better, and, if the lies could not be sustained, the numbing of feelings through alcohol was appropriate. There was no room for explanations for inner pain or unusual behavior, since inner life was hidden by alcohol.

Natalie joined in the family approach by early alcohol use and noted how she does not remember feelings during the years of alcohol use. Yet she also remembers experiencing happiness during this period:

I just felt good. You know, I just felt good. I was happy. ... I thought that was my life.... I didn't think there was anything wrong with it. I was probably excessively manic all of my life, if you want to use the terms that they list in the ... "this is what bipolar is." I've been an extremely happy person; happy most of my life. An extremely productive person. A goal-oriented person. A person who does not require a lot of sleep. Um ... uh ... an elated person. Someone who gets joy out of small things. Um. And I thought all of this was good. I didn't see any danger in it.

For Natalie, before the bipolar diagnosis, what was wrong was numbed out with periods of lost time and alcoholism. There was no language to explain difficulties because they were not addressed and were sent underground. But she claims she is satisfied that she was able to maintain happiness and productivity. (Unfortunately she felt her happiness was later taken away from her by the bipolar diagnosis, as discussed in subsequent chapters.)

Kevin

Kevin, the only male participant, is one of two clinical psychologists among the participants. He is in his late 30's. He referred several times to being shamed and humiliated during his childhood.

You know. So, um, yeah. I think the, and I think that's also related to really early stuff about, am I going to believe that I'm different from, the criticized and humiliated kid who's sort of ... um. ... Am I going to think that I'm more than that? Am I gonna, um, buck the parental introjects? Am I gonna, am I gonna be different?

He was usually shamed if he expressed too much excitement about something:

Interviewer: And, part of the reason I asked you earlier about what being normal is the way you described it is not—. It doesn't sound like much fun. Your version of normal is sort of flat.

It is. Well, it's What it is, is incredibly narrow. And it's a complete projection of my own experience growing up. I mean it's that the, that the range of, how far I had to stray away from the line in order to get criticized or humiliated or, uh, it was so small, that, I, I think, yes, I've been hypervigilant about my own behavior, um, and even feelings. Don't let anyone know that you care about this or you'll get, uh, it'll be the source of teasing and humiliation. Don't let anybody know you're angry about that or, you know. ...

He also alluded a few times to having a trauma history with problematic attachments. For example:

You know that, it's just fair shorthand to say that trauma was prominently featured in my background. So the stability of self, I'd say that, sort of issues of attachment and trust and hypervigilance, just in general, uh, around safety, around, um, yeah, that, that ... Those are, are issues that would be there regardless.

The trauma in Kevin's life was that he, like Natalie, lost a sibling when he was a child. He only mentions this in passing, towards the end of the interview, mainly in an effort to explain why Kevin believes his father criticized him whenever Kevin expressed any exuberance:

Yeah, the painful, dysphoric stuff is much more ... easier for me to ... identify with. It's really interesting. ... I think part of that, if I think about it a little bit, part of that goes back to ... the ways in which my exuberance, or the expansiveness when I was little, ... was ... squashed. That, yeah, it became dangerous to me to be too ... effusive, or ...

I can still remember ... I was with a friend in his car, we were driving around, and, and he had this five-speed, which is something I had never seen before. We were driving. And I was describing this to, it was my dad and a couple of other people And I was really getting excited about this, and, "Yeah, then he put it in fifth, and we just roared off ..." Well, my point was, we were zooming, you know, we were ...

But no, again, it was still “Yeah, you kinda got carried away there and you were really wrong with your [exuberance]. And you know, of course, that’s what, you get excited and you, you know ...” But it, it was, there was a way that, I think that it was very threatening to my dad to not be kinda hypervigilant and in control and—, very dangerous.

And, you know, I mean. Part of that was growing up. Part of that was, uh, we had a car accident when I was 18 months old and my 6-month-old brother was killed and both my parents, and—, went through the windshield and was, sort of, before lap/harness belts. And mom was holding the baby. And so, a—, the world can be a dangerous place, you know. And, he really learned that lesson in spades, so whatever lapse of control he had exerted over—, I’m sure that fit with his own dynamic to make him even more, um ... um ... afraid and anxious as he then dealt with me. ... There’s being happy or expansive has always been an act of rebellion, in a way. ...

Kevin noted his lifelong hypervigilance about his moods, even before he had the bipolar label that could explain them. He generally concluded that his watchfulness to avoid expansiveness was in response to his father’s criticism of his exuberance. Kevin ties this to his father’s reaction to his own loss of control at the time of the accident, which resulted in a child’s death.

Kevin believes that he could not develop an “easy sense of self,” since the need to control his affect seemed to be the main lesson he learned from his father.

But I’ve always been aware of ... sort of struggling to maintain a sort of easy sense of self, uh, given how I feel. I just didn’t have a framework in which to hang it. Um, there was always this internal note-taking or dialoguing.

When Kevin started college, he first learned how different his childhood was from that of his classmates:

Like the first weekend at college, parents weekend. And it just, I, it was like I was on another planet. To see these kids who I knew and thought were like me, walking around happy with their parents. And the parents came. Why would the

parents come? You know, just come to the college? You know, what—, why would they do that? And why would these kids be having a good time. I mean, they enjoy each other's company, but, like, you know [laughs]. It was like I was a, a Martian or something. Wow. I couldn't imagine my parents coming to my college for anything or—, you know. Um, and I could imagine even less, you know, having ... hav—, enjoying it, I mean. So it just gives you a little bit of a background. I mean I was up against a lot, I feel, trying to get myself ... together. And I think that I sort of carry that with me

That college moment provided Kevin the opportunity to see that his family life was significantly different from those of other people, something he has spent the rest of his life trying to understand.

Kevin's Explanations

Kevin came to label some of his experience as depression. Starting in his 20's, Kevin saw a psychiatrist for symptoms that were considered to be depression. He had "periods of low energy and withdrawal." Another way Kevin made sense of his experience was in feeling like a Martian in comparison to his fellow college students. Later on, he used tools from the language of psychology to make sense of his experience. He referred to "boundary issues" and "introjects."

Yet Kevin is still wrestling with the question of how much affect is acceptable and when to control exuberance. For example, he recounted a time during his psychology internship when he felt criticized by two internship supervisors for being too "exuberant":

... And they were appalled that I would greet them, with a patient there. You know, that sort of, you know, that just was—. This clearly worried [them] about the lack of boundaries. I mean that's abhorrent. People are famous for running over boundaries and so, and. and—. ... Again, boundaries, boy I tell you. I, I never, I never

You know, I've heard of people, kids ... um, having told stories about having gone into their parents' bedroom, and climbed into bed with them. ARE YOU KIDDING? I would NEVER cross that threshold. I would NEVER knock on that door if it was closed. I would never, talk about My heart would just, UGH. I mean, no way! I mean, it felt—. *Boundaries felt like life and death to me, growing up.* And I, I still have a really hard time, um, asking people for things, sometimes. What does that say? Yeah, just, the Oliver syndrome, you know. ... I want more.

For Kevin, controlling expressions of exuberance and maintaining boundaries have been ongoing themes. He understands these themes emerged out of the family tragedy. The only label he gave for his experience is of depression, except for the metaphors of feeling like a Martian or like Oliver. Kevin is still not certain whether his exuberance is really a problem or if his father's vigilance around Kevin's exuberance was simply his father's reaction to his own loss of control in the accident.

Rose

Rose is now in her mid-50's. She grew up in a rural area, and was the third of six children. Rose provided very vivid stories of what it was like growing up in her family. Her narratives were a series of seemingly unrelated events from her life. Her speech style was so rapid that she often did not slow down enough to explain the meaning of the stories and their connection to one another.

Rose spoke at length about her mother:

She was a, um—, my mother was a thief and a liar and a cheat. ... My mother was a shoplifter. Back in the 60's, it was tag switching. ... My mother would—, we used ta, we used to think it was funny, but embarrassing. My mother was a tag switcher. She'd pick up a, a shirt my brother needed for church or something —, we-, we were, by the front-row-seated-Catholics —, and she would take and switch tags and put the pin back in. ...

She described how her mother's moods would fluctuate between the liveliness of the "thief, liar, and cheat" approach to a severe depression, "My mother was very, very depressed all the time. Um, if she wasn't one way, she was another."

Rose described how her mother would go on borrowing, stealing, and spending sprees. For example, she would forge Rose's father's name on loan documents. During these spending sprees, Rose's mother would promise special gifts for the children. Once Rose questioned her mother about when she would get the special gift and her mother yelled at her and disappeared into her room.. Rose noted that her mother would often disappear into her room, leaving Rose to take care of the younger children.

Rose recounted other embarrassing events involving her mother, like the "black bra" incident:

Oh, my mother bought black bras, I'll never forget this. And my mother was a body powder lady. ... Well, she did that and then put this black bra on. She tried to return, to return a bra that was covered with powder. Oh my God! And I'm dying. Cause it's a really nice ladies store. And I'm dying, right. Ohhhh.

She used to try—, you know there's just certain things that just stick out in your mind. You know, I mean she was—, she was all chou chou chou [using hand motion at her ear to indicate crazy], you know, and I never gave it a name except ... mom was wacked.²

² This particular spelling of "wacked" is used throughout this dissertation because the term participants use seems closer to "wacky" than to the idiom "whacked out." The term "wacky" is defined as meaning "odd or irrational; crazy" (Dictionary.com Unabridged, April 27, 2007a). The word "whack" is defined as meaning "1. To strike (someone or something) with a sharp blow; slap. *Slang* To kill deliberately; murder." The term "whacked" appears in the dictionary only as the idiom "whacked out," meaning, "1. Exhausted; 2. Crazy; 3. Under the influence of a mind-altering drug" (Dictionary.com Unabridged, April 27, 2007b).

In other stories, Rose described how her mother would physically abuse her sister and one of her brothers. A turning point in the family was when Rose was 10: her 17-year old brother died of cancer. Her mother's problems increased after her brother died:

And even after my brother died my mother ... was ... she wasn't right. She was always sleeping. They doped her up. The pills they had back then were just horrible. You know, they'd either wound you, or, you know, up to get up in the morning and get down at night. She was always sleeping.

The "wackiness" of Rose's mother was a central part of Rose's experience in childhood. But she also discussed her own concerns. For example, early in the interview, Rose explained that she has had four brothers who have died:

I had a brother die at 17, i—, in the early 1960's. He died at 17 of bone cancer.... Then I had a brother die of lupus, which men don't usually die of lupus. He died when he was 39. ... And then I had a brother four years ago who got killed by a drunk driver. And it was my fourth brother now coming up. He was 58. He was coming up with cancer. ... So um, you know, so I've been through. ... I've got a target on my head. You know, all my brothers are dying.

Rose became pregnant at 16 and married her high school sweetheart. This happened while her mother was in a mental institution. Rose said, "Um, I backed out of my family ... because of the alcohol, um, and the craziness." She described how her whole family had problems:

My mother was, my whole family was severe alcoholics. Severe alcoholics. Um. My mother died about five months after my brother who was killed by the drunk driver. ... She died of a broken heart. She loved her boys. Except the one, except the one that was dying of cancer. She didn't like him. ... She died of a broken heart.

Rose described most of her siblings as both severe alcoholics and as "crazy."

Stories about the many tragedies in Rose's life poured out during the interview. At first it was difficult to figure out why Rose recounted all these stories from childhood in response to the question about how she dealt with receiving the label of bipolar disorder. I came to realize that Rose is "filled up" with the difficult experiences of her childhood and her life and these experiences are Rose's answer to the research question.

Rose also talked about her own behavior as an adult before the bipolar diagnosis. She remembered how hard holidays were for her:

When my kids were growing up, I would try to make it the Waltons ... because I didn't have that when I was a kid. ... Um, so I tried to make it the Waltons. What did Mrs. Walton do? She'd make special stuff. She'd get presents that meant something. I'd do all the reading to make sure that I'm me—, memorable. A tree with memories on it. And memory gifts. And books that I wanted them to read. And, oh, I worked so hard every Christmas. By Christmas ... du—, I had planned a beautiful dinner and invited relatives that, my sister over. ...

I wouldn't come out of my room. ... I'd pick a fight. I'd say "Why did you do that? Ya dad a dad a. Or get [in] a fight with my husband. And go in the bedroom. And I'd forgotten I did that 'til I was going through memorabilia And I was going through my boys' memory boxes. And um, I found notes that they had slid under the door. "It's Christmas, Mom. We love you. Please come out. We want to have a nice Christmas. Dad and I are cooking dinner." And I read that and I went, my God, I used to do that. I used to do that. Big holidays. You know, Easter, Christmas.

In her room, Rose would be "crying, sleeping. Oh, sleeping. I was, I was an award-winning sleeper." She described how she almost slept through a life-threatening emergency until her pre-school-aged son woke her up. During these periods when she was sleeping a lot, this is what she was aware of feeling:

I had thought, uh, my life was—, zero. My life was nothing. I didn't work. I had —, I used to think—, I used to think the depression was because I had no value and I never called it value. I just said a feeling of worthlessness. Because I didn't

have a job and making money. And when I was staying home with kids I had felt that I had no value. So that of course wasn't enough to get up for in the morning. You know, I'd sleep my whole life away. And then I'd get up and drink ... Coke. I'd have, I'd have my husband buy cases of, 16-ounce bottles of Coke. ... I just downed Coke all day and then by, but by 11 o'clock, I was sound asleep.

About ten years before the interview, Rose had a difficult period, which she called "going around the bend." She initially attributed it to menopause. Afterwards, when she was hospitalized overnight in a mental ward, she was given a diagnosis of depression. The incident that resulted in the hospitalization was that she "pulled my car in front of a, of a tractor trailer and smashed up my brand new Jeep Grand Cherokee." Although she was not aware of being suicidal when she drove into the oncoming truck, her doctor hospitalized her in a mental institution. This was the only time she was hospitalized for mental health symptoms, even though she had also made a suicide attempt as an adolescent.

Rose's Explanations

Rose, and the world in which she lived, had various ways of making sense of unusual behaviors or painful inner experiences. Rose called her mother and many of her siblings crazy, "nuts," or "wacked," and some of Rose's siblings called her "wacked." She also refers to some family members as alcoholics, a term as prevalent then as today.

There are also some specific phrases and metaphors in Rose's lexicon to capture particular inner experiences or behaviors. For example, Rose would describe her more energetic experience by phrases like "my rubber band was wound" or "you were bouncing off the walls." She frequently used the words "wound," as in "wound up": "Oh

I called it ‘being excitable.’ mom was excitable. Rose gets excitable. ... When something excites me, I really get wound. I mean—, we used the word ‘wound,’ ‘excitable.’”

She described difficult times as, “I was depressed and worn out.” She also had words for changing moods. She noted that on medication now:

I don’t get sad so I can’t get out of the well. And I don’t get so happy .. that I frazzle myself into a million pieces like I used to at Christmas. ... I have such, so many years of history. Of plinging or, or, or hitting the cellar. When I couldn’t climb out of the well. You know. I call it being in the well.

She noted that in her childhood world, many problematic behaviors of women were attributed to menopause. Much of her mother’s peculiar behavior was said to be caused by menopause. Rose even initially thought her suicide attempt was due to her experiencing menopause. She explained why:

I think too often menopause is blamed for this. Really. My mother. They blamed it on menopause. My mother’s best friend, when I was growing up ... committed suicide ... hung herself. Undertaker’s wife. Hung herself in the undertaker parlor. ... She used to come up and cry to my mother. And my mother didn’t know what else to do but give her a beer. My mother used to get her drunk. ... Um. That’s what women went through back in my small town. In the 50’s and 60’s. ... That’s what you did. You hid your dirty laundry. Mental illness was NOT something you talked about. And they always said, “She’s going through menopause” [whispered]. Any woman, from thirty to sixty, who did anything strange, was going through menopause [whispered]. ... If you just get through it, you’ll be all right. No matter what was wrong.

They attributed it all to menopause. ... That was something I think their husbands could relate to. Cause maybe their mothers had gone through it. Change was a physical—. They could actually understand a physical change, you know, but this, this chemical in the brain [whispered], Nnnn, no. You’re either mentally ill or you’re retarded. You’re retarded or you’re nuts [whispered].

As the next chapter will discuss, even though Rose referred to herself and many family members as “wacked” and “crazy,” both in jest and not, she rarely thought

seriously about the ramifications of being seen or labeled as “crazy” until she received the diagnosis of bipolar disorder.

Jodi

Jodi is an internist in her mid-40’s. Like the other participants, Jodi described some difficult experiences in childhood. When asked about her childhood, Jodi explained that although she was diagnosed with bipolar disorder in her 30’s, she was a “moody” child. “It’s not like this came and reared its ugly head in my thirties. Um, I would have described myself, if you had asked me, as a moody child. Did I know what that meant? Did I know why I had that? No. Absolutely not. Um, I had no clue. But I can remember that I was always super sensitive to criticism and cried very easily. That I was very shy. That I was—; I, I felt depressed and sad a lot of the time.”

Jodi was the 5th of 7 children plus a younger half-sister. Her father had a diagnosis of bipolar disorder and her parents divorced when she was ten. Her father was “a very absent parent.” As a child, Jodi was “moody,” “withdrawn,” “shy,” and “I felt very much like ... nobody liked me”

I didn’t have an easy time making friends, at all. I felt very separated from the, um, the rest of the children. I just couldn’t seem to easily ... fit myself into the s—, the social life. ... It was like going into a social situation like school and I just wasn—, didn’t—, wasn’t well liked. And I don’t know why.

Like Natalie, Jodi has blanks in her memory of adolescence. She “lost” a year when she was 15 or 16.

And then I can remember being um, in my teens ... and ... um like actually like losing like a whole year of my high school time, where I don’t like, literally, don’t remember anything. ... I know I went to school. And I did very well in school. I

was a super achiever in school. But I didn't have like a social life. I didn't do anything. I, I don't remember it. It's like the whole year was gone.

For the rest of high school, Jodi recalls finally finding a group where she could belong, but it was in the group of other people who did not belong anywhere else.

The only place that I got into was that group of intellectual geeks. Which is not really where I wanted to be. But it was the place that I fit, as closely as I could. ... They're only basically misfits because they're smart, you know. But they don't have a lot of social skills, most of them at all [laughs]. And so, they kind of bond together on the basis of being ostracized by the other kids. And that's it.

As an adolescent, Jodi knew she was attracted to women, but she chose a heterosexual lifestyle in order to feel "normal."

I really did not want to do anything that would make me not normal. ... I spent ALL of my childhood and my, you know, my teen years feeling like an outsider. God, do I want to do anything else to put me in that position?

Jodi went to medical school, became an internist, got married, and had three children. But she had a very difficult period in her late 30's, when she had three young children and her marriage was falling apart. She was starting to spend time away from her family, drink heavily, and do odd things.

I, I was very, very unhappy. ... All I knew is that at one point along the line I ended up spending. I used to—, I, I started spending a lot of time, um, away from my family. ... Um, just escaping from my house. Going to the gym. ... I was on the computer all the time. I was talking to people on line. Chatting in chat rooms. Meeting people on—, that I, that I would find online. And then meeting them in person. You know, and I was just like out this, in this whole nother—. I had this whole nother life essentially that I had set up.

During this time Jodi was diagnosed as "having an episode of depression," which she attributed to the stress in her life. Six months later, she attempted suicide, and was

hospitalized overnight. She was arguing with her husband on the night of her suicide attempt.

I got really upset and, um I, I was ... I was angry with him and, but I just—. I knew that like I couldn't function with the, all of this anger. Like it was just, I, I had to do something. ... So, I didn't really want to kill myself per se. But ... I have to get away kind of a feeling. ... I was in a lot of pain emotionally. And I was thinking. I have got to get away from these feelings. That was what I was thinking. And, ... I can't function like it—, I can't cope with this, this life any more. ...

Jodi tried to explain how she was feeling at the time:

There's no out. There's just no way to get out of this situation. Because, you know, you've got him. And you've got your, the way you feel. And you're not—. It's not going to get any better and, you know. I was like despondent at that point. I was like, it's not going to get any better. You're going to feel this way. You can't escape this marriage. You're miserable. You know. You're gonna have to stay. ... You're gonna have to, you're stuck. You know, it was kinda like this feeling like you're stuck. You're gonna have to stay. But you're miserable. So how you're gonna deal with that?

Shortly thereafter Jodi made the decision to become sober. This process started an avalanche of changes in her life. She ended up leaving her husband and moving out of the family home. She got divorced and her ex-husband was awarded custody of the children. She was diagnosed as having bipolar disorder. And she “came out” as a lesbian and started dating a woman. All of these changes (sobriety, divorce, bipolar disorder diagnosis, and coming out as a lesbian) happened in a very short period, an extremely difficult one for Jodi.

I went from having a hou—, a home, a marriage, three children, ... you know, to living in an apartment, suddenly stopped drinking, be diagnosed with bipolar disorder, moving in with a woman, ... totally changing my lifestyle. And it all came up together in the space of like ... like ... six months maybe. And it took a long time for things to settle down. I had to go through, you know. I went through

the separation and the di—, and the ...mediation process, and the divorce process. Which took a very long, long time. You know I had to work out what was happening with my children, which is another heartbreaking story. You know it really didn't work out well.

Even though Jodi is professionally successful, in Jodi's life narrative, there are several "heartbreaking" stories that "really didn't work out well."

Jodi's Explanations

When Jodi was asked how she made sense of her experience before getting the label of bipolar disorder, she responded:

I was aware that people sometimes saw me as a little bit different, different than other people. ... I didn't handle things as well as other people. ...I wasn't as happy as other people. ... I spent a lot of time, I think, in this, this kind of mild depression, where I just couldn't seem to get out of feeling ... life is a little bit too difficult. ... I feel a little bit blue and unhappy and I just can't get ... activated about stuff. ... I had more anxiety about things than some people. ... And I knew people saw me that way, you know, as tightly wound up and as kind of, uh, pessimistic and blue. ... I would like to have been a more cheerful person to be around. And more fun and—. But I wasn't, you know.

Thus, Jodi made sense of her inner experience by calling it moodiness, anxiety, a mild depression, and being different from other people. She also saw herself as "not having it all together," even when things were going better for her in college. When she was applying for medical school, one professor chose not to write a letter of recommendation for her.

I totally fell apart. [laughs]. I literally totally fell apart. Like, oh my God, I must be a horrible person. Oh my God, I must—. You know, I mean it, it just, it totally wiped me out. It was like I, I could almost not go on from there. You know, it almost was the end for me of being able to do this [laughing]. Um, you know, because I just, you know that—, that just one rejection was enough to like send me so reeling so badly that I just, I almost didn't—, I wasn't almost—, most was

not able to complete the process. ... That, like, simple things like that. ... I, I just didn't have it all together.

Jodi also explained how she had emotional difficulties in medical school and residency. She recognizes that the stress is hard for everyone, but she feels that she was particularly wound up, like a tightly coiled spring (using the same term Rose used):

And medical school I remember being very difficult. Um, um. The stress was very hard. ... I can remember having periods of depression. And, um, at one point I was so stressed out by anx—, by exams that I, I remember like, um, having some minor acne on my face and totally scratching my face up. Just out of the anxiety. It was just like—, and I—. It was so bad that I, I almost couldn't like go anywhere for like a week or so [laughs] I couldn't even tell—, beginning to tell people like what had happened. It, it was so embarrassing. I was like, oh my God, like I did this to myself, you know. [laughs]. ...

I'll tell you that one person, when they interviewed me for the residency program. One of the physicians said that I was like a tightly wound spring. ... And I'm like, What does that mean? But my anxiety was so SOOO high that it was like, you know, palpable to people. You know. And I had no clue that it was like that. I mean, I was just like, bobobobobo [like fast heartbeat]. Like you could t—, put me—, you know, if you pushed me in the wrong direction, I would be like, pop. You know, and eii, I didn't know I was like that. I, you know, and it, it turned out to be the case. That if you, if you, if you hit the spring in just the wrong spot, that I would fall apart. You know, and I didn't realize that that was the case.

Looking back (from the vantage point of bipolar disorder), Jodi is aware that her moods and energy fluctuated:

I would have to say that I, when I look back I think a lot about not being happy. And being very—. Feeling n—, depressed a lot of the time. ... And then it would alternate with periods of time where I would have higher energy or feel better. And I don't know whether that was a cy-, a cyclic pattern. Or it was, whether it was more dysthymia. Or cyclothymia. I really [have] no idea. But, um, I just know that, like, for instance I look at college where I was sort of more up. And then I look at other periods of time where I was definitely more depressed. ... But the other thing that would happen was like for instance, things would like, the amount of physical energy that I would have would change. My weight would

alter a great deal. Um, it wa—, like strange things I've fluctuated anywhere from like seven—, in seven—, like a seventy-pound range.

Until she received the bipolar diagnosis, Jodi had never put these feelings, moods, and behaviors together as a package of related symptoms or experience. Instead, she had labels for each individual symptom, like being depressed, being overly sensitive, feeling unhappy, and having weight fluctuations.

Sarah

Sarah is a 40-year-old clinical psychologist. Her childhood, like Rose's, was colored by her relationship with her mother and her mother's mental health problems. Sarah started the interview, in response to the question about getting a diagnosis of bipolar disorder, with her mother's history:

Well, let's see. Um, my mom was depressed when I was growing up. And, you know, was in, my ther—, my family, well, it's my mom who was comfortable with the concept of psychotherapy and was in psychotherapy for a long, long, long, long time. But then, um, nothing really seemed to help her that much. She just kept being depressed and depressed and depressed. And when I went away to college, she had, um, a manic episode that really had psychotic features, and had to go to the hospital. And actually it wasn't when I went to college, it was be—, it was when I went away the ... summer before ... my senior year of high school.

Sarah noted that, even before her mother's hospitalization, her mother was “chronically depressed.” Sarah knew this because:

Oh, well, she told me. Unfortunately, I mean, that's one thing. I was her confidante. I'm an only child. And, she got divorced when I was three. So—. But also she was a, a, like a barely function—, a functional depressive, probably like a functional alcoholic. You know, she would go to work. She would do her job. Probably just barely. Um. And then come home and, you know, throw off her clothes and grab a bowl of peanut butter to eat and go retreat into her room. I mean, she'd, you know, you know, throw a TV dinner in the oven for me [laughs], or ... get me to do it. ...

Sarah knew her mother was depressed. This is Sarah's main memory from childhood:

I, I, for so—, I feel that I knew that, as long as I could, I don't know, for as long as I could remember [my mother was depressed]. ... It was certainly—, it was certainly my prevalent memory of childhood. And I—, she was, you know, my m—, you know, my most powerful influence 'til I was about 16. I was pretty isolated from other people. I wasn't ... I ... She encouraged isolativeness too.

Sarah spoke several times about her emotional merger with her mother.

I, I, I've had a tendency to over-identify and over-protect my mother for years and years. ... But as I, when I grew, the way I grew up, I was so bonded to her that I sort of forgave her everything, and protected her. All the time. And over-identified with her, at my own expense. Because she was depressed and it wasn't, you know, so she couldn't help it and it wasn't her fault.

Even though Sarah views herself as having over-identified with her mother for many years, she also recognizes that she felt neglected because her mother had limited energy to attend to Sarah's needs: "I was more like a neglected kind of child."

Sarah herself had difficulties from a young age. She has little memory of these experiences and recalls them mainly through what her mother told her.

I know that when I was maybe six, seven, I was taken to play therapy. And I think it was because I was having trouble getting along with o—, I'm sure because I was having trouble getting along with kids in school and I was having temper tantrums.

Sarah has distinct memories of feeling ostracized through much of her elementary and junior high school years. She said, "I was the kid with the cooties. ... The worst kid with the cooties. [laughs]. ... Um, you believe you're the worst kid that there is, and ... you just believe it." Sarah explained that her mother was not able to help her manage her problems with her peers.

And also I wasn't very popular. I was a pretty confused kid and, you know, she wasn't, she wasn't the kind of mother who would say, well le—, you know, let's see if we can find you friends somewhere else. Maybe we'll go join a playgroup here or, you know, like that, at all. Anyway, um, so I don't know how I first knew, but somehow I just did [laughs], that she was depressed and then that's sort of why she acted the way she acted.

Sarah has thought about how her early difficulties with peers came about, as a kind of repetition of difficult experiences her mother and grandmother had:

I think I had a lot of trouble regulating my mood, probably, and I don't know whether that's because I was actually having symptoms. Now it would be, it would be interesting to know whether that was the case. I think it was because I was pretty damn unhappy, um, and ... my mom and my grandma, both, they were, it's weird, the family immigrated here twice, because [laughs] my grandmother, that side of the family is Hungarian. Um, and my grandmother—. And my great-grandmother came here with my grandmother when she was three. And so my grandmother grew up in America and got harassed for being ... a gypsy. You know, she had pierced ears, and, she was, actually she wasn't dark, she was blond, but you know, she was a little alien girl. [laughs]. And, so she got harassed for that. ... She got very, very picked on for a long time too, and didn't know how to react.

And then, then, she got married to a Hungarian man and, and then they, there's weird psychological stuff, and then my mom somehow created my grandma's life, in some weird way. ... They [went to Hungary and] came back here when my mom was three [laughs] ... Isn't that bizarre? [laughing] I don't know why, she spent the first three years of her life in Hungary as well. ... Um, so she got a certain amount of the same thing, you know, a little girl with pier—, pierced ears and who was a little immigrant child, again! And she again didn't know how to deal with it.

Interviewer: And did she tell you that she was picked on as a kid?

Oh, yeah, I mean, her response was always, this happens to all of us. Um, they don't understand, and, sort of, we're better than they are. And we, my mom defended against it by being arrogant. And, to this day, doesn't understand that that's useless [laughs]. It never helped me [laughs]. And I didn't really want it. You know, I didn't want to be—, act like I was better than they were. I wanted to be liked. ...

Sarah described her own experiences of being harassed by classmates in childhood:

For me, though, I was different. I, you know, she did dress me different. She didn't dress me in play clothes. She dressed me in clothes that were more frilly little girl clothes. And that was a pain. Finally, I think, I got around it, but also, I was uncoordinated. I was not good at sports. And you know how important that is. But I think also my social skills probably sucked. I mean I, that's more I'm not sure, but I would bet, and I think I wore my feelings on my sleeve. And I think it's that simple. You know, and I didn't know to just—, I—, they go around and see who they can get a rise out of. And, it was always easy to get a rise out of me. So I—, it stuck.

She expressed shame about how she did not feel “normal,” when teased by her classmates.

I mean if I were somebody who had a long history of abuse, I, it's silly to compare experiences, it's not fair. And I know how incredibly shame-filled that it is to people I've worked with who have it, for God's sakes. But it feels to me like I would be less embarrassed if I had that because I could then say, I am a person who started out being normal and then something happened to me that made me be this way.

It appears that having an external cause of psychological problems, such as a history of abuse, would be less shameful to Sarah than an internal cause.

Like with Jodi, Sarah's interactions with her peers improved in high school, because of her intelligence and school achievement. She made friends in the gifted and talented classes, though “nobody wanted to date me or anything [laughs], um, I was still much better liked because I was respected for being bright and for, for being interesting, I guess.” Once Sarah started finding her group, she came to a new understanding about her experience: “I think that was when I started thinking about the idea that I was depressed.” She sees some of her depression as part of her symbiosis with her mother:

I was sad most of the time if not all—, you know, most of the time. And that, I think that, well I think a lot of I got, it was, it meant I was like my mom.

Sarah's early years were spent almost entirely with her mother and not with peers

So, you know, with her telling me about how she felt and about what's going on in her therapy and things like that. And so I don't, you know, I almost wonder whether if I hadn't been depressed I kinda, woulda said, "Oh, I am too, " you know [laughs].

Sarah made a suicide attempt when she was 15.

I knew that I wanted to kill myself a lot of the time so, yeah, I think pretty much. [laughs]... I wound up attempting suicide once. ... I was fifteen.... What I remember, it was a silly gesture, I think. I think I was very angry more than, you know, dead set on killing myself. I took my mom's, a whole bottle of my mom's sleeping pills. And she was furious at me. Really, really angry. My mom gets angry when she's scared. So she took, she took me to the hospital. I wasn't treated very well. I think it was like a, you know, dumb teenager react—, reaction. They were mad at me. Everybody was mad at me. [laughs]. ...

When it was pointed out that Sarah's description of her suicide attempt focused on how other people reacted, Sarah responded that she does not have any clear recollection of her own feelings then.

I think though ... I don't think I have any real memories of my inner experience of that time. I have memories of everyone's reactions to me. ... But I don't know what I was feeling that made me do it at the time. I mean I certainly know that I felt like I wanted to die a lot of the time because I didn't want to be there. But that's a weird one too. I mean in some ways that was a sort of a of—, you know—it's not accurate because it's not psychotic—there was a little bit of a *folie a deux* thing with us. Because she sat there telling me she wanted to kill herself all the time, which didn't help [laughs].

Like Kevin, the other psychologist among the participants, Sarah uses psychological language, like "psychosis" and "*folie a deux*" to make sense of her experience. Like Natalie and Jodi, Sarah does not have much memory of her feelings in adolescence. She

seems to recall that she wanted to die much of the time, but she thinks her merger with her mother was a more powerful influence on her suicide attempt.

Sarah continued to be a high achiever in high school, went to college and graduate school, and became a clinical psychologist. Like some other participants, Sarah became very aware of her changing moods in college. Using the language of bipolar disorder, she sees herself as fluctuating between hypomanic and depressive episodes:

In college, I definitely didn't know it then, but I definitely was going through a com—, between—, I would have depressions and then I would have hypomanic states.

Interviewer: How did you see these episodes then?

That was me. So I must have been that way for a while, because I didn't find it unusual. To me it was like I had to get myself—, I wanted to get myself into a certain state, and I knew I had to get myself into that state in order to write papers, study for exams, stuff like that. And then it would go—. I think I thought that either I was burned out from studying and working too much or I was in the zone, or I was somewhere in between. I was refueling.

So the explanations Sarah used were “depressed” or “in the state,” an energized state she assumes everyone else is always in. But for Sarah, it took work to get into the state. This is how she would do it:

I think hyping myself up. A lot of anxiety. Um, isolating myself. Um, drinking—, I guess I drank a lot of caffeine. ... I guess that that I started getting myself in that state by lack of sleep and studying, studying, studying. That's probably what primed me into it. ... In college it really felt like that, either I was being hypomanic, I was able, I was on and able to do stuff, or I would crash. ... On or, yeah, worn out, exhausted, burned—. I think I said burned out. I said burned out.... I still thought of myself as a depressed person. ... Well, I though, the “on” part, I thought that most other people were like that all the time. Cause most of my friends seemed bright and articulate all the time to me.

Sarah had a negative label for her low times, “depressed,” but she did not label her elevated moods, except that “that was me.” She saw her elevated moods as being like everyone else, so only the depressed moods were labeled. Yet she did not really pathologize the depression, because she believed that “burning out” was expected for students like herself who studied really hard.

I thought a lot of this stuff was, I study really hard. I got a reputation of being a real bookworm. I did well—. I did really, really well. Um, and so, I think I bought into what the group of people around me thought was that most of the way I was was because I studied all the time.

Sarah’s college explanation for any peculiar behaviors was that she studied a lot and was smart. This seemed to be a sufficient explanation for Sarah.

During college, Sarah decided to become a psychologist. When she started taking the necessary classes, her stress increased.

I, I started getting really bad psychosomatic stuff, psychosomatic stomach stuff And I didn’t know, I didn’t even know it was psychosomatic. I was so embarrassed. I had a guy in an emergency. I, I thought I had appendicitis and I went to the emergency room [laughing], and the doctor kinda sat down and put his arm around me and said, Do you get really stressed out? You might want—. And I thought, my God, I’m so embarrassed. You don’t have to tell me this. I understand [laughing].

Sarah labels her symptoms “psychosomatic stuff,” which is a pejorative term. So it is not surprising that Sarah feels shame for having had a physical stress reaction.

In graduate school for psychology, Sarah experienced again some of the social isolation she had known earlier in school.

I got a lot more social criticism for being odd. Um, for, I think for just sort of being an Iora, what is it, not Pigpen, the one with the rain cloud? A sad sack. Droopy looking person. ... I got sort of c—, not exactly censured, but, um, [one

professor] decided that I needed counseling. And I, you know, it wasn't a problem to go to counseling. I did, but, really sort of zeroed in on my social behavior and decided, because I was very, very insecure. And timid. At the time I didn't really know it, but, I mean, I remember a couple, I, it felt like my peers in the classes, you know, just reacted, reacted to me like I was weird, a lot, and I never understood why.

The experience of feeling odd in graduate school was very painful. Sarah said, "Oh, it was awful. I mean, I felt like I was back in elementary school. The feeling that I was weird. I just felt like, well, OK, this is the same old thing again."

Sarah's Explanations

Sarah attributed some of her difficulties as a child to temperament. Like some of the other participants, she described herself, pre-bipolar diagnosis, as moody, anxious, and having fits of anger. Yet she is also aware that her family dynamics were complex and difficult.

I think that a certain amount of what I was having trouble with had to do with the, you know, my family isn't a—, just a family that has this in it and otherwise it was a pretty functional family by—. It, you know, it's the opposite [laughs]. Um, it's pretty bad. Um, and, appa—, I think like temperament-wise, I—, you, I would say I was just like a difficult baby, very difficult to soothe, very, um ... And then the people around me were pretty chaotic, and anxious, intense, and weird and, you know, so I picked up that. And just the descriptions I got of myself were that, like, you couldn't calm me down, that I would cry until I threw up, etc. etc. Um, I had temper ta—, really bad temper tantrums and anger fits. Um. I was always very, very moody.

She noted that during much of her life she did not have explanations for many of her feelings: "There was so much of my life where I couldn't really explain." The main explanation that she developed was that her childhood was difficult because other kids did not like her:

Um, when I attributed anything to anything, it was, you know, um, I'm sad because nobody likes me and nobody likes me because I'm ugly and I, you know, I can't play sports and I can't make friends, blah blah blah. [laughs]. So the idea that it was, I, it never would have occurred—, I don't think I would have believed anybody if they said, it's because you are depressed. I would have said, no, I am depressed because I have reasons to be [laughs].

Although in childhood Sarah mostly explained her feelings as a reaction to being ostracized, as an adolescent she started to explain her experience internally. Around age 14, she started at times seeing herself as depressed or as having changing moods, something she often wondered about:

Sometimes ... I could think really clearly and I would understand things really well And other times I was a bumbling idiot. And I, I think, now that I say that I remember that I experienced that when I was 14 too. But it wasn't with intellectual pursuits then. But it was some days were good days and some days were bad days. I didn't know why....I just analyzed it to death. And I thought that it was—. But I didn't try to make—. I, I believed that I had no control over it at that time.

Interviewer: But you did think about it a lot?

Yeah. I did. ... It's my mood, I thought. My mood controls the way I act and how I come off and even how I look. ... Because that, on the days when I was, I mean, some of this is just basic psychology now, I guess. But it was just, uh, on the days when I was up and on, people would compliment me on my hair, they would compli—, you know, they'd be friendly to me. On the days when I was down, I mean, nobody would talk to me. It was amazi—. And I had no—, I couldn't fake it. I just couldn't.

As an adult pre-bipolar diagnosis, Sarah mainly saw herself as depressed and temperamental. She said her husband: “always knew of me as a very depressed and sort of tempestuous person.” Those words seemed to best capture Sarah's experience of herself as an adult.

Darlene

Darlene also described a difficult childhood, living with a “crazy” mother and controlling grandmother. Darlene described her mother, using the same adjective that Rose used:

I had a wacked out mom. She’s just really—. Well she was pretty much abused when she was a child. ... Not a very loving person. ... And my grandmother, her mother, lived with us, from the time I was two. And she was a cold and conniving witch. And I lived with her my whole childhood, ‘til I got out, yeah, on my own. And she was just a very horrible person. Um, no boundaries. You know, never, I never had a moment where she didn’t barge in on me or do something use—. There’s nothing horrible in my background like, like child abuse or sexual abuse or anything like that. Just had a really unhappy, miserable time.

Darlene felt that her mother put her own mother first, rather than her children and husband:

My mom always tells me that she always had to do things the way my grandmother wanted to do them, because she was *her* mom. She always had to do what *her* mom said. And I could never understand why she would be that way, knowing how much it was hurting us. Bu—, mom came, her mom came first, not her children. And not her husband.

Darlene was the oldest of four children, but she remarked how she never learned how to do household tasks because her grandmother would criticize her and take over the task. She is ashamed that she did not learn these household skills:

I never learned how to do anything. I never learned how to make a bed, do the laundry, put dishes in the dishwasher, iron, nothing. ... And I thought, my, my mom never taught me any—, anything because as soon as I would start to try, my grandmother would redo it all. She would say, “Stop doing that. Stop th—. You do—. You don’t know what you’re doing.” You know, she would just say just bitter, mean things all the time. So, I, around the house I never, I’ve never learned to do anything. It’s embarrassing [laughs]

She gave another example of how she felt her mother did not support her when she was growing up. She always wanted to be a professional singer. She applied to colleges where she could major in voice.

And my mom said, like two days before I left for college she said to me, “Don’t, you don’t really think you’re going to be a professional singer, do you?” “Yeah.” She said, “Well, [sighs], you’re not any prettier or better than anyone else is. So I hope you don’t think you’re going to be able to do that.” It’s like two days before—. And I had spent years, you know, singing in shows, and doing all—, as much, as much as I could do and, thinking that she was behind me. And then she said that to me, I’m like, just my—, you know, my heart went down to my stomach. She says stuff like that, you know. That kind of childhood where people don’t really support you. Don’t really care.

She describes her father in “bipolar” language: “And my dad was, like one of these, one of these like—. He could have been manic, it’s possible, because he was a very, very hyper, happy, emotional, pleasant, fun guy.”

Darlene recalled how she became extremely angry and mean to her mother, starting when she was about 14. She believes this is the start of having mood problems.

She expressed shame about her tendency to get angry:

When I was, when I was 14, ... that’s when it turned on me. That’s when I changed. Because I, I just, I abused my mother verbally so terribly when I turned 14. From then on, I would just ha—, I would just snap. And I would just—. I would use the “f” word all the time. I would hit her. I mean, I would push on her like that. I would scream. I would yell. People walking down the street could hear us. And at that time I thought, she was driving me crazy! It’s not my fault. But when I look back on it, it was NOT normal. It was NOT normal. And, I think, I think that was—, I think that was part of it. I think that was the beginning. I think I, I think that was the start of it all. And I have done that to my husband for the last 22 years we were married. Off and on, not very often any more. But I used to. I was terrible when I was in my twenties. I think it’s me. I do. It’s terrible. It’s horrible, so, so. I’m so ashamed of it. It’s just awful.

Darlene went to college, became a nurse-practitioner, got married, had two children, and worked as a nurse-practitioner in a well-known practice for 20 years. But she noted that she also experienced painful feelings during her adulthood. Until the diagnosis of bipolar disorder, she understood her pain as depression.

It's tiring to talk about. ... Of those years. Those horrible years. ... Well, it's exhausting just to be sick all the time. I mean, just those years of being—. I mean I would—. Every November the depression would just start, you know. Sort of like seasonal affective disorder. I would just get so depressed and would just pray that I would make it through to April when the weather would get a little bit better. And I, I just remember looking at the, you know, the calendar, and thinking "Oh, shit, how am I going to make it through five more months?"

Like many of the other participants, Darlene now frames her understanding in psychological and "bipolar" language, like "seasonal affective disorder." She also recalls times that she now labels as manic or hypomanic. At that time, she thought that her "head was nowhere," and "not where it was supposed to be":

I mean it's, just, everything was so hard. And then, you know, and then there would be that crazy, hyper, talkative, mind-racing, [sigh]. I would forget to pick the kids up at school because I would be spending money in a jewelry store. Or in a, a—. And they would have dentist appointments and I wouldn't even get to the school to pick them up 'til after the appointment would have been over. And I, my mind was just completely mixed up and I would finally get to their school and they'd be standing out crying. And, [sigh] "Where were you?" I'm going ...[sighs]. My head was nowhere. I mean, it was just not where it was supposed to be. It was exhausting.

When Darlene was in her 30's, she was treated for depression and anxiety. She was hospitalized three times for mental health problems and suicidal ideation. "I had been hospitalized two times before finding out that I had bipolar disorder. And both times were

for serious, severe, major depression.” The first time was in her early 30’s, when she had a “panic attack.”

Oh God, the first time was so—. I had, I was very, very depressed for maybe a week. Really depressed. And, um, I just, I was trying to hold it together. Cause I, I wa’n’t talking about going into any hospitals or anything. And, um, on a Sunday, I went to church. And I was singing in the choir. And I had a panic attack. And I, the one and only panic attack I’ve ever had in my whole life. I was standing, holding a hymn book, and I just started shaking all over. The hymn book fell out, my tears were coming down, and I was shak—, you know my heart was racing and everything. I don’t know. And I ran outside. It was j—, in February. ...

So everybody just hustled me from church to the, to the doctor’s office, and the doctor wouldn’t let me go home, from the doctor’s office, and took me, and told my husband to take me way to the hospital. Don’t even go home and release the baby sitter. Go right to the hospital. So it was very—, I was just, you know, like this, you know [demonstrates collapsed in]. “OK, what? You know, what about clothes?” [said very weakly]. You know, I didn’t know what was going on. ...

They took me and put me in this room and then that room and that room and that room and—. I was just, just completely flabbergasted. I didn’t know what to do. I was just like a little baby. I didn’t know where I was or what I was doing, or what was going to happen to me, or anything.

The panic attack and years of depression were painful times for Darlene. Yet like Natalie, Darlene remembers being very happy when she was not depressed. “I was, I ... loved life. It was awesome. I was a very outgoing person. I was a very life-of-the-party type of person. Loved it, people. I was all—, we were—, we had so much fun.”

Darlene’s Explanations

Darlene has received various mental health diagnoses, including severe depression: “Um, I think I’ve had other things along with it, like co-dependency and, um, borderline personality disorder.” Her understanding of her difficult inner life seems to

center on feelings of sadness (depression) and anger. However, she looks with nostalgia at her life pre-bipolar diagnosis:

I—, a lot of times remember how I was before I knew. I think I was bipolar before I knew I was bipolar. But for some reason I handled it. . . . I didn't handle it but I THOUGHT I was handling it. You know when you're working, say you're 30 and you're working hard, you're working you know 40 hours a week and you got, you know, a social life and you're having fun and you're making money and you're— I don't know. Maybe I'm remembering those days with—, a lot more wonderfully than they really were. Which, cause I'm comparing them to now, you know.

Darlene feels an ambivalence about her life pre-bipolar diagnosis. She remembers very painful times of depression, each year dreading its seasonal arrival. On the other hand, looking back, she feels nostalgia for the feelings in those days that she was managing her life, even if Darlene now would say her life then was out of control.

Discussion

How can one make sense of these stories? These narratives were created at a moment in time when the researcher interacted with each participant. Since narratives are created in relationship, according to social constructionism (Gergen, 2001), the narratives participants conveyed in the interviews were a function of the questions asked and the interaction between the participants and the interviewer. Further, what has been presented above are abbreviated versions of some aspects of the participants' life narratives. I have distilled and organized the narratives into a structure that makes sense to me, but in the process I am essentially creating new narratives (Derrida, 1967/1997). For example, by asking about one aspect of participants' experience – getting the diagnosis of bipolar disorder – my question pulled for narratives of mood dysregulation, including intense

sadness and elevated moods, which other questions would not have elicited. Thus, the narratives must be understood as providing only a limited view of participants' experience, based on the focused question and the nature of the interaction.

The next question is why all the participants provided information about their childhoods and their families of origin. In an open-ended question, I asked them about the experience of getting the label of bipolar disorder. In response to that question, all of the participants offered narratives about their childhoods, with greater or lesser detail. For some, like Rose and Sarah, unresolved problems from their childhoods were central in their narratives. For others, like Kevin and Natalie, significant losses in childhood were mentioned only in passing and were made secondary to the main narrative.

From a social constructionist frame, one way of understanding why participants volunteered information about their childhoods is that in United States culture today, life narratives are usually chronological and stories involving health diagnoses, and particularly mental health diagnoses, are based on a post-Freudian belief system that postulates that early childhood experience impacts upon adult personality. Furthermore, all of the participants have been in psychotherapy for many years; four are health professionals; two of those four are psychologists. Health and mental health treatment in the United States, even if not from a psychodynamic orientation, is generally constructed to see patterns of experience and behavior from childhood forward. Thus, the discourse in our society about illness and diagnostic labels is framed to include early life experience.

This chapter on participants' explanatory frameworks before the bipolar diagnosis was not one that was planned. All the participants provided narratives about their childhoods and their ways of explaining feelings and behavior before the bipolar diagnosis, so it became evident that these childhood and pre-bipolar narratives were central in answering the research question of "what is it like to receive a diagnosis of bipolar disorder?" Further, receiving the bipolar diagnosis was a defining moment in their lives. They apparently felt that their narrative of crossing that threshold would not be complete without contrasting their new explanations and understandings with their prior ones.

Working from the perspective that these narratives were constructed at one moment in time through the interactions between each participant and the interviewer, there are nonetheless many common themes among the narratives, childhoods, and life experiences of the participants, as well as their explanatory frameworks. The common themes and the shared labels are now addressed.

Labels for Self

The participants discussed aspects of their lives pre-bipolar diagnosis, describing feelings, behaviors, thoughts, and even bodily sensations, using various terms to organize and label their experiences. I will discuss the participants' experiences in the historical context in which they occurred and were labeled.

Difficult Childhood and Adolescence Experiences

All six participants told narratives about difficult childhoods. Many noted “external” events that were difficult or even traumatic. For example, three participants lost siblings when they were children (Rose, Natalie, and Kevin) and one also lost her mother (Natalie). Some mentioned their parents’ divorce when they were young (Sarah and Jodi). They mentioned parents who had diagnoses of bipolar disorder or clinical depression (Jodi, Sarah, and Rose), were difficult in other ways (Darlene and Kevin), or were alcoholics (Natalie). Several described themselves as neglected in some way by their parents (Kevin, Sarah, and Natalie) or ostracized by peers (Jodi and Sarah).

They all discussed what we think of as “inner” painful experiences growing up. This includes loneliness and sadness. They mentioned symptoms like social anxiety (Rose, Jodi, Sarah, and Darlene) and intense anger (Darlene). Some participants had experiences of lost time or memories, experiences known in psychology as dissociative experiences (Natalie, Jodi, and Sarah). In terms of experiences later viewed as symptoms of bipolar disorder, all spoke of feelings of sadness and depression and occasional high energy and/or fluctuating moods while growing up. Some wanted to die or made suicide attempts in adolescence (Sarah and Rose), or became an alcoholic in adolescence (Natalie). In adulthood, all spoke of difficult and uneven moods and feelings, all pre-bipolar diagnosis. Some spoke of suicide attempts and psychiatric hospitalizations.

A logical thread tying all of these experiences together is that these participants described symptoms of bipolar disorder, since the diagnosis involves mood fluctuations

from depression to mood elevation, as well as such symptoms as irritability, anger, and impulsive behavior. Since the research question was focused on bipolar disorder, it would make sense that the participants framed their narratives in such a way that the logical organization of their experiences would be toward a diagnosis of bipolar disorder.

However, none of these participants was diagnosed as having bipolar disorder until adulthood. The stories presented above show that until getting the bipolar diagnosis, they had various ways of explaining and understanding their difficult internal experiences and the problematic behaviors of family members. From a social constructionist perspective, the similarity of themes reflects how the dominant culture then made sense of people's internal experience as well as how American culture today views narratives of the past. The participants' ages ranged from the late 30's to mid-50's, so they all grew up in a fairly similar time in the United States and they could all be said to be from the dominant American culture³.

Explanations for Early Experience

In childhood, the participants mostly discussed difficult external events, although the participants also described some internal distress and unhappiness. For example, Jodi and Sarah both emphasized how other children teased them. Sarah noted:

When I attributed anything to anything, it was, you know, um, I'm sad because nobody likes me and nobody likes me because I'm ugly and I, you know, I can't play sports and I can't make friends, blah blah blah. [laughs]. So the idea that it was, I, it never would have occurred, I don't think I would have believed anybody

³ By "dominant" here I mean middle-class European Americans living in the East coast of the United States in suburban or rural areas.

if they said, it's because you are depressed. I would have said, no, I am depressed because I have reasons to be.

Sarah was also aware of internal processes, and referred to herself as “moody.” Similarly, Jodi felt that “nobody liked me.” Jodi also knew she was “moody ..., withdrawn ..., unhappy ...shy,” but the external difficulties were more a focus of attention.

The participants generally felt alienated from their childhood and adolescent peers. For example, Sarah felt like “the kid with the cooties. The worst kid with the cooties.” Kevin saw himself as a Martian compared to other college students who looked forward to their parents' visit. Natalie always felt different from her peers and explained her alcoholism as a way to compensate for this social discomfort.

In other words, participants had to make sense of painful circumstances, including being ostracized from other children, dealing with sibling deaths, and managing problematic parental behavior. In childhood they generally assigned the cause of their problems to external sources, as is considered developmentally appropriate in the United States.

Regarding adolescence, however, the participants labeled their experience with more bipolar disorder-related symptoms than they had done for their childhoods. They noted that in adolescence they started having mood irregularities, such as depression, mood elevation, excessive irritability and anger, or excessive mood fluctuations. Although these labels come out of their current bipolar worldview, this suggests nonetheless that the participants had developed more internal and psychological ways of

understanding their discomfort when they were adolescents. This is also considered developmentally appropriate in American culture.

Yet the participants in many cases continued to describe behaviors instead of feelings, which may have been harder to articulate. For example, Darlene remembers being extremely angry at her mother when she was 14 and yelling loudly at her mother in public, saying now, as an adult, that “it was not normal.” She does not elaborate on what internal experiences might have led to her outbursts. Similarly, when Rose was 16 and her mother was in a “mental ward,” Rose became pregnant by her teenage boyfriend. She made a suicide attempt when her boyfriend tried to deny it was his child. Rose described the circumstances of the pregnancy and suicide attempt without much mention of her inner experience. She did not describe what it was like for her mother to be hospitalized in a psychiatric institution or how she felt about her mother’s unavailability during that period. She did not consider whether the pregnancy and suicide attempt might be ways to cope with, “act out,” or “reenact” something about her mother’s psychiatric hospitalization or her mother’s general mental illness.

In fact, some of the participants are not even sure what they were feeling as adolescents. As a teenager, Natalie was an alcoholic and has little memory of that time. Jodi “lost” a year when she was 15. Sarah made a suicide attempt at age 15, but now wonders if it was a “*folie a deux* thing” because her mother “sat there telling me she wanted to kill herself all the time.” She recalls that she “wanted to die a lot of the time because I didn’t want to be there,” but “I don’t think I have any real memories of my

inner experience of that time.” Thus, participants’ descriptions of mood fluctuations in adolescence may be mostly a function of looking back through bipolar lenses or seeing themselves through family members’ narratives.

Self-Labels in Adulthood

The participants talked about various feelings and behaviors in adulthood pre-bipolar diagnosis, some of which were labeled and others not. I have organized them into five categories: feelings that they labeled as depression; high energy and irritability; social isolation; somatic experience; and concerns about being crazy. I discuss each of these groups in turn.

Feelings of depression. Even before the formal diagnosis of depression, the participants referred to themselves as “depressed” as that term is used in popular culture. Feeling sad and depressed was a familiar label for Americans; it was and still is an acceptable term to describe anything from slightly lower energy or slight sadness to severe depression. Five participants called themselves depressed in adolescence or adulthood. Of those five, four made suicide attempts or were hospitalized in psychiatric facilities, or both, before the bipolar diagnosis.

In adulthood, some of the participants continued to use the description of behaviors or psychiatric shorthand to represent their internal experience. For example, after Rose drove head-on into a truck, she was hospitalized in a psychiatric institution for an attempted suicide. When interviewed recently, however, she was still unable or unwilling to claim it as a suicide attempt. She said, “I pulled my car in front of a, of a

tractor trailer and smashed up my brand new Jeep Grand Cherokee.” When her doctor asked her if she was trying to kill herself, Rose answered:

I said, “I honestly didn’t say, ‘Gee, I think I’ll kill myself today.’ But I know, I know that I saw it coming.” She goes “You tried to kill yourself.” I said “I can’t say that either but if somebody sees it coming and pulls out, is that because I just had a real bad screaming match with my husband? And getting, you know—” Um, I mean I was still like this [shows hand shaking]. You know I was, I was always like this for hours after we had one of those.

Rose was aware of how upset she was about the argument with her husband, but not that she was feeling suicidal. She seems to wonder still if the act of driving directly into an oncoming truck meant that she wanted to kill herself.

Darlene felt suicidal once before the bipolar diagnosis. The first time, she said “I was looking at my razor blades.” She notes that “I, I, I asked for help both times though. I didn’t quite—. You know, the ideation was there but I didn’t actually do it..” As a nurse-practitioner, Darlene, like some of the other participants, uses the professional language of psychology to stand in for her feelings. By saying “the ideation was there,” she is using a psychiatric shorthand to address her feelings, rather than expressing them from a more intrapsychic, experiential perspective. She describes an act – looking at her razor blades – rather than a desire to kill herself. It is as if describing, or maybe even admitting to oneself, the painful inner experience is too difficult, even now, years later.

Jodi, on the other hand, articulated clearly how trapped she felt when she made a suicide attempt:

I was in a lot of pain emotionally. And I was thinking I have got to get away from these feelings. That was what I was thinking. And, ... I can’t function like it—, I

can't cope with this, this life any more. You know, and this was sort of like, you gotta get away. So, maybe this is the solution.

Jodi was one of the participants who was most able to describe her feelings in a compelling way.

In addition to using behaviors or psychiatric shorthand to describe their feelings, sometimes the participants continued to describe experience through other people's eyes. For example, both Sarah and Natalie describe how they fear they are seen by others as a "sad sack," meaning something of a pathetic, whining person.

Other feelings. The participants described once again in adulthood experiencing other feelings, both pleasant and unpleasant, feelings that did not fit within the depression catch-all. Terms they used to describe themselves included: very irritable or angry; agitated; very happy; feeling expansive; having high energy; being wound or excitable; "plinging"; being hyper and talkative; having a racing mind; being temperamental; and being very sensitive. These experiences were still not organized into any comprehensive category. The word "depression," whether as used in common parlance or psychiatric discourse, was a useful shorthand to describe a broad range of feelings, some of which could not be explained. There is no corresponding catchphrase for these other feelings, like anger, agitation, and expansiveness. A person is understood if she or he says, "I feel depressed today." One does not say, "I feel manic today." Without a socially convenient label or category for those feelings and experiences, participants could not place them into a category that made sense.

Social isolation. Several of the participants referred to social anxiety or isolation as ways to organize some of their experiences. For example, Jodi and Sarah experienced intense isolation during their school years and their only respite was when they were considered smart “geeks” or “nerds.” Jodi said: “I spent ALL of my childhood and my, you know, my teen years feeling like an outsider.” Kevin felt like a Martian when he compared himself with his college classmates. Rose said she never went to parties: “I’m not a social person. Whosh, not social at all.” For these participants, feeling like an outsider was an experience of feeling not “normal.” Yet this isolation was not viewed as part of those prior categories of moods and feelings. Social isolation involved interpersonal interactions and internal traits (like shyness).

Physical or somatic experience. Sometimes participants described experience by using somatic, physical, or sensory terms, experience that in Western society are considered different from feelings, moods, or thoughts. They all used words that suggest somatic sources for the feelings. Rose spoke of being “wound,” “excitable,” and “plinging.” Darlene described herself as: “and then there would be that crazy, hyper, talkative, mind-racing.” Her description of her angry tirades at her mother suggests a physical causation: “I would just snap. And I would just—. I would use the ‘f’ word all the time. I would hit her. I mean, I would push on her like that. I would scream. I would yell.” Similarly, hearing Jodi’s description of her anxiety leaves a somatic impression:

But my anxiety was so SOOO high that it was like, you know, palpable to people. ... I mean, I was just like, bobobobobo [like fast heartbeat]. Like you could t—, put me—, you know, if you pushed me in the wrong direction, I would be like, pop.

Similarly Rose, as an adult, experienced a period of intense internal distress. Some of her description of it seems to involve physical sensations:

And I'm pounding and screaming and I'm going out of my head. I'm literally going out of my mind. ... [Later] ... I told [my sister] I'm going out of my head. I'm literally going out of my mind. Marge, you've got to help me. My skin's crawling. I can't stand it.

Later she described her hand shaking after an argument with her husband (the day she drove into a truck):

I mean I was still like this [shows hand shaking]. You know I was, I was always like this for hours after we had one of those.

Similarly, Kevin described how he physically feels different on different days:

There are some days that I wake up and I just have more, I, I can, I know that I have more energy. I'm in a different place. Um. I'm not gonna have the same amount of sleep. I'm gonna be much less tired. I'm going to be able to, um, yeah. I just know that I'm going to feel much different. So I do know that there are, are shifts.

These descriptions suggest internal pressure or heightened sensory experiences, but the nature of the physiological experience is not fully evident from the participants' verbal statements. Labeling parental behavior was equally difficult for the participants.

No fear of being "crazy." Even with formal diagnoses of depression (five participants), the participants did not pathologize their behaviors or have concerns that they might be "crazy." Their feelings and behaviors generally made sense to them then. Rose was even able to understand the logic of her adolescent suicide attempt. Darlene is clear that when she was yelling at her mother in adolescence, it was not her "fault." Her evaluation that the behavior was not normal is from her current perspective: "At that time

I thought, she was driving me crazy. It's not my fault. But when I look back on it, it was not normal." Although Darlene used the term, "driving me crazy," it appears that she meant the term as it is used in common parlance, as "my mother is so irritating."

Furthermore, the external society generally "normalized" the participants' behaviors. For example, when Sarah attempted suicide as an adolescent, adults were angry at her, but they did not consider her "crazy": "I wasn't treated very well [at the hospital]. I think it was like a, you know, dumb teenager react—, reaction. They were mad at me. Everybody was mad at me." Later, when Sarah was in college, she considered her mood fluctuations normal because "I bought into what the group of people around me thought, [which] was that most of the way I was was because I studied all the time."

Thus, the participants were aware of uncomfortable feelings and unusual behaviors. However, as long as other people, including the authorities (like the psychiatrists at the hospital), viewed the participants' behaviors as normal, the participants did not consider otherwise. The external situating of self is consistent with Jacques Lacan's ideas about the creation of the self. He postulates that it is only through the "gaze of the other" that one finds a label for self, even though that label always reflects the attitudes and desires of others (Lacan, 1966/1999). Lacan's ideas on how others create the self, as articulated by Dor (1997), are:

The child recognizes himself in his own [mirror] image only insofar as the other has already identified him with this image. He thus receives from the gaze of the other the confirmation that the image he perceives is indeed his. The ego ... is irreducibly dependent on ... the other.

(Dor, 1997, pp. 159-160)

Thus, participants' evaluation of how "normal" their feelings and behaviors were depended on the assurances of doctors and other people.

Parental Behavior

Even though the participants did not experience themselves as out of control or unpredictable, several described parental behavior that seemed to be that way. For example, Rose described at length her mother's erratic moods and spending sprees. Rose's mother would alternate between energetic loan or clothes buying/stealing expeditions and total emotional and energetic collapse. Rose said, "My mother was very, very depressed all the time. Um, if she wasn't one way, she was another." Rose called her mother "a thief and a liar and a cheat." Rose reported how her mother would switch tags and steal clothes; take out loans that she never intended to repay; forge her husband's names on loan papers; or steal from a neighbor at the time of the neighbor's death. Her mother was also physically and verbally abusive to some of the children.

Yet Rose had only limited labels to make sense of it. She could say, "You know, I mean she was—, she was all chou chou chou [using hand motion to indicate crazy], you know, and I never gave it a name except ... mom was wacked." Her mother saw many psychiatrists or psychologists, but the only diagnosis Rose heard that the doctors gave her mother was depression. Rose knew there was more, but no one could explain it. Another explanation that people used in Rose's world was menopause: "My mother. They blamed it on menopause." Thus, the labels available to explain Rose's mother's behavior were

“wacky” (by the family); depression (by the authorities); or menopause (by the community).

Other participants also commented on parental behavior that they could not comprehend. As a young child, Natalie wondered why her mother was drinking herself to death and made no effort to stay alive for Natalie, who was now the youngest child. Kevin could never understand why his father clamped down on Kevin’s enthusiasm and then humiliated him for moments of eagerness. Darlene’s mother and grandmother had “no boundaries.” Darlene could not understand their behavior and offered the example of her mother’s sudden and unexpected rejection of Darlene’s dream of becoming a singer. The participants could not make sense of these parental behaviors that seemed erratic, unpredictable, and unexpected. The labels “wacked” or “crazy” were used by some to capture all those unpredictable behaviors.

Limited Set of Labels

These findings suggest that there were only a few labels or frameworks that were available for participants to make sense of their own feelings and experiences as well as parental behavior. The labels were applied broadly. Having language is essential for making sense of phenomena. From a social constructionist perspective, cultural and social forces provide a language to understand personal experience, since social ideas are created and perpetuated through language and relationship (Gergen, 1994). Language and discourse, through “communities of interlocutors,” express and define culture (Gergen, 1994, p. ix). There is a vital interrelationship between and among individual experience

and societal beliefs and to fully understand an idea, one must place it in its historical context (Cushman, 1995)

To the extent that the participants were aware of internal feelings, they organized some but not all into unified categories. Sadness and wanting to die were understood to be part of depression. Irritability and anger seemed related to each other but unrelated to other feelings. Happiness and excitement were related to each other and possibly to other “good” feelings. These were all discrete categories, but energy, mood, good feelings, bad feelings, and anger were not categorized together.

Many of their feelings and experiences could be organized together as depression, and psychiatrists later confirmed (for the five participants who considered themselves depressed) that what they called depression was in fact “clinical” depression. Another organizing label involved social anxiety or isolation.

Other feelings, even very unpleasant ones like intense anger, were not so easily categorized. The participants had words to describe the feelings, but no labels that organized them into a category or cluster of categories. There was also no external validation or endorsement of these experiences.

Another area of experience was physical sensations or experience. Like the feelings of anger or expansiveness, there was no organizing framework for physical experience that felt uncomfortable. Nonetheless, some of the participants’ descriptions of behaviors suggested that they were experiencing bodily sensations or physiological pressure. This implicates the age-old question about the nature of linkages between mind,

emotion, and body. To the extent the participants had bodily experiences that impacted their moods, thoughts, and feelings, it was difficult to put these into language. This difficulty is consistent with the Cartesian dualism between mind and body, a dualism well entrenched in American society. According to McDougall (1989) (written before the advent of recent neuropsychological research), emotions consist of both a psychological and a physiological part. Sometimes the psychological and physiological components are separated from each other, so one or the other manifests without the ability to explain it.

Lacan offers another dualism or splitting, and that is between experience and language. Lacan suggests that language necessarily removes us from our direct experience.

The basic property of linguistic utterance is to evoke a reality by means of a symbolic substitute that inevitably causes a split between experienced reality and that which comes to signify it.

(Dor, 1997, p. 134)

In other words, if the participants had physiological experiences that were related to their feelings and thoughts, they could not adequately express them because language had taken over experience. In American society, we describe our moods, feelings, and thoughts, but usually do not focus on somatic experiences.

Having a representational phrase is useful. The participants did not need to describe their “depressed” feelings or somatic states in detail, as people would understand if they simply said they were “depressed.” Wittgenstein (1953/2001) explained how words like “depressed” take on meanings. He used the phrase “in pain” as an example. He noted that none of us will understand what another person means when that person

indicates that he or she is “in pain,” but we know that the word involves some kind of unpleasant sensation. As part of the “language game,” we repeat the word and apply it to others, even if we do not and cannot ever know what they feel. Part of the social contract is the assumption or pretense that we understand one another’s “pain,” even though all any of us know is our own sensory experience that we have labeled as pain. Thus, the people in the participants’ social worlds thought they understood participants’ experience when they indicated they were depressed.

These findings suggest that in popular discourse in the mid to late 20th century, acceptable categories of experience included “depressed,” “socially isolated,” “in menopause,” and “crazy.” Someone who was depressed was not “crazy.” That term applied more to behaviors that seemed unpredictable and inexplicable.

Another way that participants made sense of their life experience involved the repercussions of difficult early parental relationships. That is discussed in the next section.

Relationships with Parents

Participants understood their adult lives in part by looking at the repercussions of problematic early parental relationships. All of the participants described one or both parents as emotionally unavailable in some way, due to factors such as mental illness, difficult personality, being “wacked,” or family tragedy. We do not have evidence of the nature of the participants’ parent-child relationship in infancy. The earliest experiences the participants discussed were sibling deaths when participants were ages two to four.

We do, however, have the participants' reports of the various ways they felt estranged or emotionally disconnected from one or both parents during childhood and adolescence. For Kevin and Natalie, who lost siblings in early childhood, their parents disappeared emotionally after the infant's death. Also for Kevin, his father became overly controlling of Kevin's exuberance, but not particularly attuned to Kevin's affective life. Rose and Sarah explained their mother's unavailability as being due to the mother's depression or "craziness." Darlene felt continually unsupported and criticized by her mother and grandmother, with a final blow being her mother's last-minute criticism of Darlene's dream of becoming a singer. Jodi felt abandoned by her father after her parents' divorce when she was ten. He "made himself absent from our lives. ... He did not really want to have much of—, much to do with us."

The participants have some sense that the nature of their emotional connection with their parents had an impact on their adult emotional lives. They expressed ongoing distress about these early relationship issues. They described how they felt estranged from parents in childhood and told stories of particular incidents when a parent failed them. They also discussed different ways those parental relationships negatively impacted the rest of their lives. For example, Kevin and Sarah feel delayed in their personal and professional development because of their early family life. Rose recounted with great distress how she found herself repeating some of her mother's most upsetting behaviors, like disappearing into her room and abandoning the children at Christmas.

The participants are less clear about whether the deficits in parental support and nurturance impacted their adult experience of moods or physiological experience. As noted above, the participants had some sense of somatic sensations that were related to depressed and other moods and behaviors. However, it was not easy to articulate the nature of these bodily experiences because in Western society, functioning with Cartesian dualism, “the body” is usually seen as a separate entity than “mind” and “me.”

Neuropsychology and attachment theory and research propose ways to conceptualize how parental deficiencies in attunement in childhood may have impacted participants’ adult emotional and physiological lives. Brain research suggests that our conscious minds cannot control the biochemical experience of feelings (Damasio, 1999, 2003; LeDoux, 1996). Feelings are more powerful than thoughts and there are neurological explanations of why it is difficult to change a feeling by thinking about it. On the other hand, our cognitive naming of a feeling is a dominant process over the biochemical process itself; language plays a central role in creating symbolic representations of biochemical experience. LeDoux notes: “I’ve redefined the problem of emotional feelings as the problem of how emotional information comes to be represented in working memory” (LeDoux, 1996, p. 282). In other words, the feeling is not a feeling until we have a cognitive label for it. This suggests that how we label our experience is central in the construction of the experience, which makes neuropsychological ideas consistent with the ideas of Wittgenstein, Lacan, and social constructionism.

The neuropsychological research has found that parent-child attunement is essential for teaching the infant how to modulate and regulate its own affect (Schore, 2003a). The entire interaction in infancy is an affective and nonverbal one occurring before the child has the use of language. Schore's research and analysis indicate that early parent-child interactions have a long-term impact on the future emotional and relational life of the child. "The central thesis of my ongoing work is that the early social environment, mediated by the primary caregiver, directly influences the final wiring of the circuits in the infant's brain that are responsible for the future socioemotional development of the individual" (Schore, 2003a, p. 73). An adult's difficulty with regulating moods is believed to be related to that person's early attachment experiences. The attachment process consists of an interaction between biochemical and genetic systems with the maternal environment (Schore, 2003b).

Fonagy, Gergely, Jurist and Target (2002) expand these ideas into other areas. Synthesizing developmental, attachment, and neuropsychological research and theories, they give the name of "mentalization" to the human ability to make representations of psychological states. They make the case that the ability to mentalize is a central aspect in the development of a sense of self. They conclude that the ability to mentalize, or make symbolic representations, about one's psychological state develops from the interactions between parent and child. Affect regulation is essential to a sense of self, which in their view is created entirely by mentalization, but affect dysregulation is related to various kinds of mental illness.

Even without our knowing participants' experiences in infancy, there are aspects of participants' stories that could be viewed as consistent with these neuropsychological findings and theories. Each participant recounted at least one, and often many, times when they felt a parent had failed to understand her or his experience. Of the universe of stories that participants could tell about their relationships with their parents, participants chose to recount stories where the parent could not support the affect of the child.

Participants provided various explanations for why their parents were not emotionally available, including dealing with their own emotional dysregulation, their grief at losing children, their own out-of-control behavior, and their own unhappy childhoods. The participants, now well into adulthood, were able to analyze and explain the reasons for their parents' unavailability with great insight. Nonetheless, the participants still experienced their parents as inadequately attuned to their needs when they were children.

The participants also reported both internal and interpersonal difficulties in adulthood. The neuropsychological research suggests that participants' adult emotional dysregulation is related to their difficulties in infancy and childhood in having parents attuned to their needs. According to the neuropsychological research, young children learn emotional regulation from their parents through the parental attunement to the child. The attuned parent contains and regulates the child's emotional experience. Later the child can implement emotional regulation on his or her own, as learned from their parents. With insufficient attunement and inadequate emotional containment, there are

physiological and chemical impacts on the development of the child's brain. From this viewpoint, the participants' emotional and even physiological difficulties could have resulted from an initial lack of parental attunement, followed by physiological changes in the participants' brains.

The participants articulated some kind of connection between their early relationships with their parents and their adult emotional experiences, but could not clearly explain the connection. It is possible that the connection involves physiological factors, including imbalances in cortisol or other biochemical compounds, or some other kind of heightened physiological arousal. These may be difficult to articulate; they may also be beyond the participants' awareness.

There may be mind-emotion-body linkages that participants could not articulate but that emerge from this particular neuropsychological social construction. Participants seemed aware that their early "crazy" environments impacted their adult emotional functioning. Yet they did not connect these environments with later physiological issues, just as they generally did not connect their early losses to their adult experience. Up until the last ten or fifteen years, in the United States difficult childhood experiences were not considered to be related to adult emotional regulation or dysregulation. The neuropsychological research cited above is recent. Thus, it makes sense that the participants did not consider mind-body connections. I will continue to track how the participants worked (or not) with these explanations.

Conclusion

What is most prominent from these narratives pre-bipolar disorder diagnosis is how few labels were available to explain experience. Labels such as depression for self and “wacked” for others had to represent a broad range of feelings, emotions, behaviors, and physiological functioning. Catch-phrases like depression or crazy were used to stand in for all these otherwise unorganized experiences. There were no phrases to represent other feelings, like irritability, anger, expansiveness, and high energy. All of this changed dramatically when the participants received the label of bipolar disorder.

CHAPTER FOUR

INITIAL REACTIONS TO THE BIPOLAR DIAGNOSIS

Juliet:

'Tis but thy name that is my enemy;
 Thou art thyself, though not a Montague.
 What's Montague? It is nor hand, nor foot,
 Nor arm, nor face, nor any other part
 Belonging to a man. O, be some other name!
 What's in a name? That which we call a rose
 By any other name would smell as sweet;
 So Romeo would, were he not Romeo call'd,
 Retain that dear perfection which he owes
 Without that title. Romeo, doff thy name

What man art thou that bescreen'd in night
 So stumblest on my counsel?

Romeo:

By a name
 I know not how to tell thee who I am;
 My name, dear saint, is hateful to myself,
 Because it is an enemy to thee;
 Had I it written, I would tear the word.
 (Shakespeare, 1623/2004)

Receiving the name bipolar disorder as a diagnosis was a defining moment for every participant. For some the change was immediate; for others it took a while, like several hospitalizations, for the transformative impact to take place. Some participants were not satisfied with the bipolar diagnosis and grappled with its meaning. But whether grappling or accepting, by the time of the interview, each participant had come to the place where having the bipolar diagnosis was an organizing paradigm for much of their life experience. It impacted their sense of themselves and views of others, both of which

are explored in this chapter.

Participants' reactions to receiving the diagnosis moved through a developmental process. Initially participants reacted to being assigned what they feared was a "real" mental illness, unlike a diagnosis of clinical depression that all but one participant had previously received. The participants were initially quite distressed by the bipolar diagnosis and had negative associations to it. There was a sense that getting a bipolar disorder diagnosis involved crossing a threshold from "normal" to "crazy."

Participants' reactions reflected societal beliefs about bipolar disorder and they associated the manic or hypomanic symptoms of bipolar disorder with being out of control. They expressed concern that they would lose control and behave unpredictably, perhaps like their "wacked" parents.

Note that the questioning by Romeo and Juliet in the passage above of the meaning and power of words and labels is relevant to this discussion about how a particular society views a name and a label.

Initial Reactions to the Diagnosis

All of the participants were adults (late 20's to 50's) when they were diagnosed as having bipolar disorder. Some, like Rose and Natalie, were diagnosed recently, within three years. Others were diagnosed some time ago. Sarah, for example, was diagnosed about 15 years ago, when she was in her mid-20's. For all, the bipolar diagnosis followed other mental health diagnoses.

First “Mention” of Bipolar Disorder

Some of the participants noted that a psychiatrist had previously mentioned the words “bipolar disorder,” but the doctor had indicated that the participant did not have *that* diagnosis. The psychiatrist assured the person that she did not need to worry. Rose, for example, indicated she “had heard” the word “bipolar” when she was briefly hospitalized ten years earlier after a suicide attempt. She was relieved when they “only” diagnosed her as depressed:

They bantied that word around, as, as they talked to me, but never actually said that was what was wrong. They went back to the word “depression.” Ten years ago. And put me on Prozac. ... [My doctor] was a psychiatrist at the medical center and said it in a—, it—, just a—, uh, like—, you know, a wave. “That y-y-y-you act like maybe you’re bipolar bu bu bu bu but” [speaking as if stuttering], my diagnosis was always just depression. So I heard the word manic-depressive and bipolar. But let it go because of what I knew society says about manic depressives.

Rose indicated she was well aware of the negative views of bipolar disorder, so she was quite relieved to “let it go” when the psychiatrist assured her that she does not have *that* dread disease.

Similarly, Darlene had been diagnosed as depressed about fifteen years before being interviewed. As with Rose, the doctor made sure she knew that he did not consider her to have bipolar disorder:

I had been put on lithium a few years before that, just as an adjunct of therapy to the Prozac. And I, I remember that my doctor said “Now I’m not putting you on lithium because you’re bipolar, because that’s not what I think.” Like—, he was like, “Don’t get worried, I’m not considering you bipolar. I just wanna try this lithium to help the Prozac.

For Darlene, it was reassuring when the doctor was so clear that he did not consider to

have bipolar disorder. Darlene has a clearer memory of being told she does *not* have bipolar disorder than when she was told she *does*:

You know, I don't recall the very moment that the words [bipolar disorder] were said to me, because they had been said to me many years before, you know, to say, "No, no, you probably don't have bipolar."

This initial mention of this diagnosis and dismissal by their doctors was fuel for the participants' reactions when they later *were* diagnosed with bipolar disorder, because it suggested that now they *did* need to worry.

Note that all but one of the participants had already received formal diagnoses of depression. Some had made suicide attempts and several had been hospitalized for depressive symptoms. Natalie is the only participant who did not have a prior diagnosis of depression. She indicated she had been an alcoholic for all of her adolescent and adult life until age 44 when she became sober. She was immediately diagnosed as having bipolar disorder. Thus, the "depression" part of bipolar disorder was not a surprise to most participants. The only part that was "new" was the "hypomanic" or "manic" part of the bipolar diagnosis. Yet it is this element of the diagnosis to which participants reacted.

Initially Rejecting the Diagnosis

The participants dismissed, denied, or rejected the bipolar disorder label when they were first diagnosed. Rose thought to herself, "No, I'm just depressed" or "I'm just happy." Rose shared how her initial internal reaction to the diagnoses moved through several phases of denial, all of which took place while the psychiatrist was speaking. First Rose denied and rejected the diagnosis. Next, she decided she would be "nice" and

simply listen to the doctor. Describing the steps by which she mentally dismissed it, she first told herself that psychiatrists over-diagnose. “And, boy, they just have to stick labels on you.” She then said to herself that her psychiatrist was “trying to make too much out of this.” She thought the doctor was unnecessarily “going to extremes.” She was thinking, “Prozac’s fine, because it was fine last time.” She then reminded herself to be pleasant to the doctor, because the doctor is “free. How can you argue with free?”

As the doctor continued and described the symptoms, however, Rose could not help but listen and notice that the symptoms did seem to fit her. Rose started to feel terror, like “the frog in the boiling water.” Then, like a misbehaving child, she decided it must be that she needs to be punished for past misbehavior:

Oh my God! Oh my God! [said slowly] That *is* me. Because I’m denying it at first. Because your—, my memory ... is very selective. Some of the things I remembered here from way, way, way back when I had forgotten I did. So, yeah, OK. I’m fine. I did tha—. Erase that past. Erase that past! I was a bad girl or did something. But no, I’m fine now. I’m fine now [very fast]. So I don’t have to remember that.

Note how Rose refers to selective memory and ends with wanting to forget, again, the “bad” things she did in the past. Also note that one of her criticisms of the psychiatrist was that she was “going to extremes,” one of the very symptoms the psychiatrist was attributing to Rose. This suggests that Rose was unconsciously “taking in” the words and their meanings, even while consciously rejecting them.

Natalie also rejected the diagnosis initially. She did not know much about bipolar disorder and thought of it simply as “yippy skippy.” She recognized that she was a functional alcoholic for many years, but when she was diagnosed with bipolar disorder,

she said to herself, “I’m not manic depressive. You know, there’s no way. Cause that’s just NOT me.” For Natalie, the initial rejection of the diagnosis was easy. Things became more complicated for her later on.

Getting the Diagnosis

For most participants, having a doctor diagnose them as having bipolar disorder was initially quite distressing. For example, Kevin indicated he was initially “devastated” when he got the diagnosis, about seven or eight years before being interviewed.

Jodi, for a few years before getting the bipolar diagnosis, had been drinking more and engaging in unusual behaviors, like exercising excessively and chatting with many people online. She noted how these were quite odd behaviors for her, a shy, married internist, mother of young children. She explained these behaviors as due to the stress she was experiencing at home. She saw it then as “mostly reactive kind of stuff to what was happening in my life, um, because I, I was very, very unhappy.” The first psychiatrist to hint that she might have bipolar disorder did not give a definite diagnosis:

She said, “Did anybody ever tell you that you might have bipolar disorder?” And I—, my jaw just like DROPPED, and I was like, “NO. I mean it never even dawned on me that—.” WHY it never dawned on me I didn’t know.

A few months later, Jodi had an episode at work where she was crying uncontrollably. The next day she went to a colleague of that first psychiatrist. When interviewed, she described the shock she felt when this second psychiatrist definitively diagnosed her as having bipolar disorder.

And that visit was one of the most painful things that I have ever experienced. ... The physician that diagnosed me that day was, um, very uncaring. He really

had no clue what he was saying to me and what kind of impact this was having on me. Absolutely none. Um, and basically sat there with me and said, “This is what you have. You know, you’re going to need to be on medication for the rest of your life. This is something you’re going to have to deal with for the rest of your life. Here’s a book to read. Here’s—, go to this support group. And off you go.” Trot trot.

The sense of being dismissed without thought is captured in Jodi’s phrase “And off you go. Trot trot.” The phrase has the sense of someone giving rote directions and who never even notices the person or horse he is ordering to move along. Jodi experienced getting the diagnosis as a “blow,” both because of the meaning of the diagnosis and by the way it was delivered to her. She already felt not “normal” in several ways, as both a lesbian and a recovering alcoholic.

You have to, you have to understand what a tremendous blow to my ego it was to be diagnosed with bipolar disorder... You cannot live the rest of your life like other people. You ... are different than other people. ... You know, the—, the, the bottom line is, you’re not NORMAL, you know [laughs]. And then I have to like adopt a li—, you know, a life that is not in the mainstream, you know. On top of that. It’s like, well how much do you want to take on? [laughs hard] ... It was really hard. It was, I mean, it’s, it’s no wonder it’s taken me like five years to even to get to a space where I can go, OK, like I’m doing all right now It’s taken all of this time, really, to kinda get my feet underneath me. And just to be able to ... even talk about it in a way that I understand.

It is interesting that Jodi feels that it has taken her five years to recuperate from the devastation of initially getting the diagnosis.

The first suggestion that Sarah might have bipolar disorder was from her mother’s psychiatrist, who had recently diagnosed her mother as having bipolar disorder. Sarah said she “fought it tooth and nail” even though “his reasoning was very sound.” His thinking was that Sarah’s mother was now diagnosed with bipolar disorder; Sarah’s

grandmother also had a bipolar diagnosis; so Sarah may well have one too. Sarah's reaction to the long-distance diagnosis by her mother's psychiatrist both irritated and frightened her. "It pissed me off. Um, it probably scared me too, but I don't think I knew that it scared me."

Some of the reasons participants explained for their distress when receiving the diagnosis are discussed in the next sections.

Associations to Bipolar as a "Crazy" Diagnosis

The initial association of some participants to bipolar disorder was that bipolar disorder is a "crazy" diagnosis, unlike depression, and that this meant that they were crazy. The manic or hypomanic part of the diagnosis meant that they were or would become "out of control" and unpredictable. These reactions were based in part on societal notions about bipolar disorder and mental illness in general, and mania in particular. None of the participants commented on the fact that their fearful associations were only to mania, but it is clear that is the case, since their prior diagnoses of clinical depression did not result in the same fearful reactions

When Rose was asked about her initial reaction to the diagnosis, she said it meant "nuts. Manic. A manic depressive is somebody who's institutionalized. A manic depressive is completely out of, out of control. Somebody that has to be locked up. Or is doped up so bad that they really can't even function anyway, except they can't hurt themselves." Rose noted how in her culture of origin, one would never admit to a mental health problem. In fact, "even when my family had cancer, we said it in a whisper." She

noted that she still chokes on the word “cancer,” which is not even as negative in her mind as mental illness. “You whisper them, nobody do—, nobody knows. Nobody can find out. It’s something you gotta hide and it means you’re crazy. It means you’re crazy [slower].” For Rose, bipolar disorder means:

So I didn’t want to be the lithium-laced wack job who has to be drugged in order to have a—, have a life, because I’m mentally ill. I don’t want to be mentally ill. ... I was in an institution for 24 hours I was with people who ran up and down the hall thinking that bombs were landing on him from Viet Nam. The woman in the bed all night screamed and cried. Um. They took away my shoelaces [laughs]. They took away my watch. Ah. ... That’s what crazy people are.

Rose’s associations to mental illness and bipolar disorder are terrifying. They are of people who are psychotic, traumatized, and out of control, associations based in part on her one-night stay in a mental institution after a (possible) suicide attempt.

The only reason Natalie saw a psychiatrist was as part of her rehabilitation from alcoholism. She said a psychiatric visit was recommended in order to obtain medication to ease detoxification from alcohol. She said that when she first heard the words “bipolar disorder,” she thought “crazy”:

I didn’t think anything was wrong with me except that I drank. I was a drunk, you know. ... So I went to Dr. X. Then in the process of my intake, and two visits later, he tells me, “You know, we really need to treat you for this—, situation. The situation is I believe you’re bipolar.” [said in a deep pedantic voice].

Interviewer: So how did it affect—. What did you hear when he first said that?

Nuts [laughs]. It’s what I heard. I heard, “Oh, the doctor’s telling me I’m nuts. That’s nice. I’m going to go back and drink.” But I didn’t.

For these participants, the very first association to the notion of bipolar disorder is that one is “crazy.” Note that the participants all used colloquial and very pejorative

words like “nuts,” “wacked,” and “crazy,” rather than “ill,” “sick,” “troubled” or “mental illness” to describe their initial associations.

Worse than a Diagnosis of Depression

For all of the participants, bipolar disorder is a “more crazy” diagnosis than depression, a diagnosis all but one had previously received. Jodi articulated why bipolar disorder is more fear-invoking than depression. She said she knew people can do “strange things” when they have a diagnosis of depression:

But for some reason people look upon bipolar disorder as being MORE crazy. You are crazy! You know, if you have bipolar disorder, you’re crazy. You know, you’re mentally ill. This is a different category. You know. You have this, you know you’re gonna like fly off the handle. You’re unstable, you know. Nobody ever knows what you’re gonna do, you know. And, and that, you know, that unpredictability I think for people is, where they place—. It makes mentally ill people scary, to them. And, I, I think that’s the difference.

Um, I think people look upon depressed people as, like, pretty harmless [laughs]. All they’re gonna do is harm themselves, you know. It may be very harmful to the people in their lives who care about them, but it’s not like they’re gonna—, they’re not likely to be homicidal, or, like, you know, rage or do something. But you don’t know that necessarily about bipolar people because they’re a little bit more unpredictable with their inn—, in a state of, of rage. Or, you know, their mood is very unstable. They can get aggressive

Jodi’s understanding of her association to bipolar disorder – or really mania – involves the societal fear of the unpredictability of someone with mania. The person may be aggressive, may rage, may be homicidal, and will be out of control. These qualities are what is most frightening.

Jodi explained that from her perspective, depression is socially acceptable, not something to be ashamed of, like bipolar disorder.

Depression I could deal with. Depression I had been dealing with. Depression you feel bad. People know what it is. You know, they're starting to understand, you know, it's a mental illness. You know, peo--, it's not, you know, a matter of moral weakness. You can—, take—, you take medication if you need it. You know, you get therapy if you need it. You—, it comes and goes. You know, it's treatable. And it's not something that you need necessarily be ashamed about. It's pretty common. It's so out there. Celebrities come out there and they're like, "Oh, I have had depression. You know, it's like nn—. You know, it's not a big deal, ANY MORE.

Jodi's analysis is societally based. She refers to celebrities who have been depressed and how depression is now "out" in social discourse. It is not considered a moral defect, apparently in contrast to bipolar disorder.

When Sarah was in college, she learned that her mother was diagnosed with bipolar disorder, not "just" the depression of the previous diagnosis. Although Sarah indicated she was not traumatized by learning this, she acknowledged that she knew that bipolar disorder is of a different, and more serious, rank order than depression. She said she had the "early 70's idea" that "most really creative, bright people, introverted people suffer with depression anyway." She knew that bipolar disorder "was a different rank. I mean, it's like bipolar and schizophrenic are the, you know, the crazy diagnoses" Note how Sarah's understanding, like Jodi's, references general societal attitudes about depression as something that socially approved people, like celebrities and creative people, experience.

Kevin also sees depression as commonplace and socially acceptable: "It's run of the mill. I mean, you grab other people off the street and, um, I'm telling you, a high percentage of them have been on antidepressants at some point or other." But Kevin

indicated his initial concern about the bipolar diagnosis reflected both the societal associations to mental illness as well as his own associations. He indicated he would prefer a diagnosis of depression to one of bipolar disorder. He uses his diagnostic knowledge as a psychologist to try to diagnose himself only with depression-related conditions, but finally concludes that he has “cycling” symptoms such as irritability.

These participants understood the dominant American society today as not only accepting depression but perhaps viewing it as part of the life experience of celebrities and creative people. However, the participants indicate that both they and society view bipolar disorder, i.e., the manic or hypomanic symptoms of bipolar, as “true” mental illness. In these discourses what brings bipolar disorder into a different and more serious category than depression is the perception that mania or hypomania is “out of control” and unpredictable.

Gradations of Bipolar Disorder

Further evidencing the socially perceived hierarchy of mental disorders, with the manic symptoms of Bipolar I Disorder considered the most serious, participants made it clear they preferred getting diagnoses of Bipolar II Disorder or cyclothymia, diagnoses that are considered less serious than Bipolar I Disorder.

Both Kevin and Sarah, the two psychologists among the participants, preferred a cyclothymic to a bipolar diagnosis. For Sarah, it was initially a relief when she self-diagnosed in psychology graduate school as having cyclothymia rather than bipolar disorder, because cyclothymia is not considered as serious.

I thought I was cyclothymic. ... And that was really important to me. I wasn't bipolar; I was cyclothymic, which was just like [the] same thing but lower key. ... I thought that it wasn't so bad, I think. I thought that I had, like, a lesser version of what my mom had and I didn't have to get any worse.

Kevin still emphasizes that he has only a minor mood cycling condition, more like cyclothymia, even if the official diagnosis is bipolar disorder. Yet even as he states this, he wonders if his emphasis on the distinction is a defense mechanism to deny the severity of his condition.

You know, I'm, I'm maybe a small subset of a very mild kind of a, and maybe it's not even, you know what, a kind of qualifying, what people sometimes do to distance themselves from ... um ... [long pause].

But again, I mean, maybe it's sort of the gradations of alcoholism, right? You say, because I haven't had seven DUI's and, and, you know, been in the hospital for detox, I'm not really—, I don't really have this condition. Well, there's gradations of—, I guess you can apply the label. But—, I haven't really been comfortable with the label.

Kevin hardly finishes any of these thoughts. He seems to want to minimize his symptoms and diagnosis, but his skills as a clinician alert him to the possibility that he is engaged in denial, like how alcoholics minimize the seriousness of their condition. Notice the negative and morally evaluative nature of the analogy, since someone with seven DUI's is truly dangerous and risks killing someone on the roads.

Similarly, Darlene wondered if her initial bipolar diagnosis of Bipolar II Disorder, later modified to Bipolar I, was given only to minimize her distress:

They said hypomanic, so I—, so that meant hyp—, Bipolar II. I think people were always trying to be, like, careful not to upset me too much. You know, like, don't want you to think it's Bipolar I cause that's the serious one. It's just Bipolar II. That was the impression I got. And hypomanic, meaning they hadn't heard any outlandish stuff out of me. I wasn't, you know, having sex with six guys or, uh,

you know, spending \$20,000, or anything like that. So, and jumping off roofs or anything. I just [got] the feeling that I was kind of minorly hypomanic, you know, so that meant Bipolar II. That was the impression I got.

“Outlandish” is defined as “freakishly or grotesquely strange or odd, as appearance, dress, objects, ideas, or practices; bizarre” (Dictionary.com Unabridged, Retrieved 2007).

Darlene’s use of that word indicates that so long as she had a Bipolar II diagnosis, she was generally within the norm. Once she had a Bipolar I diagnosis, she was in the category of being a “freak,” “grotesque,” “strange,” “odd,” and “bizarre.” No wonder the participants did not want to be labeled as having Bipolar I.

These findings indicate that participants’ attitudes towards the various mood disorders reflect and incorporate societal (and DSM-IV-TR) notions of the gradations of bipolar disorder. Their internal preferences for diagnoses viewed by the DSM-IV-TR and the psychiatric community as less serious might be considered similar to negative internal beliefs about self among other denigrated groups, like internalized racism, anti-Semitism or homophobia.

Will I be like a “Crazy” or “Retarded” Family Member?

Some of the participants’ initial reactions to the diagnosis involved associations to their family members with significant mental health or cognitive disabilities. For example, Jodi is an internist in a high-pressure practice. Yet when Jodi’s psychiatrist suggested that she might have bipolar disorder, she initially associated to her father’s low functioning due to his having bipolar disorder:

He was very dysfunctional with his bipolar disorder. It included psychosis. He had multiple hospitalizations. It was pretty scary stuff. ... And, I, um ... I walked

out of there, kinda really shocked, and, um, VERY upset at the idea. Because of my father mostly. I didn't want that to be what they were going to tell me.

When the subsequent psychiatrist definitively diagnosed Jodi as having bipolar disorder, she again thought of her father's disability and "heard" the psychiatrist telling her that her life would also be one of low functioning. "All I could think of was my father. Because I knew what his life was like. And his life was horrible. He was so dysfunctional with his disease and his illness." She said at the time she simply did not know that her life course would be any different from that of her father, so she imagined the worst:

Um, all I could think of was, I'm going to be in the hospital. I'm going to lose my job. You know, I'm gonna—. I'm not going to be able to take care of my children. I—, you know, I couldn't think of anything other than, you know, the life that he had led which was—, which was barely on the functional range, you know. ... And he—, at times he was not functioning at all. You know, he was in the hospital. Um, and, that was pretty frightening to, to, to see. That, you know, you had to have somebody around all the time that was, you know, to take care of you. Well that's all I could think of, you know, when they told me that – you're going to have this for the rest of your life and you're gonna be like your dad.

Sarah started the interview by describing her mother's lifelong depression, particularly when Sarah was growing up. Her mother had been in psychotherapy "for a long, long, long, long time. But then, um, nothing really seemed to help her that much. She just kept being depressed and depressed and depressed." Sarah indicated that her mother had a manic episode with psychotic features when Sarah was away shortly before starting college; her grandmother had also had a manic episode. Sarah explained that her mother received poor treatment and inadequate medication before finally receiving the bipolar diagnosis and medication. Sarah's sense of why treatment did not work for her mother involves the severity of her mother's condition: "She just was too, you know,

severely, really severely depressed.”

For Sarah, knowing her mother was so depressed for such a long period made getting the bipolar diagnosis herself very difficult. Her mother did not improve for a long time, even with many years of therapy and medication. Sarah apparently feared repeating that situation in her own life.

When Rose was first diagnosed with bipolar disorder, she thought it meant that she was “wacked,” “nuts,” and “crazy.” She had two initial associations. The first was to a brother-in-law with an intellectual disability: “My husband’s got a retarded brother that’s, that’s severely retarded. Um, I look at him, you know an, an, an—, he should have been institutionalized but they kept him at home.” Her second association was to the psychotic people during her brief psychiatric hospitalization after a (possible) suicide attempt. Rose’s initial associations were of people with significant difficulties, as if having the diagnosis meant that she would have to be “institutionalized” or would manage in the community only due to the kindness of family.

Participants’ initial associations to relatives with bipolar disorder or other serious conditions were of the considerable difficulties these family members encountered with functioning in society, not of the family member’s courage and successes. It is as if getting the diagnosis invoked the most frightening societal stereotypes of bipolar disorder, with an overlay of the most dysfunctional characteristics of their relatives.

Having a Permanent Condition

One difficult aspect of initially receiving the diagnosis was hearing that the

condition was permanent. For Jodi, who was grappling with other new lifelong characteristics, like being a recovering alcoholic and a newly “out” lesbian, this one additional trait seemed overwhelming.

I think it was the idea that I was going to have to live with this for the rest of my life. And this is basically what he told me that day. “This is going to be the rest of your life. You don’t have, you know, something that you can just say, OK, you know, this is going to be, you know, two months out of your life. This is going to be something that we’ve now given you for the rest of your life.”

For Jodi, the permanence of the condition was part of what felt like such a big “blow.”

When Darlene was first diagnosed as having bipolar disorder, she was initially relieved at getting a diagnosis that explained her many symptoms. But she believes that she did not take it “seriously” then. “And we would talk about it in therapy and I would, you know, just kinda hem and haw, like, ‘Yeah, yeah, yeah, whatever, yeah.’” Her attitude changed only when she realized bipolar disorder is a permanent condition that is now somehow a part of her:

But when they diagnosed me as Bipolar I, I finally got it. I finally realized how actually sick I was. I mean, I knew it was biochemical. I knew there was nothing I could do about it but take medication and, you know, take care of myself. I had to do one, two, three, four, five, whatever these things were that I had to do. But that I would always have it. That I wasn’t gonna get rid of it. It was there. It was me.

Darlene’s last sentence is addressed below. It suggests that the diagnosis of bipolar disorder involved more than having an illness or condition that requires medication, treatment, and five “things” to do. It also transformed the participants’ identities and became a part of self.

Threshold

Being assigned the label also became an experience of crossing over the threshold of “normal” to “abnormal.” And like Lot’s wife, looking back at their lives pre-diagnosis was fraught with risk. Going back to that pre-bipolar time would either re-traumatize them about the difficult times in the past or evoke an idyllic time of happiness pre-bipolar diagnosis. They could now look back only through “bipolar eyes” and view their and their family members’ previously unlabeled behavior as bipolar.

The participants often referred to other people as “normal,” in contrast to self as not normal. They also continually compared their inner experiences and behaviors against an imagined standard of “normal.” For example, Kevin explained that he closely studies his mood fluctuations, noting that his mood is usually “below” “normal.” When asked what “normal” means, he responded:

Well, a euthymic mood. You know, mood that is neither—, you don’t feel energized or particularly expansive, but neither do you feel, um—. I guess a lot of the language we use at both poles, uh, have to do with space and, be, be, larger and expanding or withdrawing and contracting. Depressed has a sense of weight and social withdrawal, those kind of things. So that I was, sort of, not aware of the painful feelings, particularly, or, uh, sense of heaviness or weight. But also not feeling, um, particularly gregarious or outgoing or, uh, loquacious.

Later he admitted that he may idealize “normal.” He said, “There’s a world I hold out that’s kind of [an] idealized, uh, perfectly stable mood.”

Natalie identified her feeling of being different from other people in several ways. First she indicated that a feeling of not being normal is shared by all alcoholics:

It didn’t surprise me. I’ve always suspected there’s something different about me. Different mentally. That I don’t process the same way [as other] people. And all

alcoholics feel that way. They never fit in. That's one of the reasons they drink. Natalie also feels different in terms of biochemical brain function: "I know that there's something wrong with my brain." Similarly, Rose knew that "talking a hundred miles an hour ... and thinking that I could take on twenty projects at once" was "not right" and "wacky." Moreover, in Rose's eyes, having a mental illness is much worse than having cancer or another physical illness, which are "dignified," unlike mental illness.

While getting used to the diagnosis, the participants wanted to be "normal," which usually meant someone who does not have a bipolar disorder diagnosis. For example, Natalie, when she indicated she wished she were "normal," defined the term along the lines of Freud's ideas: "Well, according to psychology [in didactic voice], it means being able to[be] happy, hold a job, and to love [laughs]." Somehow getting the bipolar disorder diagnosis meant to participants that they could no longer expect to achieve those goals.

Other Evidence

These findings about participants' initial reactions are consistent with memoirs written by people with a diagnosis of bipolar disorder. Probably the best known representative is Dr. Kay Jamison (1995), the clinical psychologist who is a world-renowned expert on bipolar disorder. She described in her memoirs how she was shocked when she was told she had bipolar disorder, even though she was already an expert on the disorder as a psychologist, researcher, and professor of psychiatry at a medical school. She initially rejected the diagnosis, while at the same time feeling relief at having a clear

diagnosis. “I was relieved: relieved to hear a diagnosis that I knew in my mind of minds to be true. Still, I flailed against the sentence I felt he had handed me. ... I was bitterly resentful, but somehow greatly relieved” (Jamison, 1995, p. 87). Part of what was distressing was that she would have this disorder “probably indefinitely” (Jamison, 1995, p. 87), a concern similar to some of these participants. Note that she places the diagnosis in criminal justice terms. She refers to the diagnosis as a “life sentence.” The penal code metaphor should make sense only if one feels that one has done something wrong. Her use of that term is consistent with an (unconscious) moralizing expressed by participants.

The actress Patty Duke (1992; 1987) had similar reactions to being diagnosed. When she was first informed she had a severe mental illness, the psychiatrist told her husband (in front of her): “This is a very sick girl. She will come out of it and you can get her help from time to time, but this will always be a sick girl.” (Duke & Turan, 1987, p. 170). Duke was devastated by the doctor’s attitude and his assessment of the permanence of the condition. She wrote, “The finality of that statement had an impact on me that lasted for fifteen years” (Duke & Turan, 1987, p. 170).

Another person who has “come out” as having bipolar disorder is the broadcast journalist Jane Pauley. When first diagnosed, her immediate association is to an out-of-control television character with bipolar disorder. “I knew that manic-depressive disorder was now called bipolar disorder. The little I knew of it came from Sally Field’s portrayal of a psychotic mother in full-blown mania on the TV show *ER*. I never visited that place, thank God” (Pauley, 2004, p. 13).

Lizzie Simon (2002) is a young woman who wrote her memoirs about having bipolar disorder. She was first diagnosed as a young adult, shortly after a serious manic episode in Paris. Like the participants in this study, when she was first told the name of the diagnosis (bipolar disorder), her initial associations were to seriously dysfunctional people: “I imagined zombies in loony bins” (Simon, 2002, p. 22). Yet she also feels like a prisoner and has an image of being burned alive: “Get some lithium flowing through her. Poke the lithium stick through her and set her on the grill like a shish kebab” (Simon, 2002, p. 22). This is a more aggressive image than those of the participants in this study, all of whom are older or were diagnosed in an earlier era.

Similarly Andy Behrman (2002) was a young art agent, whose dramatic arrest and sentencing for art forgery became a scandal in New York a few years ago. In his memoirs he describes years of adulthood when he experienced undiagnosed and untreated bipolar disorder, including periods of out-of-control mania and even psychosis. Yet when he was finally diagnosed with bipolar disorder in his 30’s, his associations were again to the negative stereotype of the crazy person: “It’s the first time I remember hearing the term *manic depression*, and it sounds serious to me, conjuring up images of people running around a mental ward half-naked in terrycloth slippers—it sounds like the word *maniac*” (Behrman, 2002, p. 157). He did not receive a definitive diagnosis of bipolar disorder for several more years. When he finally received a formal diagnosis, his reaction was that the “diagnosis sounds so definitive that it feels like a life sentence” (Behrman, 2002, p. 187). Thus, like the participants, part of what was difficult for Behrman in getting diagnosed

was the permanency of the condition. Also, Behrman, like Jamison, feels that getting the diagnosis of bipolar disorder is like a criminal receiving a “life sentence.” Having an association to the legal system makes more sense for Behrman, since he did have interactions with the law. Nonetheless, it is striking that the associations of the memoir writers are as negative, and perhaps more violent, than those of the participants. Behrman recounts how some time later he found a new psychiatrist, who reviewed all of his symptoms. “He asks me a battery of questions. I’ve heard them all a thousand times. After forty-five minutes he tells me that I am a manic-depressive. The words torture me still” (Behrman, 2002, p. 251). At this point Behrman had had the diagnosis for a number of years. Yet the diagnosis still “tortures” him, as if he is still a victim of some ongoing punishment and imprisonment.

These writers shared similar concerns to those expressed by the participants. Since these are professionally written memoirs rather than oral narratives, the writers articulate particularly well the essence of the themes the participants addressed.

Fear of Being Out of Control

Humpty Dumpty sat on a wall.
Humpty Dumpty had a great fall.
All the king’s horses and all the king’s men
Couldn’t put Humpty together again.
(Denton, 2004)

In addition to evoking societal images of craziness and memories of dysfunctional family members with mental health or cognitive disabilities, the thought of mania or hypomania elicited the participants’ own fears that they would fall apart, behave

unpredictably, and lose control. As noted in the last chapter, some participants had previously labeled a parent's behavior as out of control, but they did not express concern that their own behavior was or could become uncontrolled. To the extent they had these fears pre-bipolar diagnosis, they did not label them or attend to them. Related to these concerns is the fear of becoming permanently debilitated and dysfunctional. The fear is that if they fall apart, would anyone be able to "put [them] together again"?

The participants' fears of being out of control seem to have two aspects. One involves an internal feeling of not being able to hold the *internal* pieces together. Natalie's statement (below) about feeling like a shattered plate captures this fear. The other involves the fear of *acting unpredictably*, as several saw their parents behave. Jodi captured the nature of that fear when she contrasted the behavior of people diagnosed as depressed versus those diagnosed as bipolar. She said depressed people are:

not likely to be homicidal, or, like, you know, rage or do something. But you don't know that necessarily about bipolar people because they're a little bit more unpredictable with their inn—, in a state of, of rage. Or, you know, their mood is very unstable. They can get aggressive

Participants did not speak directly of these fears. Even Jodi's comment about people with bipolar disorder is stated only through negation. Yet I believe there is evidence for these fears from participants' dreams, metaphors, associations, and slips of the tongue. In order to give a sense of how participants' symbols expressed the fear of uncontrollability, three sets of symbols from the narratives are addressed here – car accidents, uncontrollable nature, and broken glass. I include in this discussion some actual experiences of participants as if these experiences were dreams or metaphors.

Car Accidents

Around the time that Darlene was hospitalized in a psychiatric institution, years before being diagnosed as having bipolar disorder, she had four nightmares in a row. She said they were “all scary” and all involved “car accidents.” She described one as follows:

One was about, was about, I was driving and I was at an intersection and there were two lanes. And I, and there was a, and I was going to turn left. And there was blinding sunshine or something. And there [were] other cars coming. I couldn't tell if there were any cars coming. So I just closed my eyes and turned left and didn't know if anything was going to hit me or not. ... I was, you know, petrified that I was going to get hit.

This dream seems to be about the danger of letting go of control (closing her eyes) and moving forward or turning, not knowing or being able to see (blinding sunshine) what will happen. Although this dream can be understood in terms of Darlene's life at that time (the loss of control from a panic attack that resulted in hospitalization; fear of loss of control when hospitalized), it also seems to be an apt metaphor for the fear of losing control shared by all participants.

Darlene's dream was the only one involving a car accident. However, several participants experienced actual car accidents that had significant impacts on their lives. Rose's description of her actual car accident, years before the bipolar diagnosis, shares some similarities with Darlene's dream. Rose had dropped off some papers at a building and returned to the parking lot. She described the accident as follows:

Came out of their back parking lot. Sitting there. A tractor trailer come. Puh, I just pulled right out. Watching him come right at me. Hit me broadside. Drove me down the street about a quarter of a mile. And the whole time I'm going sideways. And I've got a Jeep Grand Cherokee I'm smashing up. Brand new. b—, brand new. To—. [laughing]. Brand new and I'm just at—. It's like slow motion. You

have all this time to think. I closed my eyes. And I went. “OK, I’m gonna die. That’s OK because I really don’t care I’m ju— not in pain. Shouldn’t I be in pain?” [laughs]. ... Finally came to a stop when I opened my eyes. The tractor trailer’s in the door. I didn’t put my seat belt on. So I’m thrown over to the rider’s seat. Um, and the cab of the tractor-trailer of course [was] in the side door, which, thank God, had eye beams in the side of the uh, jeep.

Rose noted that she was alive only because she was driving a jeep that had eye beams in its side door. She commented that she had just traded in a smaller car that would not have had “eye beams” (that symbolically could see and avert an accident). When discussing this accident, Rose captures a confusion, shared by all the participants, about whether she really is crazy. She indicated, “I never got, I never got real high that did anything I’ll say [laughs], you know, [that was] real crazy. Uh, unless of course you count trying to kill yourself. [whispered].” Even while Rose was stating that she did *not* do anything “real crazy,” she realizes that she apparently tried to commit suicide, which could be considered a symptom of being “crazy.’ But it is even more complicated for Rose. When recounting the story of her car accident, immediately afterwards and even now, Rose still is not sure whether she *was* trying to commit suicide. So she continues to wonder about the “craziness” of suicidal behavior that apparently was outside of her consciousness.

This accident seems to be about acting without conscious volitional control. Rose consciously drove out when the truck was coming, but had no conscious desire to die. She said, “I’m smashing up”; “drove me down the street”; “I’m going sideways”; “I closed my eyes”; “I’m not in pain”; and “I’m thrown over.” These phrases seem to represent the control versus lack of control bipolarity with which participants struggled. The words are also evocative of a rollercoaster ride or other amusement park ride, where

one becomes dizzy from the danger of being taken in different directions at high speed. The posture of acting passively, without conscious volition, is similar to the feeling in Darlene's dream.

Rose mentioned other car accidents in her family history. One of her brothers was killed by a car, when he was hit by his ex-lover in a tragic, disturbing incident. Rose also mentioned that her husband had been in a bad car accident. For Rose, car accidents can be deadly and can rarely be controlled.

Kevin's entire life was impacted by a car accident that occurred when he was a toddler. The family of four was in a car that crashed. Both of Kevin's parents and his infant brother were thrown through the windshield. Kevin's parents were injured; his brother died. The 18-month old Kevin must have been thrown around by the accident too and must have felt the world was out of control and unsafe. Kevin did not describe the circumstances that led to the accident, but it may well have involved a drunk driver or a driver otherwise "out of control." In this car accident, Kevin is a powerless victim of circumstances that he cannot control. This accident was the basis upon which Kevin believes his father would always strictly monitor Kevin's moods to ensure that Kevin would avoid any overly exuberant feelings or expression. That vigilance eventually became a lifelong practice for Kevin.

Since cars are driven by humans, a reference to a car accident will usually involve a mistake (or accident) by a human. This can result in a dangerous and even deadly situation, where someone in the car can hardly control the repercussions.

Nature's Wrath

Some of the participants used metaphors of natural events to make sense of what seemed overwhelming and uncontrollable. Kevin, when trying to explain how his life is not “normal,” used a hailstorm metaphor:

It's like walking down a road and having a big hailstorm coming. Duck into a cave for a few days. Then you go out and start walking. Oh, well, you're not going to make that much progress as somebody's who's just walking. Then again, I know I tend to create the rest of the world as people who walk all the time. You know, like anybody doesn't have days where they—. I just have no idea how to compare myself to other people when it comes to, um, mood stability and, and that kind of thing.

In this metaphor, what seems uncontrollable for Kevin is what is coming down on him from the outside (hail), when he is simply trying to do what he believes everyone else does (walking down the road).

Jodi described two terrifying dreams. In these dreams, ocean waves and tornados represent the overwhelming parts of her life. She said she had the first dream when she was pregnant with her third child and trying to prepare emotionally for having three children.

And I think that, there was this period of time where I was thinking, “I don't think I can do this,” even though I very much wanted to have another child. And the dream consists of me standing at, at, a, um, at the side of the ocean, um, at the waves, with my children. ... We're at—, at—, the waves are lapping at our, at our feet and ankles. ... I have the younger one in my arms, and I pick, I'm picking him up. And I, I have my oldest by the hand. And I tell him, he has to jump over the waves now. Because I can't pick him up any more. ... And I think I was really torn by, um, knowing that I was starting to separate myself into so many pieces, of, um, of people that needed me [laughs]. And it was getting to be really hard. And I, I, I knew I was—, I was already—, see I have this e—, I was already starting to worry that I, I just couldn't do, do it all. I couldn't take care of them.

Um, which has proven to be actually, [laughs] unfortunately the case, that I couldn't really take care of them the way I wanted to. To my heartache.

When recounting this dream, Jodi recognized that she was feeling overwhelmed when she had the dream. She is hoping that her son can “jump over the waves” by himself since she cannot “pick him up any more.” But the tenor of the dream is about how it may be impossible to find a way to hold on and avoid drowning, as the ocean laps at her “feet and ankles.”

Jodi's second dream is even more frightening. She had this dream recently, when she was feeling very anxious about her life and fearing that her life was “falling apart and I didn't know how to cope”:

And the dream consists of me being in, um, repeated sc—, sin—, scenes where I'm seeing approaching tornadoes and running ... I repeatedly see approaching tornados. And what I do is, I'm running from places of shelter to another place of shelter. And every time I get to the new place, another one comes at me. And so I, I continue to try and find a place where I am safe. [A place] ... where there's not something coming at me that's going to be like disastrous. And, you know, I guess there's been periods of time in my life that have been like that. ... I, I get to these points where I think, you know, everything's falling apart, you know, and I can--, I have no place to be where I'm safe

Like Kevin's hail, Jodi's dream image places the uncontrollable outside of her, as tornadoes coming towards her. Like Kevin ducking into a cave to avoid the storm, Jodi seeks the safety of shelters, but every shelter proves illusory or temporary.

Natalie offered an image quite similar to the one in Jodi's first dream. Recently Natalie had an adverse reaction to a bipolar medication. She felt like her psychiatrist was not hearing how depressed she was and how out of control that depression felt. Her sense is that his only concern was to make sure she was not suicidal:

It felt like quicksand. ... He just wasn't hearing me. ... I wanted him to know that I was like dying. Swimming. Dying. Sucked under. What other terms did I use? Can't stand it. And all he was looking for was, "Are you suicidal?"

Natalie was feeling a significant loss of control with this depression, like nothing she had ever experienced before. She uses the metaphors of sinking in quicksand, being sucked under, and drowning. The image of quicksand is of something outside one's control, which is slowly and inexorably pulling one down to death.

Kevin also used an image of the ocean and its tides when describing one way to understand his experience. He said:

But there's a way that I objectify myself I think when I see myself as a product only of these chemicals that ebb and flow like the tides. Uh, there's a way I depersonalize it. There's a way that I, um, make it more fated and fixed.

In Kevin's view, he has no control over these "fated and fixed" chemicals. In this metaphor, these chemical tides are not necessarily overpowering, but they are clearly functioning by their own control and totally outside of Kevin's control.

Darlene's image of "blinding sunshine" would also fit in this category of overpowering natural events. Although sunshine usually connotes actual and symbolic light or lightness, "blinding sunshine" involves an excess. This positive attribute has now turned into a devastating assault, which can remove one's ability to see. It is unlikely that even "eye beams" can protect a person from "blinding sunshine."

These images involve a variety of potentially overpowering natural events. Ocean waves pull you under water; tornadoes pick you up and throw you around haphazardly. Hail is cold, hard, and painful. Blinding sunshine can make you unable to see. Each of

these weather images is of an unwelcoming and dangerous external environment that is able to overwhelm the person.

Broken Glass

Several participants described experiences or dreams involving glass, broken glass, or broken pottery. It occurred for Natalie during that recent incident of having adverse reactions to her psychiatric medication. She felt that her world was breaking apart.

Well, I called it my plate shattering. It's what it felt like. Like somebody took a plate and dropped it. ... And I couldn't do the job. And I was so depressed. And it was something I had never been through in my entire life. Even, you know, going, watching my mother die I had never, ever, ever, ever been there before. And it was so scary because I was, could not control it. I could not use any part of the tools I have as a human being to control any of it. I couldn't rationalize my way out of it. I couldn't understand it. I couldn't see half of it. All I knew is that somebody had taken the shell of who I am and hit a hammer and broke it. And there I was, just a pile of pieces. And I didn't have enough glue to put it together. Nor did they know which piece went where. It'd be like looking at a puzzle and not having a picture of it and trying to put it together. Um ... I was, best way I could put it, I was absolutely defeated in the sense that I could not function ... at all. I lost my faith in God. I lost my faith in myself ... and I just could not see my way out of it.

In Natalie's case, it appears that the depression was medication-induced. But no matter what started it, Natalie's feelings of despair are eloquently captured in her description of feeling like a broken plate that cannot be put back together again.

Darlene described a fantasy she once had of breaking glass. This happened after a loud and intense argument first with her daughter and then her husband:

So she [my daughter] left the room and I started yelling at him [my husband]. And I screamed at him I, I don't know for how long. Until he went outside on the back deck and s—, shoved the glass door, the sliding door, and I punched it as hard as I

could, praying that, that glass would break. I just wanted it to shatter. I wanted it—, I wanted it to break, you know, cut my hands and everything. I couldn't wait for that to happen. And it didn't happen. So I went upstairs to my room.

Darlene's desire to break the glass came during a incident of uncontrollable anger, which

Darlene is certain is different from "normal" anger or irritation.

I mean, I, it wasn't—, it wasn't like a normal, "I'm mad at you and I'm going to be mad for a few days." It was an explosion. And it was, it was like, it was a manic thing. It was something I had absolutely no control over. And I know people do stuff like that and it's, they're normal people. They don't have bipolar. But, there's something i—, there's a feeling that—, I can tell it's different. It's, there's some kind of snapping. It's just not nor—, it's just not right.

Darlene tried to explain how frightening it is to experience "an explosion" inside, which cannot be controlled. Now she is mostly embarrassed about the incident, but she does not elaborate on how frightening it must have been to feel so out of control of her feelings and behavior.

Rose's narrative also contained several references to glass or broken glass. The first reference is in describing her mother's out-of-control behavior. She noted how her father managed to get Rose's mother off of prescription medications.

He got her dried out. But the minute he'd dry her, he'd get her off pills, she'd go right back. She, she was taking alcohol with her pills. He'd find her in the middle of the floor with broken glass.

Rose later mentions that she was injured by broken glass from her car accident. When seeing her doctor a few days after the accident, Rose did not initially tell her doctor about the accident, but her doctor asked her about the cuts on her hand. "She was, 'What are all the, all the cuts from?' And, um, I said 'broken glass.'"

Rose also described a time in her life when she felt very out of control, long before the bipolar diagnosis. She was feeling both agitated and depressed during this period and was arguing frequently with her husband.

I was screaming at my husband. ... I literally would just, I didn't care how much noise I made, I didn't care how much I hit him. Threw myself on the floor. Smacked myself into the wall. I would go nuts about nothing. And I mean literally going nuts.

Rose described what happened during one argument:

I got down on, I was in, we lived in an A-frame. I got down on my hands and knees and was pounding and screaming abe—, so he could hear me, so he could feel sorry for me. And I'm pounding and screaming and I'm going out of my head. I'm literally going out of my mind [whispered]. And I looked up [at the] side glass doors and saw myself [whispered, then laughs]. I mean that was one of those aha moments [louder]. ... Cause I was always telling him I was gonna kill myself. Always gonna kill myself.

This image does not involve broken glass but glass that reflects the truth. When Rose saw a reflection of herself on her hands and knees pounding on the floor and screaming, she realized how out of control she was.

Due to time limitations, I did not investigate the associations participants might have to these dreams and metaphors. Even if I had, it would have been incomplete since I became aware of most of these images only after working with the interview transcripts. This particular layer was not immediately apparent.

Some of the dreams and images presented in this section occurred before the bipolar diagnosis, suggesting that participants' fears of losing control existed prior to the bipolar diagnosis. However, as noted in Chapter Three, pre-bipolar diagnosis, the participants assigned the label of "wacked" or "crazy" to other people, not themselves. I

suggest that since the participants had received no indication from other people that their behavior was inappropriate or out of control, they did not need to address these fears consciously. The diagnosis of bipolar disorder apparently brought into consciousness these fears of behaving “crazily” or losing control.

While many, if not most of us, may have fears of losing control, it is likely that the concern would not be as present in both conscious communications (e.g., metaphors) and unconscious ones (e.g., dreams) as with this group of people. These dreams and metaphors seem vividly to capture this powerful aspect of participants’ experience.

Discussion

Initial Negative Reactions

In this chapter I presented reports by participants and a few people who wrote memoirs about having bipolar disorder about their initial reactions to the label of bipolar disorder. One way to understand their initial negative reactions is based on the research on affective forecasting. People tend to overestimate the duration of the emotional impact on them of future negative events (Gilbert, Pinel, Wilson, & Blumberg, 1998; Wilson, Wheatley, Meyers, Gilbert, & Axson, 2000). People also tend to imagine that their emotional reactions to negative events will be more intense than they actually are (Wilson & Gilbert, 2005). This is one way to make sense of this particular finding.

The participants’ initial reactions can also be viewed as societal associations to how bipolar disorder is a more “serious” diagnosis than depression, a diagnosis previously received by all but one participant. When they made this point, they almost

always referred to mental illness in very colloquial language, using terms like “wacked,” “crazy,” “nuts,” and “lithium-laced wack job.” Participants’ initial reactions also reflected the most psychotic and out-of-control manifestations of mania.. They referred to extreme and “outlandish” behaviors of manic people, such as: “having sex with six guys or, uh, you know, spending \$20,000 ... and jumping off roofs.” They also referred to bipolar disorder in morally disparaging terms, implying that people with bipolar disorder have “loose” or “bad” morals.

These findings are noteworthy, especially considering that this is an articulate and socially sophisticated group of people. Every participant had a command of a rich and expressive vocabulary; their thinking was complex and nuanced; their analyses often pointed and insightful. Moreover, the people who wrote memoirs are professional writers. Therefore, it is reasonable to conclude that their use of pejorative colloquial language and their references to the most extreme manic behaviors served a purpose for the narratives.

It is likely that these initial negative associations to the term bipolar disorder by participants and the memoir writers are shared by others in American society, including those without a bipolar diagnosis. Here is one piece of recent societal discourse that supports the participants’ reactions. The context of the article is as follows: in response to the negative societal associations to words like “mad,” “madness,” “crazy,” “nuts,” and “wacked” (the very words participants used when they were first diagnosed), the National Alliance for the Mentally Ill (NAMI) and other organizations have urged people to avoid use of such terms due to their negative connotations. In response, Andy Borowitz (2007)

targeted the “political correctness” of the NAMI position in a satire. His “article” states that the National Collegiate Athletic Association (NCAA) had changed the name of the March collegiate basketball tournament from “March Madness” to “March Bipolar Disorder.” The point of the spoof is that the term “bipolar disorder” is synonymous with “madness.” The implication is that the only difference between the terms is that “madness” is an unacceptable, pejorative term whereas “bipolar disorder” is the proper term for the same thing. Also, evidence that the term “madness” refers to the manic symptoms of bipolar disorder and not the depressive symptoms is that the March basketball event is sometimes referred to as “March Mania.”

Our society continues to be inundated with movies and cultural products that portray an exaggerated version of mental illness. Cultural images were even more charged in the second half of the 20th century when the participants came of age. One association from my childhood (the same period as several of the participants) is the following song, which had a catchy yet haunting tune:

Remember when you ran away and I got on my knees and begged you not to
leave because I'd go berserk? Well...
You left me anyhow and then the days got worse and worse and now you see
I've gone completely out of my mind.. And ...

They're coming to take me away, ha-haaa.
They're coming to take me away, ho-ho, hee-hee, ha-haaa
To the funny farm. Where life is beautiful all the time and I'll be
happy to see those nice young men in their clean white coats and they're
coming to take me away, ha-haaa. ...

(Napoleon XIV, 1975)

Even reading those words now conjures up the frisson of fright I used to feel when hearing this song. The mixed affect is like the delight in watching horror movies, which can be terrifying yet also arousing and engrossing. I think the feelings evoked by this song involve both the fear of going crazy and the horror of being taken away and locked up.

Thinking about the power of these cultural images, it should be no surprise that when someone is first told they have a diagnosis of bipolar disorder, they associate to psychosis or they fear becoming an institutionalized “zombie” with “terrycloth slippers” in a “loony bin.”

In addition to the societal associations that bipolar disorder is “real” mental illness and means “crazy,” some of the participants had received the clear message from authorities (psychiatrists) that bipolar disorder is a much more serious disorder than depression. This occurred when participants were assured years earlier that they do *not* have bipolar disorder, as though that were a terrible fate narrowly avoided. Since the assurance was in the form of a negation, the impact of the affirmation (now, years later) makes the diagnosis feel even more serious. Darlene’s story is a representative one:

I, I remember that my doctor said “Now I’m not putting you on lithium because you’re bipolar, because that’s not what I think.” Like—, he was like, “Don’t get worried, I’m not considering you bipolar. I just wanna try this lithium to help the Prozac.

The unmistakable message was that bipolar disorder is something to be worried about.

With the diagnosis, both society and the medical establishment were telling them that

they have a serious disorder and they are (or will become) “crazy.” The “gaze of the other” was now reflecting something much more serious than before.

One way to understand why the diagnosis felt so devastating to the participants is to consider that the participants had swallowed whole these societal preconceptions. Their initial reactions were almost a rote repetition of the stereotypes. Participants were all adults when diagnosed, so they had many years to learn about “crazy” people, who, until that moment, were “other,” not “self.” Thus, the dilemma for these people involves incorporating what was formerly “not me” into a sense of self. Klein (1959/1985), Bion (1959), and Sullivan (1953) provide a framework for understanding this process.

When an infant experiences unbearable anxiety in relationship to the “mothering one,” as Sullivan calls the parent, the child is unable to contain aspects of the experience. The terror of aggression, the shame of dependence, and the rage at imperfect parenting create strong feelings in the infant. As a result, these feelings become “split” off and repressed, but still powerful, as “shadow,” “projections, or “projective identifications.” This affect becomes “not-me” and is out of conscious awareness. The affect that is located in this no-man’s land is the content of nightmares and terror movies, that is, all that is unknown and uncontrollable. Other people now carry these dangerous qualities, not us.

These participants would understand, as all members of the society do, that the dominant group projects into the other all that is disquieting or frightening (Bion, 1959). A member of the dominant group may treat the propaganda about members of the “other”

groups as obvious facts or as given attributes. Bion goes on to explain that occasional contact with members of the “others” may confirm the stereotypes. A person who suddenly finds him- or herself in the out-group will now have to face all of those “givens” about the out-group in him- or herself. That person will likely experience shame and humiliation, feel defective, and assume that he or she contains all of those dangerous qualities associated with members of this group. He or she will also have to face the idealizations placed in this group, which may feel as foreign as the denigrated projections.

The process of incorporating previously undigested stereotypes is similar to the developmental process in childhood in which young children hear ideas from their parents, which the children then treat as absolute truth. Even older children will repeat their parents’ off-hand comments, which the child might incorporate in an indigested manner. For example, my 11-year old nephew, Jacob, recently announced to his grandparents that he would “have a midlife crisis” if he had to do homework over the weekend. He probably heard his mother use this phrase; he may not fully understand its meaning, but he does know that it is associated with unpleasant angst. For the participants, however, what was undigested is considered by society to be much more serious than a midlife crisis.

The dominant group of people without mental health diagnoses has created and maintained the group of “wacked” and “crazy” people as a denigrated other. . These people would be the raging, unpredictable, psychotic, mad, and out-of-control “maniacs.”

Our fear of our own craziness is now safely located in that particular group of others, some of whom support our ideas by acting pretty crazy when we see them, like the homeless people who mutter to themselves and smell bad. We can also locate a romanticized image of the brilliant madperson, thereby also splitting off brilliant craziness. Even if we occasionally have experiences that feel a bit out of control, like suicidal ideation, we can calm our anxiety by knowing that we are still not *that* “outlandish” as someone who is *really* crazy. And even if we are sometimes creative, we can recognize that we are “normal” creative people, not crazy brilliant ones, like Vincent van Gogh (believed by some writers to have undiagnosed bipolar disorder).

If something happens that we are now labeled as one of “them,” we first repeat to ourselves all those terms we always heard about *them*, often from a very young age. The findings from this chapter, including participants’ use of pejorative language and their dreams and metaphors about loss of control, suggest that they had taken in as “the gospel truth” the societal projections about “crazy” people, probably from very early ages. This process may explain why the participants initially repeated the derogatory words and the extreme projections about people with mental illness.

Another way to understand the shock of the diagnosis is that the participants initially felt that the bipolar disorder label simply did not fit with their internal experience. As noted in Chapter Three, the participants did not have categories in which to place their elevated moods and nobody before had ever suggested that their behaviors were crazy (since depression was not viewed as crazy). Thus, the participants are

particularly vulnerable to thinking that they are about to be cast unexpectedly into a socially denigrated group.

For the participants, being diagnosed with bipolar disorder represents moving from the dominant group of “normal” people into the group of “crazy maniacs.” The diagnosis implies that they might become something they have not yet been (crazy and out of control) and this is what felt so terrifying. It seems initially to have more implications for the future than it does for understanding the past. Klein (1959/1985) postulated that one of the terrors humans face is the terror of being “out of control” or going “crazy.” It seems to be the case that the image of the “bad mother” in these participants’ narratives was one of being unpredictable and out of control. And following Klein further, it is possible that this represented a split in the participants themselves. It was easier before the bipolar diagnosis to locate all of their own inconsistencies in their “crazy” and “bad” parents and not in themselves. After getting the bipolar diagnosis, they had to face the possibility that unpredictability might also be inside of them. Their dreams and metaphors suggest that this possibility was quite frightening.

Fears of Loss of Control

The participants’ dreams and metaphors indicate the depth of the fear of losing control.. There are various ways to interpret these dreams and metaphors. The symbols of cars, car accidents, ocean waves, hail, tornadoes, blinding sunlight, breaking glass, breaking pottery, and reflections in a glass are all evocative images of uncontrollable

forces. In each of these images, the human (which can be thought of as the self, the ego, or the actor) has little control in the face of overwhelming external circumstances.

In the nursery rhyme, Humpty Dumpty broke apart and could not be put back together, even by the most powerful people (all the King's horses and all the King's men). These metaphors and dreams suggest the phenomenological experience of this group of people is to connect their own experiences and fears of loss of control to the bipolar diagnosis. Further, it is likely that the images, taken together with the interview material, indicate that the participants experienced the label of bipolar disorder itself as "shattering" or overwhelming a previous understanding of self that could never be restored.

The dreams and metaphors about "nature's wrath" and how there is no safety from external and uncontrollable forces can also be understood from the perspective of Jacques Lacan (1966/1999; 1968). Interpreted in that vein, the message in these dreams and metaphors is that there is no shelter or safety in the bipolar label, in medication, or even in reliance on external authorities (e.g., psychiatrists) to establish the threshold between "normal" and "crazy" or "manic" (Rogers, 2007). Overwhelming forces can interrupt lives and this can be "disastrous," using Jodi's term. To understand the meaning of each person's dream, the person would have to think about what is being communicated by the dream, what experiences may have triggered the dream, and how acknowledging the truth that is being communicated in that medium might disrupt the

person's entire understanding of his or her mental health, life, and relationships (Rogers, 2007).

Conclusion

The process of coming to terms with the bipolar disorder label required that participants attempt to incorporate this new and troubling identity into their sense of selves. As the participants digested the meaning of the diagnosis and got used to "having" it, they started to interpret their life experiences through the framework of bipolar disorder. They also arrived at a kind of Kleinian "depressive position" in relation to the diagnosis. The subsequent chapters track how participants moved through these processes.

CHAPTER FIVE

FINDING MEANING AFTER THE BIPOLAR DIAGNOSIS

Over time, the participants created various meanings of the bipolar diagnosis for themselves. They became familiar with the symptoms of bipolar disorder as set forth in the DSM-IV-TR and as understood by the psychiatric community. They learned about how the disorder is defined by mood dysregulation and cycling, manic or hypomanic episodes, and depressive periods. They also recognized, to some extent, how the defined disorder might fit for them. During this process, their negative associations to the diagnosis became modified and their relationship to the diagnosis became more complex and nuanced.

Bipolar Disorder as an Organizing Framework

After the initial shock of the diagnosis wore off, the participants realized that the diagnosis provided an organizing system for a broad range of their prior experiences.

Kevin, for example, stated:

I've always been aware of ... struggling to maintain a sort of easy sense of self, uh, given how I feel. I just didn't have a framework in which to hang it.... So I guess part of what I'm saying [is] learning the diagnosis, I think, did help make sense of experiences I had of myself and in that way was organizing.

Many participants noted that they felt relief at having a diagnosis that explained so many of their experiences. For example, Rose said, "I finally knew what was wrong."

Yet for Rose, as others, the relief was tempered:

So it's um .. it was—, finding out I was bipolar was .. the best and the worst thing. Because it was, it just opened up so mu—, so many more, oh [sighs], aha moments.

Some of what felt like “aha moments” for participants is that the diagnosis explained and gave language and structure to experiences that previously could not be understood, let alone even acknowledged. As noted in prior chapters, participants had a label of “depression” for when they might have felt sad, exhausted, and depleted. What the new diagnosis gave them was a label for prior experiences on the manic or hypomanic continuum, such as elevated moods, excessive irritability or anger, and fluctuating moods. Several participants now label those prior experiences as symptoms of bipolar or pre-bipolar disorder.

For Kevin, the diagnosis clarified his lifelong moments of exuberance or “bursts of enthusiasm.” Kevin talked about his relationship with the diagnosis as one that:

has ebbs and flows and changes. That after being horrified about it and sort of giving it a try, um, it helped me really make sense of a lot of things that I experienced growing up. Times, particularly times when I felt really good and I wasn't quite sure why, um. I think, beginning with adolescence. Certainly I can remember, being in 7th grade and, um, even younger, even, absolutely even younger, having these bursts of enthusiasm or, just being euphoric about things and, of course, that being severely punished.

Darlene now thinks that her manic symptomatology started at age 14. It was then that she started yelling at her mother:

I think that was the beginning. I think—, I, I think that was the start of it all. And I have done that to my husband for the last twenty-two years we were married. Off and on, not very often any more.

Darlene attributes her lifelong episodes of anger as part of a range of early manic symptoms.

You know, my manic symptoms are not all positive. I'm also, I'm a rapid cyler

and I'm a mixed, mixed states manic person. In other words, I, when I, especially the mixed states thing. I get extremely mean, just really, really irritable, mean, furious, hitting things. I'm just very horrible. ... And I say terrible things, and, um, I'm that way for a long time.

Even though Darlene is ashamed of how ‘horrible’ she is in what has now been labeled a manic or “mixed” state, she, like some of the other participants, finds it helpful to understand these symptoms as clearly defined symptoms of bipolar disorder, rather than simply an inherent “horribleness.”

Similarly, Rose looks back at her life and sees a long history of behaviors that she now associates with bipolar disorder. She described herself before the diagnosis as a person who was “... chemicals, or whatever, that ... were making me a—, an unholy mess and depressed sometimes.” She still sees that she was an “unholy mess,” but she attributes it to “chemicals,” that is, an untreated bipolar condition.

Yet some of the participants still struggle with whether to assign a pre-bipolar diagnosis to earlier behaviors. Sarah wishes she could look back and label her difficulties as pre-bipolar:

It would probably have been a big relief in some ways, as much as it would have probably made me feel bad too.

Interviewer: What would be a big relief?

The idea that, God, I was ob—, identifiably pre-bipolar from, you know, age three, four. And if somebody had jumped in and said, “This kid needs help regulating her emotions,” now, you know, that would have been awe—. And, you know, now, [with] somebody like that, they do.

Sarah still wonders if her unhappiness as a child was “pre-bipolar temperament.” She thinks about other behaviors in childhood and questions whether they too foretold a

future bipolar diagnosis:

I was the kind of kid who, talk about slow to warm up. You know, big time. Um, I would, you know, you had to tell me over and over again that I was going to like something that I had done and loved, and I still would scream and not want to do it [laughs].

She sees that her lifelong challenges involve “difficulty controlling my emotions. ... You know, it has been about emotional things, so maybe that i—, you know, if there is a predisposition or sort of a--, you know an early trickle that you can follow ...” Sarah did not finish this thought. It appears that she still has difficulty following that “early trickle” through her life and designating aspects of early experience as pre-bipolar.

The organizing framework of bipolar disorder provided for participants a structure and explanation of experience that the participants could now label, attend to, and understand. Another part of the process of digesting and coming to terms with the diagnosis involved evaluating what aspects of prior experience to incorporate within the container of the bipolar framework.

The Diagnosis Became Meaningful to Self

Even though the diagnosis was initially distressing, over time participants recognized that it made sense for them to be given a more “serious” diagnosis. Several participants explained how they had always felt that “things were not right,” something that a bipolar diagnosis explained. Others addressed experiences of feeling “out of control” – the experience they had most feared. For example, the bipolar diagnosis makes sense to Darlene when she thinks about the times she yelled at her husband and daughter. The feeling was of an “explosion” or “some kind of snapping.” Now labeled bipolar, it

makes more sense to her.

Participants created meaning for the diagnosis only after they researched the diagnosis and thought about the symptoms attributed to it. For example, Natalie noted:

When I originally heard the words, you know, and looked it up, and did some research and talked to my doctor about it and everything, um, I became comfortable with the idea that, well that a lot of it made sense to me in ways that, how I was acting.

Later, apparently during what became labeled as a manic or hypomanic episode, she knew something was not “right,” even though she was enjoying herself tremendously:

My serotonin level was so high it was better than cocaine. ... I said this, this is not right. People don't feel this way. But I don't want to give it up because it feels so good, you know. Why should I deny myself this natural high, you know? So it's very hard. It's very hard to go into your psychiatrist and say, “I'm having too much fun. I'm enjoying life too much.”

Yet she knew she needed to tell her psychiatrist “because I know it's not right.”

The diagnosis made sense to Sarah when some of her previously unlabelled symptoms improved when she started taking Depakote, a medication for bipolar disorder.

I was mostly feeling really, really anxious. And, um, I wouldn't say exactly ... paranoid but you know how—, well, yeah, on the verge of paranoid. The kind of overpersonal—, negative overpersonalization that depressed people do. Everybody in the room is talking about me, looking at me, thinking about me.... So it wasn't everybody's again—, out to get me, or a plot. But it was that I was so, so preoccupied and so afraid of people. And that took the edge off that. And actually if I don't take Depakote, that stuff comes back.

Some of the relief for Sarah is that her intense anxiety, paranoia, and “negative overpersonalization” could be identified as part of her bipolar condition and treated by bipolar medication. The uncomfortable paranoid behaviors could then be put into a comprehensible context.

Some memoirs of bipolar disorder also address the relief at having an organizing framework. As quoted in the last chapter, Jamison was very clear about this point: “I was relieved: relieved to hear a diagnosis that I knew in my mind of minds to be true. Still, I flailed against the sentence I felt he had handed me. ... I was bitterly resentful, but somehow greatly relieved” (Jamison, 1995, p. 87). Patty Duke had a similar reaction after diagnosis: “From that moment on, I wasn’t frightened. It was such a relief, almost like a miracle, really, for someone to give what I’d gone through a name and a treatment” (Duke & Turan, 1987, p. 287).

The Diagnosis Made Sense in the Family

As they took in the meanings associated with bipolar disorder, the participants learned about the research documenting a high genetic intergenerational transmission of bipolar disorder. Several participants then analyzed which relative they “got it from.” As noted earlier, some initially found the diagnosis frightening because of low functioning family members with bipolar disorder or other mental health diagnoses. Others assumed, based on family history, that they would develop a mental health condition. Natalie, for example, indicated she expected some kind of mental illness to be passed down to her, but did not know which one. She listed mental illnesses of relatives from earlier generations, including one with agoraphobia, another with psychosomatic illness, and two who committed suicide. Using humor based on stereotypes about another mental illness, Natalie explained why she prefers bipolar as a diagnosis over other possible ones.

I, you know, I expected something. Um, so was I surprised that I was given some diagnosis of a mental illness? No. Bipolar? Ehhhh, I didn’t know anything about

it. I'd rather that than schizophrenia. I'd rather not be talking through aluminum foil.

Some participants consider the bipolar diagnosis as possibly the correct diagnosis for previously undiagnosed family members. Both Rose and Natalie believe various family members, now dead, had undiagnosed bipolar disorder. Rose analyzed her family of origin and concluded that her mother and most of her brothers probably had bipolar disorder. She feels regret that she did not recognize it until recently. One brother died shortly before the interview; Rose had only belatedly concluded that he too had bipolar disorder.

It's—, it makes me feel sad in a way because I wish I would've known. I'm not sure I could've gotten my brother any help. And of course my mother had been in and out of psychiatrists' offices and nobody ever diagnosed her with anything but depression.

Rose always experienced her mother as “wacked,” but the only name given by psychiatrists was that her mother was depressed. Now Rose, with her new-found knowledge about bipolar disorder, thinks bipolar disorder is a more appropriate diagnosis for her mother.

Even though Natalie was generally critical of the bipolar diagnosis, she begrudgingly concluded that it helped explain some of her mother's behaviors.

But when I read about it, I said, “Huh, my mom was probably manic.” She was probably bipolar. I mean, lots of things about her that I remember that would have put her place right there. Except that nobody was treating it. ... Well, like when she did things, she did things like, you know, she would iron everything in the house, you know. Sorry, mom, I don't need my underwear ironed, really. Or when she was depressed, you know, she drank herself into oblivion

Before thinking about people through a bipolar lens, Natalie just said about her mother,

“It’s mom,” or “That’s just mom being industrious,” meaning no further label or explanation was necessary. But looking back through the bipolar perspective, Natalie, like other participants, perceived as bipolar not only their own experience but their family members’ behaviors.

In time, the diagnosis of bipolar disorder provided a linguistic handle for explaining a number of symptoms or experiences that had not previously been organized into a cohesive category. The perception of bipolar disorder as a more serious diagnosis than depression also confirmed some of participants’ feelings that something significant was “not right” with them. The diagnosis also had a significant impact on their sense of self and identity, as discussed in the next section.

Self and Identity

Some time after the initial diagnosis, the participants moved into a new period of coming to terms with the diagnosis and all the meanings it could have for them. During this process they faced questions about self and identity. The diagnosis created a double-edged sword for participants (an interesting phrase meaning something that helps and hampers at the same time). On the one hand, it was a relief to have an inclusive organizing framework that explained many of their lifelong feelings and behaviors, as well as those of family members. On the other hand, they came to experience the framework as so comprehensive that they wondered which aspects of their experience could be held as “my self,” not colored by bipolar disorder.

For these findings, I use the terms “self” and “identity” as participants used them

and as they are often employed in American discourse. The two terms are sometimes used interchangeably; at other times “self” will refer to intrapsychic experience and “identity” will refer to how one is seen (or imagines being seen) by others. These terms have a long history of being interpreted with regard to psychological life, as is discussed below.

Why Self and Identity?

The diagnosis impacted the sense of self and identity of all of the participants. They all said words to the effect of “it IS me,” rather than, “this is something I have and will have to deal with.” Rose, for example, when first hearing the symptoms of bipolar disorder, said, “Oh my God! Oh my God! That *is* me.” Natalie said at one point, “I am a classic bipolar.” Darlene, when first coming to terms with the diagnosis, said, “I would always have it. That I wasn’t gonna ... get rid of it. It was there. It was me.” These words suggest that bipolar disorder is experienced not an appendage or separate phenomenon impacting on the person, but as the essence of the person herself.

These responses might be surprising to someone familiar with disability literature. Many people have physical or even mental health diagnoses that are not experienced as affecting their identity. Moreover, the disability community has worked hard over recent years to change the public perception of people with disabilities to be “people first” rather than “handicapped” people. The disability is something a person lives with rather than something that defines the person. For example, I am considered a person with a visual disability, rather than a blind or visually impaired person (Scotch, 2000; Spaniol, 2001).

Although this may seem like a word game only, but it is one of those changes in language that can significantly impact thinking and perception.

Disability perspectives have not been well integrated into the community of people with psychiatric disabilities in general (Wahl, Wood, & Richards, 2002). This is particularly true for middle- and upper-class people like these participants (Stefan, 2001, 2002). These participants were generally unfamiliar with the disability discourse; none of the participants defined themselves in disability language, such as being a person with a psychiatric disability. Even if participants were cognizant of disability constructs, the participants' narratives indicate there is something inherent in the bipolar disorder label that challenges and even undermines one's sense of self and identity. This process is discussed in this section.

Opposing Selves

One of the repercussions of being assigned a label of bipolar disorder is that it divides the experience of self into different and opposing selves. The term, "bipolar," by definition means "having two opposite or contradictory ideas or natures" (*The American Heritage Dictionary of the English Language*, 2000). The nature of the term "bipolar" inherently creates an unbridgeable divide between opposite "poles." Accordingly, participants grappled with questions about different selves and whether it is possible to develop an integrated experience of self.

Natalie captured well the dilemma created by the definition:

The term "bipolar" means nothing to me. Cause if you think about it, it means by two polarities. And that doesn't make sense. It needs a different term. It needs a

different name. I think manic depressive was a fine name until they decided that people didn't like it. So they came up with bipolar [laughs]. I mean, manic depressive is the more descriptive term. It is! Than bipolar. What? Do I have two heads? Two, two polarities? Do I think I'm on both sides of my brain? You know. What is bipolar? Two sides of a magnet? [laughs]

Similarly, Darlene, when describing the difference between her “highs” and her “depressions,” said: “I have to, to—, totally figure out who I am. Was that me or was this me? Or am I someone in between? Who am I? I went through years trying to figure that one out.”

The participants generally identified more with one “side” of the bipolar polarity than the other, even if the identification was a painful one. Sarah feels that the adjective “depressed” fits her more than something like “bipolar”:

When I just spontaneously think of myself, what am I? I'm depressed. When I get hypomanic, it just feels odd. ... I guess it sort of feels like that everything that's not depression is a respite and then I go back to depression. ... [but] maybe I over-represent the negative.

Later, she indicated that since the depression feels like “just me,” she finds it difficult to name the depression as “illness”:

It's hard to figure out when it's that and when it's just me. You know. I mean, that's what's hard to sort out. ... Whenever I've read about somebody who's had bipolar disorder, actually even schizophrenia, ... it seems like it's pretty easy to tell what's them and what's their illness. I can't really tell. I mean, I can tell what's me and what's manic, hypomanic, but I can't tell what's me and what's depressed. I think I've over-identified with my depression. Or, whatever. Incorporated it into myself so much.

Sarah does not have difficulty naming the hypomania as illness, but she recognizes that “my depression” feels like an integral, not a separate, part of self.

At the end of the second interview, Sarah was still grappling with this question

and why she self-identifies “as a depressive and not as a manic-depressive.” Sarah still does not have a comfortable understanding for this, but believes both she and others see her that way.

Like Sarah, Kevin indicated his dysphoric mood feels more ego-syntonic than his exuberant mood:

Yeah, the painful, dysphoric stuff is much more ... easier for me to ... identify with. ... I think part of that ... goes back to ... the ways in which my exuberance, or the expansiveness when I was little, ... was squashed. That, yeah, it became dangerous to me to be too ... effusive.

Yet most of the other participants identified more with their “manic” selves – the expansive, happy, grandiose, and high energy experiences – than their depressed selves. They felt that the bipolar diagnosis took away their happiest experiences by labeling those experiences as either bad or false. For example, Darlene noted how her prior manic periods, which she no longer experiences, felt like “me.”

I loved life. It was awesome. I was a very outgoing person. I was a very life of the party type of person. Loved it, people. ... We had so much fun. Um. When I first started taking Depakote, you can't imagine. The way you go from here [motions high] to there [claps hands low] and just sit there. And there is no affect. There is just—. It was a horrible feeling. It was awful. Um. I just wish, just ro—. Flighty and happy and just a really crazy person. Just lots of fun. I really loved it. And when I saw the difference between being that way [and the medicated way]. Because I thought that was me. That's who I was. That's who I always thought I was.

Darlene states that she loved those exuberant feelings. She calls herself “just a really crazy person,” but in this sense she uses the term “crazy” to mean energetic and creative, another meaning of the term “crazy” in English. Yet perhaps the line separating the two meanings is a thin one.

Even though participants had identified more with one side or the other of the polarity, none of them pathologized or even labeled their “manic” experience pre-bipolar diagnosis. It was experienced as “a respite” (Sarah) or as “that’s who I thought I was” (Darlene).

With the bipolar diagnosis, however, participants were told that their “highs” were simply products of disease. They were instructed not to trust any feelings of happiness or exuberance, as these could be symptoms of mania. For example, Natalie noted that as soon as she had “some outlook on life that is positive, ... and they’re telling me it’s a disease.”

Participants expressed feelings of embarrassment when they thought about prior wonderful experiences that are now pathologized. Rose, for example, concluded that she is not as smart as she had thought she was; it was only manic thinking that made her believe she was clever. She said, “I realized I wasn’t the sharpest crayon in the box. And that was disappointing because my brothers, my brothers are all brilliant.” But unlike her brothers, she now concludes that her beliefs were simply manic grandiosity:

I had a grandiose idea of what I was able to do. I am the smartest kid on the block. All I have to do is read, and I can do it. ... But the only reason I did it was because I was bipolar. BECAUSE ... my rubber band was wound. [loudly]. In other words, I was always going, “Sure, I can do anything.” I w—, I guess there’s lucky I didn’t jump off a building and thought I could fly or something.

Similarly, Kevin was embarrassed that his thoughtful poetry and deep philosophical analyses might have simply been grandiose flights of manic ideation:

It was also, um, a little embarrassing, to think that times that I had just felt—. One experience that just came—. I was writing this poem. I was feeling so elated about

it. This is the best thing that's ever been written! And I was just—, and you know, to, to think that some of those experiences were not glimpses into truth, or into the way I could feel about myself, but were ephemeral byproducts of, of, uh, a biochemical disorder, was also a loss for me. The loss of meaning

As Kevin noted, participants keenly felt as an irreparable loss the pathologizing of their exuberance. Kevin articulated this well:

I had always known that my feeling bad was a problem, but here's someone telling me that the times in my life where I had felt any joy, any ecstasy, any sense of purpose or meaning or—you know, some of those things that come along with slightly elevated, hypomanic kind of experience—that any of those things that I felt or thought were also pathology. This took away a huge chunk of what my, my sense of where I was hoping to be in life

In effect, the pathologizing of exuberance felt to Kevin like “chunks” of self were cut out.

This sense of loss was also addressed by Andy Berman (2002) in his memoirs.

Although he eventually followed instructions about managing bipolar disorder, he felt his “recovery represents a tremendous loss” (p. 261).

Natalie strongly challenged both the diagnosis and its implications that she must reject aspects of her self. She rebelled against the definition of bipolar that would take her happiness and energy away and label them “dangerous”:

I just felt good. You know, I just felt good. I was happy. ... I thought that was my life. ... I didn't think there was anything wrong with it. I was probably excessively manic all of my life, if you want to use the terms that they list in the ... “this is what bipolar is.” I've been an extremely happy person, happy most of my life. An extremely productive person. A goal-oriented person. A person who does not require a lot of sleep. Um, uh, an elated person. Someone who gets joy out of small things. Um, and I thought all of this was good. I didn't see any danger in it.

Then all of a sudden, I'm being told manic is dangerous. That it's dangerous to be happy. And I said, bull! I'd rather be happy. I'd rather be manic than to be flat-lined. Than to be some of the people on this earth who have no enthusiasm. Who

have no spirit. Who have no sense of beauty in the world. Who have no feeling of presence of the day, the moment, the gee, that wind feels nice. Or gee, the trees are pretty today. Or gee, I wake up and I feel good. And I thank God that I'm here, you know.

Natalie refused to give up her joy or to join in the construction of joy as disease. But she realized that in engaging with the medical world and taking medications prescribed for her, she was running the risk that her joy might be removed by medication:

Darn it, the highs are really good. They are. And I like being happy. ... You know. And I don't know if I want to get it unhappy, undone. I don't want to be placid. I don't want to be flat-lined. I don't want to walk around and see gray. I like the colors I see. ... And I like the wind on my face. And I like singing songs. And I like the fact that I can go out and hang with people and act silly and not be embarrassed and—. I like having unconventional thoughts. And I like to be able to pray to my God in a way that is sincere and spiritual to me but isn't necessarily within the confines of my religion. I like all of that.

Interviewer: So why do you have to give it up?

If he slaps another pill in me, it will be gone. That is my dilemma.

Like Natalie, Dr. Kay Jamison (1995) wrote in her memoirs that she desperately wanted to stop taking medications and actually did once, with a disastrous result. Yet for Natalie, Jamison, and other participants, the loss of exuberance felt devastating. Taking the medication felt like an enormous loss of a prior self and a prior life. Moreover, the medicated self felt like a foreign self.

It was quite challenging for participants to try to integrate the two poles into a cohesive sense of self. Natalie, for example, noted that she is trying to do so, but the metaphor she uses to describe the process is a painful one.

In retrospect, you know, I don't care what mania is, it's safer than depression. So much safer than depression. Right now I'm kind of walking the razor blade

between the two and it's ... it's very difficult. ... Hurts every step. Because, I know I have to stay on it. That little razor blade. I can't go to one place and I can't go to the other. I can't just let my feet go, cause then I'll slice myself in half. But each step is painful because I want to be somewhere else.

Natalie has found a middle road that sounds like a good solution. But her vivid and painful image shows how tenuous and dangerous her solution feels to her. Her razor blade image is similar to the two-edged sword metaphor mentioned at the opening of this chapter.

The difficulty of finding an integration is well voiced by Kevin: "I just think that it's very complicated, this thing about renaming parts of self as foreign, as not self. And maybe I just haven't done the right kind of reading about how one, how one integrates those, those two ideas." Kevin, who is quite well-read, seems to be thinking that an answer exists for how to integrate an internal and a "foreign" self, if only he would read more to find it.

Behrman (2002), in another memoir, abandoned efforts to solve for himself the dilemma of which self is more "me." He wrote, "There's no sense in trying to determine which me is the real me—in the end, I need the medications if I'm to lead a balanced life. I have a chronic illness, and I can't survive without them" (Behrman, 2002, p. 263). For Behrman, the identity as someone with a chronic illness that needs to be treated is the identity he finally claimed.

All Behaviors Are Suspect

As participants learned from their psychiatrists and others that any exuberant experience could be a manic symptom and not an authentic feeling, they started

questioning all experience. Authenticity of experience – the goal of much psychotherapy – became prohibited. Like efforts to root out terrorist networks, every feeling had become suspect. For example, at one point Natalie wondered if her new-found religiosity were simply a manic behavior.

It got to a point ... I was believing all of my beliefs in God were hyper-religiosity based on being manic. ... I felt really terrible about it. I thought well, then I'm lying, I'm living a myth. You know, that, you know, maybe it is my brain on drugs, which the serotonin—. ... I talked to my current priest ... about the hyper-religiosity. ... And he said I had one of the gifts that God gives, is the ability to see Christianity from a child's point of view.

Although Natalie wondered about her fervent religiosity, she chose to believe it was acceptable and was lucky to find a priest who did not discourage it.

To guard against “illegal” moods, thoughts, feelings, and behaviors, participants developed a hypervigilance about every thought or act. For example, Kevin noted, “I just think it makes me, it makes my reactions, my feelings always suspect.” Kevin was hypervigilant about his moods even before the diagnosis, because he felt that any exuberance in his family was criticized. Yet his vigilance had a socially endorsed basis post-diagnosis:

I mean now that I'm making the connection to my own feelings about ... myself and whether or not I'm out of line, you know. Whether or not I'm pathological or bad, in that sense. Clearly, clearly, it's been there. It's just a, a, a different set of concepts, to do the same kind of, uh, vigilance.

Note that Kevin employs the psychiatric view that hypomania is “pathological.” Yet he also uses moral evaluations: “whether or not I'm out of line” or “whether or not I'm ... bad.” If bipolar disorder is simply a chemical imbalance, morality would not be relevant.

This is discussed further below.

Darlene also talked about her hypervigilance and difficulty trusting her experience:

I don't necessarily think that I'll be OK, that I'll behave properly all the time. ... I do a lot of self—, second guessing sometimes. You know I'll come home from being somewhere and I'll think, "Do I sound like crazy?" [softly].

Note that Darlene too is describing her behavior in moral terms, as she is referring to whether she will behave "properly."

Darlene provided a poignant example of how she second-guesses herself, by rethinking a particular event "a thousand times." It involved a passing comment made by the future father-in-law of her daughter, a man who happens to be a physician. Her daughter told her: "He says you're wild."

And I said, [exasperated sigh] "OK. What does that mean?" So, "I don't know, he just says you're wild." And I—, you know, when somebody says that to me, I get nervous. What does that mean? What did I do? What was I doing that caused him to consider me wild? And say it to my daughter? ... But that's something really important to me. And [daughter] said, and, and my husband was trying to lighten the load there and he goes, "Well how come he didn't say that I'm wild? I want to be wild." You know, so he kind of did that and my daughter said, she said, "Mom, no, it's OK. I think it's kind of cool that he thinks you're wild." And I said, "OK, you know [sighs]."

In this story, Darlene comments on how her husband and daughter were not particularly concerned about the man's comment. Yet it cuts to the core with Darlene, perhaps to a moment of inadequate vigilance. She continued,

I'm in the process of making dinner and I'm thinking to myself, "What did I do? What was I acting like? What did I say? Where were we?" [softly, then sighs]. You know, because I want to know. ... What, what was I doing? What did I say? Who was I with? I reviewed the entire evening in my head a thousand times after

she said that, trying to figure out what I did. And I couldn't think of anything really. So that made me even more nervous. Cause I thought to myself, "I thought I was really well behaved. And he called me "wild." Oh my God. What am I like when I'm having fun? What is he—? Oh geez, you know. ... It is a pretty constant theme with me.

This incident may have been particularly difficult for Darlene because the man is becoming her daughter's father-in-law. It may also have been thorny because the man is a physician, who presumably might figure out that she has bipolar disorder. It is touching how a passing comment could have such power for a participant and how the inability to trust one's behavior can create such continual self-doubt.

Darlene has managed the problem of trying to sort out what is "proper" behavior and what is not by generally delegating this to her husband. She said her husband knows when she is "acting bipolar." He will say, "it's bipolar," and she'll be able to stop.

And he knows now, he can tell by the, by the tone when I start. And he'll immediately tell me what I'm doing. And, and I can immediately stop it. We've gotten so clued in together.

Darlene described a recent event when she was angry at her husband and wondered if this was appropriate anger or "bipolar" anger:

And I said, and I, I, I just got all freaked out. I thought for sure I wa—, it was something abnormal for me. ... And I, I just got all crazy And I—, so I went through this whole thing. And I was really mad. And maybe too much so, I don't know. ... And I thought, I, the whole time I was yelling at him ... for sure he was going to say, "Are you bipolar?" I just was waiting for him to say it because I seem—, I was thinking maybe I'm a little bit overly, over the top mad. But he never did. ... So HE can tell the difference too. ... So that's why I know I'm not just giving you examples of your basic disagreements. They're, when I tell you the ones that were manic, I know they are manic.

It is noteworthy that Darlene uses words connoting out-of-control behavior during this

incident: “I ... freaked out”; “I ... got all crazy”; “I was really mad.” Yet even though she uses these terms, Darlene is indicating, at least consciously, that she was not out of control but this was simply “normal” anger. Her use of language is indicative of two points about our society. One is how loosely in American English we use these terms. It is a common expression to call oneself crazy or freaked out as part of “normal” behavior. On the other hand, Darlene’s language may indicate an unconscious fear that her anger this time, as on some other occasions, may be out of control.

Nonetheless, Darlene indicates she has an internal sense of when her anger feels “manic” and when it feels “normal.” Yet it seems safer for her, and perhaps even comforting, to have someone else (her husband) confirm this. Other participants mostly grappled with these dilemmas by themselves.

Internal Experience is Also Suspect

For most of the participants, the more challenging struggle involved the evaluation of internal experience of self rather than just external behavior. Kevin, for example, is constantly analyzing his feelings.

The biggest struggle I’ve had, to tell you the truth, is, uh, and it’s almost a constant debate I go through in my mind, even to this day, um, how much of my experience of life, my experience of self, experience of other people is, uh, a result of this quote unquote illness, you know.

This is the core of the question about self that the participants faced. It is about how much one allows an illness label to define oneself. Kevin compared himself to his standard of “normal,” i.e., someone without a problem with depression or mood dysregulation.

How, you know, people I know who don’t have either a depression problem or

any kind of cycling, they take themselves for granted. They take their experience of themselves, the world, how they feel, how they're going to feel tomorrow, for granted. I don't know how I'm going to feel tomorrow. I don't know if I'm going to, I don't know if I'm going to feel, fantastic. I don't know if I'm going to feel normal. I don't know if I'm going to feel like crap.

Kevin attributes his insecurity about self to an unstable day-to-day experience of moods.

Yet a different question involves the authenticity of experience. Kevin wonders what aspects of his internal experience are "real" and which aspects are "disease":

Do I say, well, because I'm, I'm having a really hard time this week. ... is it because of this, is it this illness? Or is it me? ...It's a very deep philosophical issue. Uh, you start wondering what's really real? Is the me that is, you know, confident and exuding that to other people, and, building things, uh, you know, building a career, having confidence that those things can go well? Is that real? Or is that some kind of hypomanic kind of emotional thinking?

Like Darlene's concern about behavior, Kevin's concern is about feeling. Both involve the question of whether an experience is "real" or "simply" chemical. This is what drives Kevin to a constant monitoring of moods.

ALWAYS second guessing. Always. I'm hypervigilant about my own mood to the point that, and then you know, to the point that other things suffer. ... If I'm in more of an upswing, monitoring my irritability, monitoring my, um, level of, um, I don't know if I would say risk-taking, it's not—, or even impulsivity is too strong of a word. But just sort of monitoring that. ... I'm trying constantly to sort out how much of my experiences do this.

Kevin expressed the crux of the problem about how part-selves as pathologized as not-self: "We're hard wired to, to incorporate our feelings and our experiences as part of ourself."

With regard to continual self-vigilance, Natalie, at the end of the interview, suggested an additional set of questions that had not been asked:

“When you look in the mirror, who do you see? Do you see a bipolar? Do you see a normal person?” Um, when you address yourself in the morning, do you address yourself as, “Hi, Ms. Bipolar.” Or—. Is that something that crosses your mind all day long?. Am I being—? Are my actions genuine? Are my motives genuine or are they a result of bipolar? I think that that would be a good question.

She explained that her response would describe how monitoring her behavior is “on my mind constantly”:

Yes, it’s on my mind constantly. What are my motives? Um, I’m always doing a check: Am I being too happy? Am I be—, you know, overreacting? Am I, you know, too happy? Um, when I wake up in the morning, do I look and say, “you bipolar gal”? Yup. When I go to bed at night, do I look at the mirror, do I say, “yeah, you bipolar gal”? Yup.

Thus, one of the repercussions of the bipolar diagnosis is a questioning of both behavior and inner experience. It is difficult to experience an organized sense of self while wondering which experiences are authentic and which are “chemicals.” Yet as Kevin just showed, a continuous ongoing evaluation of moods may serve to avoid other emotional considerations. “Mood fluctuation” may become a stand-in for all feelings or experience.

Identity

With questions about sense of self and vigilance about moods, feelings and behaviors, participants found it difficult to find an identity label that they could hold onto. The term identity here is meant to refer to labels of self that one presents (or considers presenting) to other people.

For Natalie, the question of identity was particularly complex because she went directly from self-medicating with alcohol to being medicated with bipolar medications.

When she was first diagnosed, she struggled with questions of identity.

I said, I'm not manic depressive. You know, there's no way. Cause that's just NOT me. I don't—.

Interviewer: What IS me?

I don't know, yet. Um, because I've not had a period of my life that's been unmedicated, except as a child. I hope to go off my medication in September. Um, to see who is me.

Natalie believes that her difficulty in developing an identity label was related to a long history of alcoholism, and a bipolar diagnosis as soon as she became sober.

My particular situation is that I'm a recovering alcoholic. So at the time that I went through detox and rehab, I immediately came out on medication. So I've never known myself unmedicated. I started drinking when I was twelve. So, and using drugs. Um, so there is no me that I know of outside of a chemically induced me. So I said, "How can they diagnose me as bipolar if they don't even know who the hell I am, because I don't even know who the hell I am?"

She does not refer to her childhood traumas of losing a sibling and her mother by age 10. In any event, she desperately wants to find out "who is me." Part of Natalie's search for "self" involved a strong desire to stop her bipolar medications. She indicated that the medications change her in the same way that alcohol or illegal drugs did. She wants to experience herself unchanged:

I feel like a pill puppet. My mood has changed so drastically based on how my medications go about. Um, pump up this, decrease that. You're manic so we're going to give you this. You're not sleeping so we'll give you that. You're depressed so we're gonna really do this. And [sigh] yeah, my mood alters. And my spirits change. And my way of looking at life changes.

But it's scary because it's changed by pills. It's not changed on the inner me. ... Alcohol ... did not allow me to live a normal life, um, or to react normally to life's situation, because it was always masked by alcohol or drug use. Illicit drug use. ... And now I feel it's no different being masked by pharmaceuticals

prescribed to me by a psychiatrist. It's just a matter of one's written on a pill pad and one is taken in a bottle.

Natalie noted that wanting to go off her medication is a powerful drive. "It's a VERY strong pull. It is. It is. It is about the only desire I have at this moment." She wants to "find herself," as was said in the 1960's, even if she finds out she is a bipolar person.

I will say that I believe that I am a classic bipolar person. But I want to go off my meds to prove it.... I know based on ... my knowledge now of the definitions and how I do truly feel that I can tell, go back and tell Dr. X after our three-month experiment of having taken me off of medication that I'm going to sit in front of him and I'm gonna say, "OK, you're right. I'm bipolar. Bad me." ... But there's just some things you gotta do. And this is just one of those things I gotta. I got to go off medication. I got to be unmedicated. ... To find who that little core person is. That isn't changing. That isn't using. And that isn't on medication.

Note that Natalie also uses moralistic words to evaluate her decision to "discover "that little core person" who exists without medication. She thinks she will have to tell the doctor, "bad me," as if her efforts to seek her identity turn her into a misbehaving child.

Rose also went through periods of identity grappling. She started by denying that she could be "this" to concluding that if she is "this," she is no longer Rose.

How can I—, how can I—, be this? You're not, you're not Rose any more. You're a bipolar manic-depressive [whispered]. That's what you are. You're not Rose.

For Rose, the bipolar identity effectively prevented her from being Rose any more. Later she also expressed ongoing confusion about her identity.

I don't know who I am any more. ... That's what bothered me the most. Now I don't know who I am. I [don't] have to be smart anymore because I don't have a big deal job and I don't need big deal money. That used to be my identifier. But if that's not who I am and if all that was phony, who am I?

Rose was aware that she had defined herself by her work and her status before. But after

being diagnosed, she stopped working, so her identity would have to be found elsewhere. Yet she is also making a more profound comment. She sees her prior professional success as fake or “phony,” since it may have been impacted by bipolar disorder. In her eyes, the chemical imbalance of mania essentially eviscerates all prior experience. Rose discussed with her therapist, Nancy, her questions about who is the “real” Rose:

Nancy said, “Oh, you have an opportunity to find out.” [very softly.] “Oh, but what if I don’t like her? [laughs] What if I don’t like her?” And that’s what I’m doing now. Is trying to figure out who I am. Because that person was, uh, I don’t know, chemicals

Like Natalie, who feels that she could discover who she is only without putting drugs into her body, Rose feels like she is a different person than before. This new person is trying to figure out who she is, because all she was before was “chemicals.”

Notice again how the participants structure the question in black-and-white terms, effectively saying, “if I have bipolar disorder, I am not Rose anymore.” This theme is common across all the participants. It appears that having a label whose definition (bipolar) consists of opposite and non-integrated mood states necessarily results in questions about identity.

Using Bipolar Identity As an Excuse

One of the identity themes was to wonder how great a role in identity the bipolar disorder label would play. Participants were concerned about using “it’s bipolar” as a justification for every behavior. Kevin said, “I can always say, ‘Well, I’m really struggling with something today. My mood must be, must be on a downswing.’ It’s always an explanation for absolutely everything.” Kevin acknowledges that there is a

way he may use his moodiness as an “explanation” for too many behaviors or experiences. “My vigilance and labeling everything that way can really distract me from, ... to my peril, from what else may be going on in my life that I’m not paying attention to, [like] stresses that are building up.” Kevin explained how over-identifying with the bipolar label might result in using it in a defensive manner:

Some people find great comfort, I know, in being able to label and name confusing aspects—, to know they’re not alone. ... There’s other people that go through this and have support groups, you know, all kinds of things that go on. There’s also a way that, like abuse survivor, like alcoholic, like any other label, it can become the main focus of identity and be used in a way to organize oneself to explain everything, to—, in a way that is actually defensive. You know, you’re like, “Well, I’m bipolar, so of course I do this and I do that.” Well, no, maybe you’re also an asshole. Or maybe you’re—, maybe you were upset about something.

Kevin’s point is that using bipolar disorder as an explanation for all behavior provides an easy excuse for inappropriate behavior. Yet his statement is in the context of identity and seems to address a deeper question about the demanding task of finding an identity when one has a diagnosis of bipolar disorder.

Other participants also noted a desire not to use bipolar as an excuse for behavior.

Jodi, for example, does not place bipolar at the center of her identity:

I don’t like to explain away too much with the label. I’d like to be able to say, more like, you know, these were just things that happened in my life, and this is just the way I am. You know, and I, it’s not because I have necessarily, I have a disorder, or a problem. It’s just, you know, I, I, this is me, you know. I, I’ve done these things; I’ve had these—, had these things happen. And this is the way I’ve responded and that’s just the way it is, you know.

The concern about over-identifying with bipolar disorder “to my peril” is related to the participants’ hypervigilance about feelings and behaviors and their loss of

authenticity. No aspects of self or identity felt safe and comfortable once they were given the bipolar diagnosis.

Developmental Delays

Another repercussion is a feeling that one's problems, now labeled as bipolar disorder, delayed the participant from achieving his or her professional or personal goals.

Kevin, for example, said:

There's a way that I can underestimate the impact of my cycling mood disorder thing. And there's a way that I can really overestimate it. I think it depends on what mood I'm in. ... But the fact is I am—, I want to say—, significantly developmentally delayed in terms of life course, I think, in meet—, reading, me, meeting milestones. ... I, I just think its effect has been huge on my life. Huge.

Sarah also feels that both her personal and professional development were delayed due to her bipolar disorder. She believes she took too long to obtain her Ph.D., a delay which she attributes to psychological problems associated with bipolar disorder. She indicated she is particularly concerned about the delay because she feels the bipolar medications cause accelerated aging. She sees how her mother has aged, taking the same medications Sarah takes.

She's still bright. She can still drive. She can still add things and whatever. But it's getting mor—. You know, she, she just, she's gotten kinda more dizzy, dumb, um, just sh—, word finding difficulties, etcetera etcetera. And yeah, my medicines do that to me too. And so I'm afraid of that. That's a s—, scary thing. I'm scared that—. I'm, it's not like I'm gonna get old or get Alzheimer's or—. It's that I'm just gonna get slow and stupid and ugly before my time. ... And, um, so it's made me think, come on, come on, ... Maybe it's gonna be til you're 45 to get your career in gear but that's all right. Because what if by fifty I'm a blithering idiot, you know. [laughs] I mean, I'm exaggerating, but, you know.

Note that the two participants who comment on feeling delayed in terms of their

professional career are two psychologists, both of whom are highly accomplished. Their sense of their professional delays appear to be more related to identity issues (how they imagine others see them) than to internal sense of self. Kevin explained these concerns:

To perhaps reasons why I haven't gone farther in my life. Or why I struggled so far—. I mean it has, it has a lot more implications for identity I do think I carry around a way in which people will be sort of wondering about me. ... Why isn't he in a—. You live in a group house? What's up with that? You're [in your forties]. ... Why haven't you? You're just now moving to private practice. Well, that's sort of ... late. It's late. I do everything late.

When Kevin frames these questions others might ask about him, he uses the third person, suggesting that other people might be talking about him, “wondering” why everything he does is “late.”

Recovery

Some of the participants were asked how they viewed the idea of “recovery,” to see if this is a label they chose to take on. The interview question was premised on the term “recovery” as it is used in the psychiatric disability literature, meaning that one has learned strategies for managing the symptoms of the psychiatric disorder (Spaniol, 2001; Spaniol, Wewiorski, Gagne, & Anthony, 2002). None of the participants describe themselves as a person with a psychiatric disability and only one (Sarah) referred to the psychiatric disability literature or the meaning of “recovery” in that literature. The participants thought of the term as it is used in common parlance (cure or remission of an illness) rather than its application in the psychiatric disability literature. Several of the participants were familiar with the term “being in recovery” as it is used in the Alcoholic

Anonymous discourse, as a lifelong condition that needs to be managed, but none of the participants claimed that label for themselves.

Rose: focuses on “control” rather than “recovery”:

The way I think of it, the way I got this thing laid out in my own mind, is that I’ll never recover. I’m taking medication to control. ... Because it’s not like cancer. ... Because it’s not like getting radiation and then, then the tumor’s gone or whatever. I feel like I’m controlling my situation, not actually recovering from it.

Rose explained her conclusion by noting how her recovery is dependent on her taking medications for the rest of her life. “Have I recovered from going up and down? Yes, because that’s because I’m controlling.” She notes that her illness of reference is cancer, “between my dog having it and then my brother just having it.” So when she compares bipolar disorder to cancer, she concludes that she is not in remission, because if she were, she would no longer have to take drugs for her condition. Yet her choice of words is interesting. The word, “control” implies that without the medication, she would be “out of control.” The theme of being in or out of control is evident throughout the participants’ narratives.

Natalie uses the term “recovery” from her alcoholism as used by Alcoholics Anonymous. “I use the term ‘recovering alcoholic’ because that is the accepted term. I’m an alcoholic. I’ll never change. I will always be an alcoholic. I’m an alcoholic trying to live a better life.” Yet Natalie does not choose to apply that meaning to her diagnosis of bipolar disorder. Rather, her approach is similar to Rose’s. She does not think of recovery from mental illness, because that would imply “being totally well”:

Recovery is uh, uh, eventually being totally well. You recover from surgery. ...

I'll be able to totally deal with it. But I don't think you'd be totally well or else I wouldn't need medication.

Sarah is familiar with the psychiatric rehabilitation ideas about recovery and tries to use them:

If you could just sort of tell yourself, look, you have a chronic illness. So you're gonna make some accommodations for it, like one of em is, you get worn out more quickly than the average person. ... Chronic illness. ...But hey. Whatever. You know.

Yet Sarah finds it very challenging to hold onto that approach:

Once I get a negative idea inside me [laughs], I can never get rid of it [laughing]. So if I'm going to turn this into something awful, then that, you know, that's a, that's going to be a bigger problem, is, I guess, what I'm saying.

Thus, even though participants feel that their symptoms of bipolar disorder have had a significant impact on their lives, they do not have a handy phrase or adage to explain to themselves and others about the current role of the diagnosis in their lives. They have some phrases, like "I am controlling my situation," or "It's a chronic mental illness," but the way the participants speak of this is very tentative and the solutions seem to be individual and tenuous. A momentary slip of forgetting to take medication might result in loss of control. Or even though one claims this as a chronic illness, one can still experience debilitating depression and self-criticism. The wolves are always at the gate.

The fumbling for a way to address recovery suggests that by questioning and challenging some aspects of the bipolar diagnosis, participants lost some of the relief they had felt at having a comprehensive diagnosis that organized so many of their prior experiences. On the other hand, the participants had also developed a more comfortable

and refined relationship with the diagnosis.

Presentation of Self with Bipolar Diagnosis

After digesting the diagnosis and working to come to terms with it internally, participants then had to face how they would represent themselves to other people. The question involved both the packaging of an identity label and the planning for the imagined reaction by the other person. As discussed above, the participants had been adjusting to having the diagnosis and finding ways that it made sense for them. But they had to face the possibility that other people may have the same negative reactions to the term “bipolar disorder” that participants did when they were initially diagnosed. The other person may not have had the time to digest the meaning of the diagnosis as the participants have had. A few of the themes about disclosure and presentation of self to others will be discussed now.

Societal Prejudice

All of the participants indicated that they believe there continues to be societal prejudice against people with bipolar disorder. Participants sometimes referred to it as fear or stigma. Several mentioned the societal association of bipolar disorder with “crazy,” an association most of the participants had had when first diagnosed.

The concern is that the prejudice is about mental illness in general, with bipolar disorder considered one of the “biggies” of mental illness, as Sarah noted:

I mean it's, it's like, not just bipolar itself. It's more, this is more about mental illness in general. It's just that I'm aware that bipolar is one of the biggies. A major Axis I. Bipolar, Schizophrenia. What else is there?

Natalie also spoke to societal attitudes about mental illness and towards anybody who is an “other”:

I'd rather not have it. I mean, I would be dumb if I said, oh, it's fine. You know, cause there is a stigma. People don't like people with mental illness. Just like they don't like people with disabilities. They don't like people who are different from themselves. They don't like people from the way they look. You know. Uh, there's certain people I chose not to tell because I know that they have judgments. And that their judgments are cruel and unfounded, but that's their judgments. Uh, do I want to go through the hassle of trying to justify things and trying to make myself prove that my mental illness is not debilitator---, debilitating? No.

Natalie believes the prejudice against mental illness is stronger than the prejudice against alcoholism:

I think alcoholism is more acceptable right now, because there isn't enough known about bipolar. Um, and because one is considered a habit more than one is considered a mental illness. You know, the drinking is a habit that you can break. Nobody understands the psychological and physiological addiction of alcohol, but bipolar is a mental illness and therefore your brain is wrong.

Natalie's explanation for the different levels of prejudice is that with bipolar disorder the defect is seen as inherent in the person, but with alcoholism the defect is perceived as only in behavior. Jodi had a similar reaction: “I have this idea, this idea of society's perception of the problem and that it's, it IS something to be ashamed of. It is a, a failing or a weakness or—, you know. It's something to be hidden.”

The political tenor of the times was also considered. Sarah, for example (interviewed in June 2003), noted that she has been more afraid of societal prejudice since 9/11.

It's the political environment that'll make you paranoid. ... After 9/11 I had this weird thought ... I have a feeling that there's going to be a lot less tolerance for

any kind of emotional or other circumstance that explains why people would ever break a law. Because people are going to go, “It’s unpatriotic.” And that’s that.

Sarah is speaking to the heightened societal paranoia after 9/11 and how she believes the paranoia of the country will be played out with regard to attitudes towards people with mental illness labels.

Some participants referred to other people’s experiences of prejudice. Sarah, for example, mentioned the prejudice experienced by Martha Manning (1994), a professor who had difficulties in academia after disclosing that she had endured a significant depression. Sarah also referred to a client who was not hired by the Post Office after disclosing her bipolar disorder diagnosis in the job interview.

Participants also discussed the specific fears people may have of someone with bipolar disorder. Jodi, for example, stated, “The idea of being not mentally stable or in charge of your emotions, I think for a lot of people is very unsettling.” This concern relates to the image of being out-of-control, one that the participants themselves feared.

Some participants indicated that they would disclose the diagnosis, using alternate terms to identify it. For example, Kevin said he would use phrases other than “bipolar disorder” or “manic-depressive disorder.” Sarah stated: “I used to say manic-depression and now I would never say that because it sounds frightening. Now I would say ... ‘affective disorder’ When people hear manic-depression, they think crazy.” The sense is that the prejudice is linked to the terms and not necessarily to the symptoms. Participants’ concerns about presentation of self were particularly prominent in connection with work.

Disclosure at Work

Most of the participants indicated they would prefer not to disclose having bipolar disorder, particularly at work. They might disclose if they thought it was important to do so, but disclosure would be difficult and could result in painful feelings. For Rose and Darlene, one of the repercussions of having bipolar disorder was their decisions not to work any longer. They felt that a work schedule and a demanding job would be too challenging. Having to face the question of whether or how to disclose also felt daunting. The other participants are working in professions (Sarah, Kevin, and Jodi) or looking for government work (Natalie). Yet all felt concerns about presentation of self in a work setting.

Jodi feels that she needed to tell her co-workers because her behavior at work is not always appropriate for a physician, who is supposed to be cool, objective, and in control:

If you're in a, a position of such significance, you have to be constantly thinking about, um, ... who needs to know, why they might need to know, when you're going to tell, and what you're going to tell. ... To my dismay, I've had to, I've had to tell people, um, which I didn't want to do. ... But the bottom line is, um, with the people that I work closely with, I, I need to let them know. Because I am not like other people sometimes, in the way I respond to situations. Um, I can't always maintain the level of cool that I would like to see. Um, and there are times, if I'm particularly stressed, that I will fall apart, um, and, it has a very big impact on my job at times.

Jodi feels distress about having to tell co-workers. "It stinks. Oh my god, it's HORRIBLE." Jodi believes someone who interacts with her will be negatively impacted by her behavior:

It affects, it affects the person that has it. It affects the people that they're in relationship with. There's no getting around that. Um, it affects the people that they work with. It affects—, ... look at what I've just told you about my life. ... Do you think my children's lives would have been different if I hadn't been—, had this problem? I'm sure they would have been.

Considerations of disclosure invariably led to discussion of shame.

The Interaction of Shame and Disclosure

Shame was a constant theme whenever participants discussed disclosure, imagined or actual. Jodi feels shame for those behaviors that are related to her bipolar disorder, but the feelings are intensified when she thinks about having to tell others about her diagnosis. Kevin acknowledges feelings of shame, which he has addressed by rarely disclosing.

I do feel a lot of shame around people's imagined reactions. But it's untested. Except for intimate relationships, it's largely untested and I think it leads to a kind of being ashamed of myself. It's ... acting in a way that, as though big chunks of me are shameful. Chunks of my experience. And I can't really talk about it in a way that, that I experience it.

For Kevin, not only are the experiences shameful, but it is still difficult to find words to organize and articulate his experience. Considering how articulate Kevin is, his sense of his inability to put into words his experience is significant. It suggests that that which is most shameful still does not have socially endorsed constructs to capture the experience in words.

Of all the participants Rose's discourse was most peppered with phrases like "nuts," "wacked," and "crazy," terms which suggest both her shame about the diagnosis and an effort to hide those feelings through humor. Yet Rose was also reflecting the

social world in which she lives. For example, she indicated her husband said hurtful things when Rose was hospitalized in a psychiatric hospital after her suicide attempt. She quoted her husband as saying, “Your children are going to find out you’re in the psych ward; your family’s gonna find out. And they’re going to say, ‘Well, she’s been nuts all along’ [whispered].” When she accused him of having no sympathy for her, he responded: “‘It’s because I didn’t want you make a public spectacle of yourself.’ He called it ‘going public’” This suggests Rose’s sense of her own husband’s shame at Rose’s condition. She explained her view of her husband’s concerns:

As near as I can figure, he doesn’t want me to not be OK. And to know that I have to take a pill to be OK. I don’t think it’s so much selfish on his part. That, “God, I’ve got a defective wife.” Or “she’s nuts.” I think it’s that he doesn’t want to know that there’s something wrong with me.

Rose’s shame is tied to her fear that her husband may think she is “defective” or “nuts.” On the other hand, she believes “there’s something wrong with me,” and that her husband fails to acknowledge it. Rose’s shame about the disorder is also evident in the metaphor she uses for choosing nondisclosure. “In the beginning I hid it like, like leprosy. You know, hide it under your skin and don’t let anybody know.” Unlike leprosy, which is on the skin, mental illness is “under the skin.” Yet Rose analogizes bipolar disorder to leprosy, a devastating, debilitating illness that until recently was incurable.

Bipolar as Mentally Incompetent

Of all the participants, Sarah was the most concerned about disclosure, including to the interviewer. Sarah mentioned a myriad of reasons why disclosure is dangerous, from societal prejudice to other people’s experiences. Yet Sarah had her own experience

of prejudice. She indicated at the end of her second interview that she has not disclosed to her father and his family, “because they’re VERY mainstream people. And my dad’s, my dad and my siblings are a little racist, a little, you know, [laughs].” Her father does know about her mother’s bipolar disorder diagnosis, however. Sarah described how her father used this knowledge against her mother and how that impacted Sarah:

But when he wanted to uh, his wife is Catholic and ... she wanted to get married in the Catholic church with my dad. ... In order to do that, he would have to have his first marriage annulled. So like, Okay, that’s a little weird [laughs]. Um, so he succeeded in doing that by, uh, on the grounds of my mom being mentally incompetent [laughs]. ... She had never even shown signs of depression at the time that she was married. ...

It like didn’t do anything quantifiably negative, but ... it hurt my feelings. ... He and actually his wife too, tried to stress that it had nothing to do with me and they weren’t trying to reject me in any way. ... I can’t avoid the fact that symbolically you are disowning me, and it hurts [laughs]. ... He’s a lawyer, so, it’s like he’s using whatever he can think of. But it’s soo—, it was so, uh, cold-blooded.

There are layers of meaning for Sarah when her father got his marriage to Sarah’s mother annulled on the basis that Sarah’s mother was mentally incompetent due to having a diagnosis of bipolar disorder. In terms of Sarah’s life, her father’s act arguably disowns her legitimacy. It also could disown Sarah’s experience of herself as a competent person with a bipolar disorder label, since she might have interpreted it as labeling her mentally incompetent, a frightening prospect. At the very least, this experience significantly impacted Sarah’s willingness to discuss her situation with other people.

Other Repercussions

Besides impacting their sense of self and identity, participants believe bipolar disorder reverberated on many other aspects of their lives.

Daily Challenges

Participants faced a barrage of daily challenges, from managing symptoms, medications, and feeling unheard by psychiatrists. Darlene talked about the practical consequences of bipolar disorder.

I feel exhausted to be me sometimes [laughs]. And, it's like, it's like um, during the, during, open my calendar in the beginning of the week and what I have to do for that week. And I figure out how much I'm going to need to get enough sleep. It's going to be hard work for me. ... Sometimes I'm having a rough time. Sometimes I'm down. Sometimes I'm not dressed. Sometimes I just can't quite make it. And the medications I take make me very drowsy and very sleepy and it's very hard to get up in the morning. Um, like to go to work at eight o'clock in the morning. I cou—, almost never do it. I don't think I could do it.

The exhaustion from the disorder and the side effects from the medications are some of the reasons Darlene concluded she cannot work now, even though for about 20 years pre-diagnosis she had worked as a nurse-practitioner in a high-profile practice. She feels some shame about not working now.

Sometimes I feel a little badly that I'm not a better role model for my children. That, the fact that I'm not working. I'm not showing them that a woman can be out there and, you know, have a fabulous job. And I'm not showing them that. ... I'm not doing that because I'm bipolar. ... Cause my kids never really, they were pretty young when I stopped. And they, to this day, will say something like, "Yeah right, you're going to get a job" [said ironically]. You know, they'll say things like that to me and I think, "You guys don't know. I had a REALLY good job."

For Darlene, as all of the participants, shame was a continual undercurrent in daily life.

Shame About Self

Participants indicated feeling shame in areas other than disclosure. They expressed these feelings throughout the interviews verbally and through nonverbal

communications like laughter. Darlene noted that she still feels shame about her most manic behaviors, even though she believes the behaviors were biochemically caused:

You would think I would be OK with it, because it wasn't my fault. But I still blame myself for a lot of that stuff. I just—. I, I, don't know why, that doesn't make any sense. I shouldn't be blaming myself because it was, it was a biochemical imbalance, but—, I just, I don't know. I expected—, I expected myself to be, you know, on top of it. And I wasn't back then. Course my medications weren't right back then either.

Even though Darlene explains her behavior as a function of a biochemical imbalance, she still feels shame about how she acted.

As noted above, participants explained that what feels shameful is how there is something defective at their core. Sarah said, "Something about me. Yeah. It's that simple." In some ways Sarah envies someone who "had a long history of abuse." Since she believes her life was not normal from the outset, she cannot claim an external cause to her pain, like an outside abuser. Sarah indicated that her experiences feel shameful, even though she would like to attribute them to an external cause, like a chemical imbalance:

Talking about a lot of my life is shameful.... I mean if I were somebody who had a long history of abuse, I— it's silly to compare experiences, it's not fair. And I know how incredibly shame-filled that it is to people to I've worked with who have it, for God's sakes. So, it's not, so if somebody were sitting next to me, they'd say, "What?" For what I'm about to say. But it feels to me like I would be less embarrassed if I had that because I could then say: "I am a person who started out being normal and then something happened to me that made me be this way."

But I guess the problem is that it feels like—. There was so much of my life where I couldn't really explain. ... And yet this must be silly because that's true of kids who were abused too. ...

This is an indication of the depth of Sarah's pain. It also indicates how desperately Sarah,

like other participants, wants to find an external explanation for her pain and other symptoms. This is discussed more in the next chapter.

In this section I discussed how the diagnosis of bipolar disorder never wandered far from the participants' external lives or their internal affective states. Like a deep bell's extended reverberations, each contact with bipolar disorder, even just in thought, would set off a string of resonances at different levels. Like Sarah's story of her father's remarriage, participants sought to find meaning from these reverberations in their lives, no matter how painful they might be.

Discussion

In this chapter, I presented the many ways participants worked with the bipolar disorder diagnosis after they had overcome their initial negative associations. I tracked the ways they found or created meaning around having the diagnosis. This process was a developmental one. After their initial negative reactions, participants started to learn how the psychiatric profession sees bipolar disorder and its symptoms and manifestations. Once they were familiar with the psychiatric definition of bipolar disorder, the participants experienced feelings of relief for finally having a diagnostic label that organized and explained a range of experiences that previously had not been categorized together. They indicated that it made sense to them to have a more psychiatrically serious diagnosis than "just" depression, because they had felt during their lives that something was "not right." A more "serious" diagnosis confirmed that impression. The diagnosis also explained some of the peculiar and troubling behaviors of family members, even

those who are dead, and even those who had never been diagnosed with bipolar disorder. Having a linguistic label to capture these ideas, feelings, and beliefs felt useful to the participants for their self-understanding. The label and the medication also gave them hope that there was something they could do to avoid loss of control, since one of their fundamental fears is of losing control.

The participants soon realized, however, that they had to create new ways of conceptualizing their identities with the bipolar disorder label. This was challenging in various ways (discussed below). Some of the feelings of relief and support from having a comprehensive organizing framework were tempered by the difficulties establishing new identities. This was evident, for example, when they were addressing the question of whether they were in recovery for bipolar disorder. Participants did not have a comprehensive response. Even without a response that categorized a large swath of experience, the participants have each grappled with making meaning of the diagnosis. Each has created a range of meanings for themselves.

After considering the bipolar diagnosis, accepting some aspects of it and rejecting others, the participants then had to prepare for presenting themselves to others. They had to decide whether and how to tell other people about having this diagnosis. All the participants noted the ongoing societal prejudice against mental illness in general, and fears of bipolar disorder in particular, which made disclosure questions challenging. Their concerns about disclosure were particularly notable around employment. Some believe it is necessary to disclose to employers or co-workers, yet the thought of

disclosing at work evoked intense feelings of shame.

Participants also explained how bipolar disorder is present in their daily lives, from practical issues like managing medication to feelings of shame about their inappropriate behaviors. There are few aspects of participants' lives that remain untouched by bipolar disorder.

Self and Identity

Participants found they needed to reevaluate their sense of self and of identity because various aspects of the bipolar disorder definition called into question their prior understandings. One repercussion of the bipolar definition is that participants experienced its inclusiveness as taking over their identity, not leaving any untouched parts. For example, sometimes when referring to bipolar disorder, participants said, "It IS me" as if their bipolar disorder appropriated or misappropriated their entire identity. The question participants had to face is what is left of "me"? This sense of "me" is the comprehensive sense of self that William James called the "Empirical Self" (James, 1890/1950).

Search for Identity Coherence

Opposing poles. Another difficult part of the bipolar definition was its incorporation of opposing poles. This created a "me" that is divided into irreconcilable manic or depressed selves. Participants acquiesced in this division, often choosing one side or the other of the bipolar continuum to represent what felt like the real "me." The participants did not experience these different selves as in dialogue or in conversation with each other, which theories of the dialogic self might suggest (Bakhtin, 1981;

Halbertal & Koren, 2006; Hermans, 2002). Rather, the participants often experienced these different selves as two sides of a coin, that is, when one self is present, the other is not. Natalie pictured them as two sides of a magnet: “Do I have two heads? Two, two polarities? Do I think I’m on both sides of my brain? You know, what is bipolar? Two sides of a magnet?” Her metaphor is useful in capturing how the two sides seem to be repelling, not just opposite each other.

In spite of this definitional problem, the participants tried to create an identity coherence or “ego synthesis,” as Erikson (1959, p. 109) conceptualized it, between their bi-polar selves. This was difficult because these two sides were experienced as repelling each other and not in dialogue. It was also difficult because the participants generally preferred or felt more comfortable with one side of the polarity.

The participants resolved this identity dilemma by relying on the concept of bipolar disorder as a cycling disorder. The entirety of the definition helped contain the two sides into one integrated label. Kevin, for example, offered a way he could explain his condition to other people (even though he does not use it, finding the explanation too complicated):

You know, I have this cycling mood disorder thing. And sometimes I just don’t want to be bothered with people. And sometimes I’m really gregarious and want to hang out. And sometimes I feel really bad and sometimes I don’t.

Even though Kevin may not articulate this understanding to other people, it is useful for his own self-understanding. In this way, the bipolar label provided an identity coherence that included various selves, from feeling gregarious to feeling really bad.

The pathologizing of mania. Another difficulty with achieving identity coherence is that the psychiatric profession and society pathologizes manic behaviors more than depressive ones. Manic behavior is seen as out of control and is treated as a kind of psychotic process. Intense happiness is viewed only as pathology. This attitude was experienced by participants as the killing off of an important part of self. As Natalie stated:

I didn't think there was anything wrong with it [before]. I was probably excessively manic all of my life, if you want to use the terms that they list in the ... "this is what bipolar is." I've been an extremely happy person, happy most of my life. An extremely productive person. A goal oriented person. A person does not require a lot of sleep. Um ... uh ... an elated person. Someone who gets joy out of small things. Um. And I thought all of this was good. I didn't see any danger in it. Then all of a sudden I'm being told manic is dangerous. That it's dangerous to be happy.

The denigration and loss of such an essential part of self was excruciating for the participants. From the Lacanian perspective, these experiences of elation and expansiveness are manifestations of *jouissance*, a kind of pleasure and satisfaction that is also connected to excess and anxiety (Dor, 1997; Rogers, 2007). In Lacan's view, this *jouissance* will provide information about the experience of mood and chemical changes, so medications to eliminate it are ill advised (Rogers, 2007). Yet this perspective is inconsistent with that of the psychiatric establishment.

Moreover, it was difficult for participants to create a cohesive sense of self that excluded these core ideas of productivity, happiness, and elation. Kevin explained why it feels so difficult to lose this part of self:

We're hard wired to, to incorporate our feelings and our experiences as part of ourself.... So you, somebody comes into a psychologist's, psychiatrist's office and talks about themselves and all of a sudden they hear that all these things that they think are self are really not self. ... Well, the damage that does to you ... that damage that does to your sense of self ... can, I think, lead to a, a loss of agency
....

This is the essence of the challenge participants faced. They had to figure out how to manage that important part of self after the psychiatric and societal attitudes transformed and transmuted these experiences from self to not-self.

Although depression is also pathologized in psychiatry and in society by virtue of the DSM-IV-TR label, depressive behaviors are not as feared and denigrated as so-called manic ravings are. As Jodi stated,

I think people look upon depressed people as, like, pretty harmless [laughs]. All they're gonna do is harm themselves, you know. It may be very harmful to the people in their lives who care about them, but it's not like they're gonna—, they're likely to be homicidal, or, like, you know, rage or do something.

The pathologizing of mania makes it difficult to integrate into a cohesive identity. The process was made even more difficult by the vagueness of the definition of mania.

Blurred threshold for mania. Participants did not easily know how to define and recognize their “manic” or “hypomanic” selves. Psychiatrists told them that some of their prior behaviors were manic or hypomanic; this diagnosis was simply based on participants' reports of prior behaviors. Although participants knew for many years what their depressed self felt like, they now had to extrapolate from the list of behaviors the psychiatrist labeled as manic or hypomanic to determine what other feelings or behaviors should also belong in that category. They were learning that their manic or hypomanic

self included irritability, anger, high energy, happiness, and intensity. It remains unclear to participants, however, what else this self contains. They ended up working this on a case-by-case basis.

Participants contended with whether moments of being happy, “wild,” religious, or emotional were captured by the pole that was categorized as “mood elevation.” If so, what was the threshold? It was a difficult boundary to negotiate, both individually and in terms of societal meanings. The psychiatrists could not easily figure this out. One participant asked her priest about her religiosity; another relied on her husband to notify her if she was being “bipolar,” which to that couple meant “too” angry or “too” intense. It was difficult to integrate this elevated self into a cohesive sense of self when the threshold for being happy or being manic is so tenuous.

Physical sensation. Another aspect of the Empirical Self with which participants grappled involves physical sensations, part of what James calls the “material self” (James, 1890/1950). This was not easily articulated but could be inferred by participants’ rapid style of discourse, their descriptions of their “racing” thoughts, and metaphors used to describe feelings and behaviors over which they felt they had no control. It was a challenge to incorporate this physical self into these other aspects of self. Participants were aware that their physical and sensory experience impacted their experience, but they did not focus much attention on this self.

Search for “Selfsameness”

In addition to seeking an identity coherence, the participants also sought a feeling of a continuous sense of self, which Erikson called “selfsameness and continuity in time” (Erikson, 1959, p. 22). This is the feeling that one is the same person, even through different internal experiences and with different people. The participants wanted to feel that they were the same person before the bipolar diagnosis, when depressed, when irritable, when happy, and when medicated.

Observing ego. Another self was like an observing ego, a self that could see all these selves without choosing favorites. This self was described by Natalie:

“When you look in the mirror, who do you see? Do you see a bipolar? Do you see a normal person?” Um, when you address yourself in the morning, do you address yourself as, “Hi, Ms. Bipolar.” Or—. Is that something that crosses your mind all day long?. Am I being—? Are my actions genuine? Are my motives genuine or are they a result of bipolar?

They also wanted to feel selfsameness between this self and the other selves.

As noted in Chapter Four, getting the diagnosis felt like crossing a major threshold that changed everything. The medication also felt like it changed everything. One’s moods seemed to change regularly. The participants struggled to find a sense of selfsameness, with shifting moods and a medicated self. Yet it was exceedingly difficult, particularly since these different selves felt so divergent.

The medicated self. The participants, as well as those who wrote memoirs of bipolar disorder, had the most difficulty experiencing their medicated self as part of that continuous sense of self. Natalie expressed this difficulty particularly vividly:

I don't think I can know who I am until the time is when I'm off drugs. ... I feel like a pill puppet. My mood has changed so drastically based on how my medications go about. Um. Pump up this, decrease that. You're manic so we're going to give you this. You're not sleeping so we'll give you that. You're depressed so we're gonna really do this. And [sigh] yeah, my mood alters. And my spirits change. And my way of looking at life changes. But it's scary because it's changed by pills. It's not changed on the inner me. ... [Going off medication is] a VERY strong pull. ... It is about the only desire I have at this moment.

How can one experience selfsameness when one feels that one core self is being manipulated by drugs? This was a complex and daunting dilemma for the participants.

The Role of the Other

Participants did not engage in these two tasks (seeking identity coherence and working for selfsameness and continuity) in isolation. The outside world was continually present in tasks such as relationships, work, and disclosure considerations. The participants were always aware of what their psychiatrists, their parents, their partners, and society would say about their thoughts, feelings, and behaviors. For example, the participants' partners often told them (post-bipolar diagnosis) that they were behaving in a "manic way." Jodi recounted:

Every time I would get like a little bit excited about something, it would be like, you know, maybe that's a little manic symptoms. ... You don't want somebody saying, "Darling, you look a little manic today," or, "You're acting a little manic today."

With psychiatrists telling them that their past behavior was sufficiently manic to warrant a bipolar diagnosis, friends and family telling them that their present behavior is over the top, and society telling them that their future behavior will be out of control, it was very difficult for participants to hold onto their prior sense of self. The participants

were much less familiar with the manic label than the depression one and were even unsure of what constituted mania. The participants wanted in part to reject the manic label. However, with all these external pressures, it was too difficult not to internalize a sense of self as manic and out of control. Natalie's description of a manic episode reflects how she has internalized some of the messages that mania is "bad":

But my serotonin level was so high it was better than cocaine. ... I said this, this is not right. People don't feel this way. But I don't want to give it up because it feels so good. ... It's very hard to go into your psychiatrist and say, "I'm having too much fun. I'm enjoying life too much." ... I know it's not right. ... You, it's li—, it's the feeling you have after sex [without having had] sex. Or after a good meal and you don't gain weight.

Although Natalie has internalized a sense that her good feelings are problematic, her evaluation is based on how she has been told by psychiatrists and other people that feeling so good is "not right."

As a result of the continual messages from the outside world, the participants developed a hypervigilance to determine when they were *acceptably* happy and when *too* happy. The distinctions were always titrated to an external evaluator. The importance of the other in these identity tasks is consistent with the views of Lacan, who indicated that one's sense of self emerges from "the gaze of the other" (Lacan, 1968). Erikson and other identity theorists also recognize the importance of the "other" for developing a sense of self. Erikson stated, "The counterplayers of the 'selves' are the 'others' – with which the 'I' compares the selves continually, for better or for worse" (Erikson, 1968, p. 217). In other words, "subjectivity depends on a social context" (Caminero-Santangelo, 1998, p. 89). For these people, the social context defined the disorder and labeled behaviors as

manifestations of the disorder. The participants' subjectivities were necessarily molded by this context.

Before the bipolar diagnosis, the participants had difficulties in life, but their sense of identity was comfortable. The bipolar diagnosis changed this. The actual comments of other people, like psychiatrists, friends, and family, impacted their sense of self. Societal attitudes also controlled the participants' sense of identity. These societal factors included the bi-polarity of the definition, the pathologizing of elation and mania, the association of bipolar disorder to loss of control, and the association of bipolar disorder to craziness. With messages from other people and from society that labeled, categorized, and analyzed the participants' feelings and behaviors, they had to reconsider everything about self and identity.

Loss of Authenticity

The participants also had to forego some sense of authenticity due to the pathologizing by society and by the diagnosis of some of their "authentic" experience. Participants' concern about authenticity arose in the context of wondering which experiences were "real" and which were merely "chemicals." With the DSM-IV-TR's medicalizing of behavior and experience, the external society had redefined the participants' experience. The impact of the "other" rendered authentic experience problematic. This was a central dilemma for participants. This question was related to the participants' anxieties about attaining identity coherence. If aspects of self cannot be trusted, are not "real," or are "only chemicals," how can they be incorporated into a sense

of self? Or should they be omitted from a sense of self? Or which parts should be included? How can one attain authenticity, which involves individuality (Taylor, 1991), a trustworthy selfsameness (Erikson, 1959), and a sense of “me” (James, 1950)? What does it mean to a person to be told that what he or she experiences as real is not real? Or that what feels really part of oneself is not self or is not real? These are all part of the central dilemma that these people face. As Kevin stated,

Part of what was so hurtful to me was ... I had always known that my feeling bad was a problem, but here's someone telling me that the times in my life where I had felt any joy, any ecstasy, any sense of purpose or meaning or, you know, some of those things that come along with slightly elevated, hypomanic kind of experience. That any of those things that I felt or thought were also pathology. This took away a huge chunk of [my experience]

For participants, experience, feelings, or even sensory perceptions cannot be taken for granted. The participants tried to determine whether emotional states that felt very real to them were really part of self, in spite of what the external authorities said. Yet they also considered whether these experiences were not-me quasi-external phenomena that only masqueraded as authentic experiences. Developing this distinction involved a struggle to find a baseline for what is “real” experience. As Kevin further stated:

The biggest struggle I've had ... is uh, and it's almost a constant debate I go through in my mind, even to this day, um, how much of my experience of life, my experience of self, experience of other people is, uh, a result of this quote unquote illness?

Most people can count on some socially shared sense of reality. From a strict socially constructed perspective, all aspects that the individual experiences as real are affected by the society in which he or she lives. Yet however it is created, these people's

sense of reality is necessarily disrupted by being told that aspects of themselves that they thought were genuine, real, or core experiences of self are simply products of a biochemical imbalance.

Although the participants experienced their own individuality and subjectivity, experiences were often achieved only after a “constant debate,” where the person evaluated whether what he or she experienced should be interpreted as real, first to self and then to society. Determining which side wins in each debate is a formidable task.

Conclusion

This chapter investigated how the participants found meaning in their lives in having the bipolar disorder diagnosis. They did not necessarily achieve identity coherence, but they did find meaning with bipolar disorder, in a number of ways. The next chapter addresses how the participants worked with the societal explanations of the nature of bipolar disorder to eventually develop their own resolutions to the meaning of bipolar disorder in their lives.

CHAPTER SIX

EXPLANATORY FRAMEWORKS FOR BIPOLAR DISORDER

The previous chapter addressed how the participants sought meaning from the bipolar disorder diagnosis. A related question with which participants wrestled involved the nature of the disorder and its etiology. There are several options available in American society to explain the etiology and nature of bipolar disorder. This chapter investigates how participants worked with these explanations.

Biochemical Imbalance Explanation

Participants were told by their psychiatrists that they have a chemical or biochemical imbalance that can be regulated by ingesting various chemicals to correct the imbalance. This view is the predominant view in American society and by the time participants were interviewed, they were familiar with and generally comfortable with this perspective. Yet they all still indicated that other factors may also influence their feelings, moods, and behaviors. Since the dominant societal paradigm is the biochemical imbalance one, by questioning this view, the participants were essentially challenging their psychiatrists and the prevailing American belief system.

Biochemical or Physical Imbalance

The participants indicated that they see themselves generally as biochemically or neurologically different from other people. Darlene addressed the chemical imbalance explanation:

Doctors have said this to me: It's just like having diabetes or having high blood pressure: you gotta take medication. You have it. It's a, it's a, brain chemistry

thing. ... I believe it's chemistry. I do. I believe there's some brain chemistry wiring problem. And I think I was born with it.

Natalie expressed it slightly differently. She sees herself as having a different physical brain than other people and she attributes the difference to her addictive personality.

Some people are more comfortable than others, e—, you know, when it comes to mental illness, and to me it is a problem in my brain. My brain doesn't function the way other people's do. And it's the same with alcohol. And it's the same with drugs. And it's the same with coffee. And cigarettes. And anything else that can be addictive. My brain is an addictive brain. If you were to take my brain out, plop it down on a table, plop, we'll say, a non-addictive person's brain on a table, dissect it, you'll see that my brain is physically different.

It is notable that Natalie refers to her brain as almost a separate entity from her self, concluding that her brain is an “addictive” one that is physically different from other people's brains.

Problems with the Chemical Imbalance Construct

The participants generally accepted the idea that they have a chemical imbalance.. All of the participants are under the care of psychiatrists, so incorporating the medical-biological view of bipolar disorder is to be expected. What was unexpected, however, is how that explanation was not a fully satisfying one for any of the participants. Even the participants who relied on the biochemical imbalance explanation the most still acknowledged that that particular explanation does not capture everything about their internal experience or behavior.

Kevin discussed one reason why the chemical explanation is inadequate. He explained this from an internal-external dichotomy.

But the standard things we say about, “Oh, it’s just a chemical imbalance, and we’re just going to give you this to rebalance you.” Well that keeps it at a distance. And, and, makes people—, how people sort it out. That’s why people don’t want to go on medication. They want [to] be them—, they don’t want to let, they don’t want to be somebody else because ... the pill makes them somebody else.

In this analysis, if “the pill makes them somebody else,” then the change in personality comes from an external source, namely, the pill. Delegating one’s “agency” to an external force is problematic, in Kevin’s eyes:

Well, the damage that does to you--, and I know—, that damage that does to your sense of self, or your confusion about that ... can, I think, lead to a, a loss of agency [It] can mean, “I’m not in control of my life.” ... Do we need that illusion of, of control? Need that illusion of, um, that what I do matters? Um, what I feel means something?

The chemical imbalance explanation tells the label recipient that he or she does not have control or agency over his or her behavior; instead, chemicals do. Kevin postulates this as problematic.

Darlene addressed a different problem with the chemical imbalance explanation – its lack of comprehensiveness. She expressed confusion about why, when her husband says, “it’s bipolar,” she can stop a behavior.

But it’s interestingly to me, interesting to me is that when he tells me, “You’re bipolar, he doesn’t have to say, “You’re starting into your mixed states.” He just says, “It’s bipolar.” It’s like our key word. That when he catches me early enough, I can stop. Which—, that’s interesting to me because you would think if it’s chemical, then I—, it would be too late—, I mean there would be nothing I could do about it. If it was biochemical, why—, why—, how could I stop?

If the behaviors were due solely to a biochemical imbalance, no behavioral intervention would be able to impact them. Darlene tries to understand her apparent volitional control

over her behavior, but stumbles at expressing an alternate explanation. She wonders if her control is a function of her medications or her efforts to control her behavior. “I am on medicine and maybe the fact that he catches me just in time, I can, you know, you know, push it down somehow or another.” She then describes a recent situation where she was very depressed, but managed to get herself up and moving:

I was crying and I just went up to bed. And the next morning when I woke up, I felt like hell, but I said, [sighs] “I can’t do this again. I cannot get depressed” [very softly]. So I got up and did it. So, you know, I guess part of it is n—, something that you have to talk yourself out of.

Yet even while recognizing that she can stop certain feelings, like anger or depression, from morphing into full expression, Darlene indicates that she feels she has no control over certain experiences of mania, like being hyperactive or talking fast. “I can’t stop those.”

Sarah raised a third problem with the chemical imbalance explanation. She stated that although it may be the politically correct view of bipolar disorder, she fears that most Americans have negative stereotypes about people with bipolar disorder and do not accept this explanation in the depths of their hearts. She said,

It’s just that, even though I’m sitting here telling you myself that what you have to do is call it a biochemical illness, and, you know, analogous to diabetes, and then you don’t have to blame yourself, ... that doesn’t work for me. I could try to make it work. But it doesn’t. ... But I’ll tell you that nobody else thinks that way when they hear about somebody who has it. If somebody is crazy, they are crazy. It’s not that they have craziness.

Sarah is perhaps speaking to the underbelly of the biochemical imbalance notion. The positive side is that it should reduce prejudice by locating the “bad” part in brain

chemicals, outside of conscious awareness or control. Yet she seems to be saying that most Americans still see people with bipolar disorder as “crazy” people, even if the prevailing explanation for bipolar disorder is a non-blaming one related to a chemical imbalance.

These were three of the ways participants discussed how the dominant explanation for bipolar disorder was problematic for them. Kevin’s comment about how one impact of the biochemical imbalance explanation is a loss of agency or of control brings us back to the issue of control, an ongoing theme for the participants. Kevin may speak for all the participants (and all Americans) when he states:

Do we need that illusion of, of control? Need that illusion of, um, that what I do matters? Um, what I feel means something?.

Other participant experiences involving control are now discussed.

Loss of Control

As discussed in Chapter Four, the participants feared being out of control. Yet several had actual experiences of loss of control, experiences that were difficult to explain.

Out-of-Control Experiences

Darlene was the most outspoken about how she felt she had no control over her intense outbursts of anger throughout her life (pre and post-diagnosis). Describing one incident, Darlene noted that these angry outbursts felt outside of conscious manipulation:

It was an explosion. ... It was something I had absolutely no control over. It’s, there’s some kind of snapping. ... I have no control over this.

Rose also described, pre and post-diagnosis, of feeling like she could not control her feelings or behavior.

Other participants had brief episodes of loss of control post-bipolar diagnosis. Natalie, for example, experienced a severe depression while on Risperidol. This is what she calls her “plate shattering” period, a devastating and life-changing experience.

Risperidol makes you dumb. It dulls your intellect. Makes tasks harder to do. It makes you stupid, is what it makes you. So I started a job and I was unable to perform simple tasks. ...Um, so I got paranoid, and the paranoia turned to fear and the fear turned to being mortified and terrified of going to work. And that has never happened to me before, ever in my life. And I would literally quake and cry on my way to work. ...I had no clue. ... I didn't know what the hell was going on. I was just so freaked out. I couldn't believe it. ... It was sheer terror. And I had nothing to be afraid of. ... Me without Risperidol could have done the work. I see that now. I did not see that then.

At the time of this painful experience, Natalie did not understand what was happening to her. It is only later that she made sense of it, attributing her fear and affective state to an adverse reaction to Risperidol.

Jodi also had negative side effects from a medication, an atypical antipsychotic that she was prescribed for anxiety. She says she was “shaking and twitching” and looking like “a mental patient”:

I mean, I was so newly diagnosed, I didn't really know. ... And the next thing I know, I'm on these escalating doses and I'm walking around like I'm bumping into walls. And when I'm not bumping into walls I'm, I'm shaking and twitching. And I mean [laughs], I look, I look like s—, I look like a, a mental patient. ... I mean I really looked, I looked like somebody who just got out of the hospital. I mean I really looked bad [laughing]. ... Oh, it was very frightening. It was like, you know, being—, it's—, it was like a loss of control.

Although Jodi and Natalie now see these disconcerting experiences as simply

medication-induced reactions, the experience did not feel any less frightening. Having an external explanation for the cause of loss of control did not provide significant relief.

These experiences substantiated participants' fears upon initial diagnosis that a bipolar diagnosis meant they might lose control. For those participants (Jodi and Natalie) whose loss of control was explained as a medication reaction, having the external explanation was helpful only after the experience had ended. For participants whose loss of control was explained as simply a function of bipolar disorder (Darlene and Rose), the explanation provided only a modicum of relief. The bottom line seems to be that experiencing a loss of control is frightening, no matter how the experience is later explained.

All of the people who wrote memoirs of bipolar disorder described myriad episodes of out-of-control manic behaviors (Behrman, 2002; Jamison, 1995; Simon, 2002). Their stories involve acts much more extreme than anything the participants reported. Even so, the memoir writers continued to fear losing control. And even with their dislike of being medicated, they indicated they decided to stay on medications in the desperate hope of avoiding a repetition of those feelings of being so out of control.

Demonic Possession

Another way to investigate the phenomenological experience of loss of control is through participants' metaphors. Two of the participants, Darlene and Kevin, used a metaphor of demonic possession to describe experiences around lack of volitional control.

Darlene used the metaphor when trying to describe her experiences of loss of control:

It's like you're on a treadmill and you're running so fast that you can't stop. ... For me, it's, it's the manic, um, racing feeling that, that just mind-racing thing that I just can't stop. ... [It's] like being possessed or something. I don't know. I, I just. I just get a sensation and I just know that I'm about to do something I'm not going to be pleased about later. I'm just, something's happening and it's going to be bad.

Darlene's description does evoke how we may imagine the feeling of being possessed by an external "bad" entity. She first "gets a sensation." Then she "knows I'm about to do something" and she also knows "it's going to be bad." These stages of "possession" suggest that she knows when the chemicals or the "devil" takes over her body, but she does not feel able to stop it. Although Darlene is using the term as a metaphor and not in a concrete way, the metaphor seems to capture energetically the experience.

Kevin used the metaphor of being "possessed" in a different context. His reference was to support his case that the biochemical imbalance explanation is problematic.

We're hard wired to, to incorporate our feelings and our experiences as part of ourself. ... So you, somebody comes into a psychologist's, psychiatrist's office and talks about themselves and all of a sudden they hear that all these things that they think are self are really not self. They're really—, you know, "actually you've been demon possessed your whole life and, uh, everything you've said is now the result of—. I'm going to give you a pill for it, which is going to make you normal."

In Kevin's reference, the experience of being demonically possessed is in being labeled as having bipolar disorder and a biochemical imbalance. The psychiatrist has become the priest who has made the determination that the patient is possessed.

Similar metaphors were used in memoirs of other people with bipolar disorder.

Dr. Jamison (1995) also alluded to demonic possession. When contrasting her experience to that of her sister, she noted:

... when both she and I had to deal with our respective demons, my sister saw the darkness as being within and part of herself, the family, and the world. I, instead, saw it as a stranger; however lodged within my mind and soul the darkness became, it almost always seemed an outside force that was at war with my natural self.

(Jamison, 1995, p. 15)

Similarly, the television journalist Jane Pauley (2004) described a sense of being inhabited, in her case by an “alien.”

I don't think a stranger would have noticed anything remarkable—I wasn't swinging from the chandelier.... Although the villain was the illness and the victim was me, only a doctor could make such a distinction. My daughter, Rickie, was the most overtly affected by an alien presence. She did battle with it openly, which is to say, with me.

(Pauley, 2004)

Pauley uses two contrasting metaphors. She is relieved that she was not “swinging from the chandelier,” but is aware that she was inhabited by “an alien presence” with whom her daughter “did battle.” The chandelier image harkens to a crazy person or an ape that is out of control and unmanageable. The alien reference is similar to a demonic possession metaphor. In light of the findings from this dissertation, Pauley's distinction is instructive. Her relief at not being “really” out of control (swinging from chandeliers) seems to ignore the fact that her daughter experienced her as out of control (or controlled by an “alien”).

These people are discussing somewhat different phenomena using similar

metaphors. Darlene is describing times she has felt a loss of control that is like the image of being demonically possessed. Kevin describes how getting the label felt like he was being condemned as a person who is demonically possessed. Dr. Jamison grapples with whether the demon is within self or a foreign self invading the self. And Pauley tries to show how she never lost control, but in doing so she admits that her daughter experienced her as alien possessed. All of these images, however, are powerful. Darlene's series of metaphors also provide a vivid impression of the internal feeling: being forced to run quickly while on a treadmill, "snapping," having an "explosion," and "demon possession." The demonic metaphor represents the feeling of loss of volitional control to external (i.e., biochemical) forces.

There is no concrete religious personification of a devil as in earlier eras. Rather, the demonic entity in these narratives is comprised of amorphous and perhaps frightening neurotransmitters operating outside of conscious control. The use of the demonic possession metaphor suggests the depth of the experience of powerlessness, confirming participants' worst fears of loss of control.

Other Explanations Participants Considered

While indicating their acceptance of the biochemical imbalance explanation, the participants offered other explanations that they found equally or more useful for understanding themselves and their moods, feelings, and behaviors. They all indicated that it was important to address these questions. As Kevin explained:

Well, doesn't it make sense though that it would fit into, like other aspects of identity? ... I mean that it would make sense to me, I guess, that it would, it

would exist in a context of an overall personality. And the meaning of it, like the meaning of anything else that goes on in somebody's life—. I mean, there are people who think that if, uh, you know, something bad happens in their life, that it's completely their fault. There are other people who think they have nothing to do with it. Um, and there are people who think, it's no big deal. They can handle it. You know, everybody makes different meaning out of, out of the things that, that, uh, happen.

For Kevin and the other participants, having a clear sense of one's own explanation provided meaning for one's life.

Personality and Life Experience

Most of the participants were careful not to explain all of their behaviors or the behaviors of others by a bipolar disorder model. Yet they had difficulty determining where to draw the line between chemistry and personality.

Sarah, for example, struggled with how much of her mother's failure to nurture Sarah adequately could be explained by her mother's bipolar disorder and how much should simply be explained by her mother's personality:

There are different kinds of people who have bipolar disorder and there are different kinds of peo--, ah, you know. All schizophrenics don't have the same personality. You know, my mom does have a personality and a lot of what she did she did because of the kind of personality she has. Not because she was bipolar.

Sarah has the same questions about her own paranoia:

That seems to be something that is al—, at least some of the time, part is just my insec—, to some extent part of my character too. I mean of course that's something that you develop that you keep—, you know, a depressive, like worldview or something But I also think that, you know, there's bio—, certainly biochemistry, you know, we're, geez, where does one stop and the other start? [laughs]

Sarah indicated that it is always difficult to make the distinction between symptoms of bipolar and other factors, like personality: “But it’s hard to figure out. I don’t know, it’s hard to figure out when it’s that and when it’s just me. You know. I mean, that’s what’s hard to sort out.”

Although Jodi is a physician (and would be most expected to endorse the medical model of a biochemical imbalance), she was very cautious about her attributions. Jodi said:

So I think, having a label is convenient because the WORST periods of my life can sort of be understood in this—, that context. Um, but I don’t know that I want to explain my entire emotional life by a disease model. ... Let’s have it be not that simplistic. Cause it’s not. It—, nobody—, nobody’s life is that easy. And that easy to be explained. ... When symptoms get to the extreme, or emotions get to the extreme, maybe you can start going there.

Jodi’s explanations involve emotional sensitivity. She is cautious about how much to give to the bipolar disorder rather than simply labeling it as life experience.

I’d like to be able to say, more like, “You know, these were just things that happened in my life, and this is just the way I am.” ... It’s not because ... I have a disorder or a problem. It’s just, you know, I, I, this is me, you know. I—, I’ve done these things; I’ve had ... had these things happen. And this is the way I’ve responded and that’s just the way it is, you know. Um, other people might do things differently but this is just the way things have happened for me. Um, ... and ... I don’t like to explain away every single mood by “This is my bipolar.”

Jodi notes she experienced trying emotional situations, which “have created emotional binds”:

I don’t know that you can go, oh, OK, well, it’s because you have bipolar disorder that you’ve been, like, all over the place. ... You’ve had a marriage that fell apart. You know, you’ve had major problems there I think that there certainly [have] been things that have happened that have created emotional binds. And, you know, complex situations that I’ve responded to and, with complex emotions.

And I think that, sort of the beauty of being a human being, that you have that capacity. You know, without that, where would I be?

For these participants the biochemical explanation was useful to make sense of some aspects of experience. Yet they still claim their humanity by recognizing life events, character, and personality as central in their experience.

Personal Responsibility and Control

The participants considered unfavorable personality quirks as explaining some of their behavior. Even though these were negative characteristics, it involved something over which the participants had control, rather than something, like chemicals, that was outside of control. Rose, for example, listed other personal attributes that could be the source of her odd or difficult behaviors, rather than a chemical imbalance:

But I don't want to blame, I don't want to blame it for everything. Because sometimes I was a bitch [whispered, then laughs]. It was, sometimes I was just being ornery. Or trying to get my own way. Or stopping. Or whatever.

Interviewer: So how do you sort out which is which?

It's hard. It's hard. And I'm still doing it.

Rose's alternate explanations show improper behavior, like being "a bitch," being "ornery" or "trying to get my own way." Even though negative, these are behaviors that Rose could control. Yet even now, after a year of sorting out her life post-diagnosis, Rose is not sure when her behavior could be attributed to "chemicals" and when to "being a bitch."

Other participants also referred to negative characteristics that are still preferred to being powerless over chemicals. Natalie indicated that she does not know her true

nature so long as she is medicated: “Maybe I’m a son of a bitch. I don’t know. I don’t have any way of knowing. So I keep thinking, go off my meds and see what happens. See who I am.” Natalie would rather be a “son of a bitch” than to be a person who is a good person only because she is medicated.

Kevin recognized that some people prefer explaining everything by bipolar disorder and not claiming personal responsibility: “You’re like, ‘Well, I’m bipolar, so of course I do this and I do that.’ Well, no, maybe you’re also an asshole. Or maybe you’re—, maybe you were upset about something.” For Kevin and most of the participants, an explanation that involves volitional control is preferable to an explanation involving lack of control, even if this means taking personal responsibility for being a “bitch,” “ornery,” a “son of a bitch,” or an “asshole.”

At the same time, however, the participants seem ambivalent about taking responsibility, as evidenced by their use of colloquial terms and profanity (e.g., bitch, son of a bitch, asshole). Just as they used negative colloquial words to explain their initial understanding of bipolar disorder (e.g., wacked, crazy, nuts), their use of colloquial terms to describe the behavior over which they have personal control may indicate difficulty claiming that personal responsibility.

Female Physiology

As discussed in Chapter Three, one of the explanations provided to a participant in childhood for any unusual behavior of a woman was that she was experiencing menopause. As Rose stated:

I want to tell you this much. I think too often menopause is blamed for this. Really. My mother. ... My mother's best friend, when I was growing up ... committed suicide ... Now that I think about it, it was, it was bipolar. She was full-blown bipolar. She used to come up and cry to my mother. And my mother didn't know what else do to but give her a beer. My mother used to get her drunk. ... Um. That's what women went through back in my small town. In the 50's and 60's. ... That's what you did. You hid your dirty laundry. Mental illness was NOT something you talked about. And they always said, "She's going through menopause" [whispered]. Any woman, from thirty to sixty, who did anything strange, was going through menopause [whispered].

With the benefit of hindsight, Rose now recognizes that menopause was the societal explanation available in her small town in the 1950's and 1960's for any unexplainable female behavior. Apparently getting drunk was considered an appropriate way to deal with menopause. Even now, Rose initially explains her behavior as due to menopause, but catches herself when she notices that she is reverting back to that earlier societal explanation. "About ten years ago I had, I went through menopause and had a, I shouldn't blame it on menopause, there was a lot of reasons. I had a, I call it 'going around the bend.'"

The other female participants at times used metaphors suggesting that female hormonal patterns influenced their behavior. For example, at one point Sarah commented that she is unreliable because of her depression and that she frequently cancels appointments. She analogized her behavior to women who use menstruation as an excuse for avoiding an unpleasant task. "And more like somebody who cancels at the last minute, or, you know, um, or, gets sick and says it's because of her period when it's not. [laughs]." In this analogy, menstruation is used as an excuse, one that is private and cannot be challenged. One way to interpret this analogy is that women's physiology can

be used to explain a range of women's behaviors. Moreover, because of the societal prohibition against discussing women's bodily functions, it is an explanation that is safe from further inquiry.

Childhood and Developmental Factors

Another explanation participants endorsed was one that integrated the biochemical imbalance explanation with history of childhood trauma, neglect, and attachment difficulties. The two participants who most endorsed this as a viable explanation were Sarah and Kevin, the two psychologists. Sarah, for example, feels she was groomed to be bipolar, because her mother was depressed throughout Sarah's childhood and often emotionally unavailable. Sarah sadly reported that her mother's depression is one of her core memories of growing up:

It was certainly my prevalent memory of childhood. ... I was raised in a sense to be a bipolar person by my mother as much as I have whatever genetic tendencies to it that I do, because that's who she is. And I—, she was, you know, my m—, you know, my most powerful influence 'til I was about 16. I was pretty isolated from other people. I wasn't—, I—, she encouraged isolativeness too.

Sarah discussed how she believes her bipolar disorder developed through a complex combination of “nature” and “nurture.”

Well, I had depressive symptoms probably from early adolescence myself. I mean I had problems from, God, probably day one. It's hard for me to figure out, to sort out what that's all about. ... My family isn't a, just a family that has this in it and otherwise it was a pretty functional family by—. It, you know, it's the opposite. [laughs]. Um, it's pretty bad. Um, and, appa—, I think like temperament wise, I, you know, I would say I was just like a difficult baby, very difficult to soothe, very, um ... And then the people around me were pretty chaotic, and anxious, intense, and weird and, you know, so I picked up that. And just the descriptions I got of myself were that, like, you couldn't calm me down, that I would cry until I threw up, etcetera, etcetera. Um, I had temper ta—, really bad temper tantrums

and anger fits. Um. I was always very, very moody.

Sarah sees her diagnosis as emerging from the intersection of genetic predisposition and childhood experiences. Sarah's explanatory framework is a psychological explanation that integrates a variety of etiologies, including physiological arousal, attachment, emotional regulation and dysregulation, genetic influences, and learning.

Kevin's view is also a psychological one that integrates attachment theory, trauma history, and biochemical imbalance. He develops this integrated explanation over time.

He first compared his reactions to those of someone else with the diagnosis.

Part of my own experience of it is, is, a real confusion about what this all means for who I am. ... A woman [I know] ... who has also been diagnosed bipolar. ... has a very continuous sense of herself. So, I know that it's possible to have this diagnosis and not be quite so shaken by it. So it makes me think that, um, some of the way that my legs get kicked out from under me at times may have more to do with intrapsychic and personal issues than affect regulation.

When he saw that this other person has "a very continuous sense of herself," he concluded that the explanation for his experience also involves "intrapsychic and personal issues." Yet he still is confused about how the biochemical imbalance may influence psychological issues:

But you know, how do you learn affect regulation? You learn from the environment, you learn from those near to you. If your own, if you don't have a stable baseline to judge against, I mean, if the mother changes not because of just your own experience of the mother but because today you are awash in despair because that's where your biochemistry is. How do you then, how does this affect your, your, your normal development? And I think there's a real circle of, you know, all that's stuff's running together.

Kevin concluded that as an infant and child he did not learn affect regulation as other children do. He wonders about an interaction between his mother's inability to provide

containment and his own chemical imbalance as an infant.

Kevin believes the explanation he provides for his experience does matter, if for no other reason than to counter the medicalizing of experience in American society:

Why does it matter what I call it? If I call it—, if I locate it from an attachment-trauma paradigm, interacting with a Bipolar II piece. These are all my—, all my pieces. ... Now we say, you've got a disease. We have to medicate you and make you into somebody that, quite frankly, the medicine's probably not likely to make you into anyway. Maybe it takes the edge off. Maybe it makes it a little better. ... There's a very narrow window of behavior that is increasingly becoming acceptable to people. ... You think of medicating away behaviors and feelings is something that, you know, we do. So you see a kid who gets upset, do the parents say, "God, what happened to you?" ... Or do they say, "We're gonna call a psychiatrist and increase his medication because he's out of control."

Kevin noted that the emphasis in today's society on medication seeks to explain all behavior, particularly out-of-control behavior, by a medical model. He commented on how people engaging odd behaviors were previously given labels such as "cranky." It is similar to Natalie's initial attribution of her mother's behavior as "that's just mom being industrious," when now she believes her mother's behaviors were symptoms of bipolar disorder.

Kevin's and Sarah's explanations are complex ones that accept that a chemical imbalance may be one factor among many to explain their psychological and personality functioning. It makes sense that the two psychologists provided a psychologically complex etiology of their affect dysregulation, since this approach is consistent with many psychological theories of development. Yet, as discussed in Chapter Three, all of the participants recounted difficult childhoods and many had significant childhood traumas. All the participants volunteered childhood history, which indicates that they

make a connection between their childhoods, traumatic events, and their bipolar diagnosis. As would be expected, the non-psychologists did not articulate the connection as specifically as the psychologists did; such an integrated analysis would be difficult without graduate training in psychology. Yet since all of the participants had been in psychotherapy, several with psychodynamically oriented therapists, their perspectives might have been influenced by the discourse in psychology around questions of attachment, attunement, and emotional regulation.

Eventually the participants recognized that they had to develop their own resolution to questions of self, identity, and explanation. The resolutions participants had created for themselves at the time of the interviews are discussed in the next section.

Coming to Terms with Explanations and Self

At some point in every interview, the participants presented themselves as having reached a resolution about questions about identity and explanations, a solution that provided some comfort and peace.

Jodi indicated she feels richer for having had her difficult experiences.

I'm in a, I'm in a place in my life where I'm experiencing a, a really good relationship and tremendous joy. Where would I be without knowing what it was like in that despair? That despair! I wouldn't be able to experience this now. I can tell you that right off the bat. But I KNOW what it was like to feel the way I felt, you know, four years ago. ... And I have this appreciation for where I am now, that I don't think I ever would have had if I hadn't gone through that. So, it's not—, is it a disease? Heck, NO. That's not a disease. That's just life. It's just, you know, somebody's life, you know. Giving them the twists and turns of, you know, life. The wonders of it, you know. I just think it's—, I think it's great. It's not, it's not all bad. It's not all a problem, you know.

Jodi expressed acceptance about her personality and emotional sensitivity:

For the ups and downs of everyday life, you can just go: This is, this is the way I am. Maybe I do things a little bit differently than other people do. But I don't know that it's all because I have bipolar disorder. Maybe it's, I'm a little bit more sensitive to life, and, I'm a little bit more emotional, and, you know, ... I express my emotions a little more readily than some people.

Natalie also expressed feelings of happiness with her life. "For me it's—, I'm just happy. I'm glad to be alive, um, and finally living." Natalie's definition of bipolar would be life-based, not pathology-based: "So I would say that for me, it's just simply overly happy, overly sad. That's what I would say." Even so, she still rails against the medication: "I don't worry about things. But I hate the pills. I hate what they do to me. I hate the fact that I can be changed by a pill, so drastically that I'm a different person."

Darlene's resolution incorporates recognition of the losses of personality she has experienced since being diagnosed with bipolar disorder:

I'm NOT that life-of-the-party person [any more]. ... [I was] VERY extroverted. ... I'm, phew, really introverted now. ... My husband used to take me on business dinners with him all the time because I would keep the conversation going It was fun for me. But it has since come completely reversed. ... I'm just like, "Oh, I don't want to go. I don't want to make small talk" [very quietly]. ...

Darlene described the benefit of her new personality style:

Some days I really hate it. Some days I really don't mind. I'm OK with it. I like, um, being stable. I like my kids knowing that they have somebody they can count on.

Even though Darlene still experiences the loss of the extroverted person she used to be, she feels satisfaction knowing that she provides a stable base for her children.

When Sarah was asked to give her final thoughts for the interview, she was still struggling to tease out the relationship between her experiences and the diagnosis.

No, I don't think so. I think that ... No, I, I wish I could—, I realize that I haven't—, I don't know. I haven't had—. It's weird, I seem to be somebody who when it came down to it didn't have—. I have more fear of stigma than actual experiences of being stigmatized as a bipolar person. But see I'm somebody that's been stigmatized for being DIFFERENT all my life. ... Different, and different bad, obviously. And actually it's been different bad because of difficulty controlling my emotions probably too, now that I think of it. You know, it has been about emotional things.

Sarah still believes that she was harassed by other people because she was different and had difficulty managing her affect. Her effort to find resolution involves maintaining a separation of “illness” from “character”:

This is what is pretty much the way the NAMI people push for schizophrenia. ... To really think that it is a thing, a systemic, chronic illness and it's not about my character or really about my history. And that when I go to my therapist and talk about even my depression, or something about psychodynamics, I have to be really careful to try to not, to put a boundary there, even if it's an artificial one, from the diagnosis, because I start losing hope really easily if I don't.

Sarah recognizes that if she does not create this boundary between illness and personality, “even if it's an artificial one,” she will engage in continual self-criticism and self-doubt: “What's wrong with me? Why aren't I working harder in therapy? Why aren't I this? Why aren't I that?” She concluded by recognizing the importance of finding an inner integration: “It doesn't really matter what that is, but you have to find a way to integrate it into your self-concept; that helps you function well.”

Rose's resolution involves a comparison to members of her family of origin. She feels grateful to be alive since her parents and all of her brothers are now dead. She concludes that bipolar disorder is not so bad, when compared to cancer.

I, I, I'm probably playing games with myself, but this is what I do. Bipolar is my schlep. That's my thing. One of em got cancer. One of em got lupus. Another one

got cancer. They all had alcoholism. ... If all, if as bad as I got, from the man upstairs, if he said, you gotta have something, Rose ... and it's bipolar, that's fine. Because I can still walk around whole, and with medication. As long as I keep taking it, and not start lying to myself again, ... I'll be fine. Cancer you can't cur—, well, you can't cure the kind they had. ...

I was brought up with these people. What's the link? ... I said, "Do I have a bulls-eye on my head about the cancer?" ... But then when I came up with bipolar, which is chemical, which is actually a physical, you know, thing, I'm hanging on to it for dear life [laughs hard]. It's like my crutch, saying, "That's what God gave me ... was the chemical imbalance in my personality."

In her resolution, Rose merges the chemical imbalance with the personality explanation. This merger may have been inadvertent, as a slip of the tongue, but it suggests that Rose has found a way, perhaps unconsciously, to integrate different explanations into a cohesive understanding.

Like some of the other participants, Kevin contrasted his behavior in his current romantic relationship with his earlier behavior.

Before, I would make connections ... [and] then I would leave them, or ... there would be a big shift or disruption or something. There was a sense that, well, somebody else couldn't tolerate me and I couldn't tolerate myself, over the long haul, in some way.

Kevin is referring to managing and containing intense affect, processes that he used to find challenging. He initially credits his partner for the change in his behavior:

There are ways that I really get in the way of allowing myself to feel better. Even when I feel good, I take that away. ... Maybe that's been the single most important thing about my relationship ... has been her kind of hanging in there

However, by the end of the interview, Kevin also claimed some of that change for himself: "So maybe that's the take home message of the day – to play with the idea of making more room for myself and whatever moods I'm in. The meaning I give it all." He

seems to be recognizing that he is better able to contain his affect now than previously. He also may be allowing himself a wider window of acceptable affect.

The participants will likely continue to think about these questions and modify their resolutions over time. Nonetheless, when interviewed, each had found a position that provided some comfort and that integrated different societal explanations for bipolar disorder.

Discussion

In this chapter I reviewed how the participants worked with the explanations that were available to them for understanding the life experience of a person with a diagnosis of bipolar disorder. The prevailing societal explanation is of a chemical or biochemical imbalance and all of the participants acquiesced in this explanation.

Participants also described, however, a range of problems they experienced with the biochemical imbalance explanation. One of those problems involves the externalization of causation. Although the external cause (chemical imbalance) may alleviate blame, it had other repercussions. One of those repercussions is the loss of a sense of agency or control over self, the one process that the participants most feared. Some of the participants described as terrifying their own episodes of loss of control. Even when the attribution for the loss of control was an external causation (adverse reaction to a medication), the feeling of being out of control was experienced as quite distressing.

Participants preferred explanations involving personal responsibility and internal

causation to those involving external causation, even if the personally controlled behaviors were negative ones. For example, being a “bitch,” ornery, or an “asshole” was preferred over being someone who cannot control her or his behavior because of a chemical imbalance or a medication reaction. Having control and doing obnoxious behaviors was better than losing control and feeling unable to claim responsibility.

In terms of explanatory frameworks, participants employed various explanations available in the culture, in addition to the biochemical imbalance one. They all developed integrated explanatory frameworks for their feelings and behavior. Their integrations included such factors as personality, character, women’s physiology, developmental difficulties, lack of attunement with parents in childhood, childhood trauma, genetic predisposition, and learning (from a bipolar mother). Although each participant created her or his unique explanatory framework, they all seemed to choose from among the same universe of choices.

The last set of findings sets forth participants’ efforts to find resolution among the competing explanations and to find personal acceptance of one’s situation. Each participant had reached a point of some self-acceptance, although they all indicated some aspects of their self-questioning is ongoing.

The Metaphor of Demonic Possession

Some of the participants and memoir writers offered the metaphor of demonic (or alien) possession to describe aspects of their experience with bipolar disorder. These references involved experiences with bipolar disorder when they experienced a loss of

personal control over their behaviors or reactions. At those times, it felt like some “bad” external entity was in control of their behavior or experiences. Although the demon in current usage (vague brain biochemicals) is different from the concrete notion of demons or devils of old, the metaphor captures aspects of the experience of loss of volitional control. However, loss of control even to “good” chemicals, like medications, still felt to some participants like demonic possession simply because of the lack of control.

Childhood and Developmental Explanations

By volunteering childhood history, all of the participants linked their current emotional and behavioral lives in some ways to their childhood and early developmental histories. In addition, they described significant childhood traumas or inadequate emotional attunement with a parent, or both. Kevin and Sarah, the two psychologists, presented the most psychologically sophisticated linkages as they explained their experience as a complex interaction between genetic predisposition, biochemical imbalances, trauma, inadequate nurturing from their mothers, insecure attachment, and other psychological factors. The linkages by the non-psychologists were not articulated in the same psychologically complex way. Nonetheless, by detailing feelings and episodes from their earlier years, these participants also claimed the relevance of developmental and psychological explanations.

The psychodynamic paradigm locates the etiology of problems in early experience. This explanatory framework may be particularly suitable for participants’ understanding because it conceptualizes their difficulties as products of their actual

experience, difficult though it may have been, rather than the product of an external (demonic) agent like a biochemical imbalance. In other words, they can experience more personal responsibility for being who they are. The psychodynamic understanding of personality may also be a more familiar paradigm, one that pervaded the culture at the time they were coming into intellectual maturity. Also, several of the participants have been in psychodynamically-oriented psychotherapy, so these constructs are familiar and have been used in their adult self-understanding.

Integrated Explanations

The explanations participants chose are likely the entire set of explanations available in American culture for explaining the etiology of bipolar disorder. The integrations that were most similar were those by the two psychologists, which indicates that there are specific explanations – or at least specific ways of articulating those explanations – available to people trained as clinical psychologists. Jamison (1995), a clinical psychologist who has always worked in medical settings, described a similar integrating framework: “I’ve never been able to fathom the often unnecessarily arbitrary distinctions between ‘biological’ psychiatry ... and the ‘dynamic’ psychologies” She further asserted that there is a necessary connection between biochemical and psychological factors. “The challenge was in understanding the complexity of this mutual beholdenness, and to distinguish the roles of lithium, will, and insight in getting well and leading a meaningful life. It was the task and gift of psychotherapy” (Jamison, 1995, p. 88).

As discussed in Chapter One, most of the psychiatric and medical professions have rejected any role for psychodynamic and depth psychologies in explaining the etiology and functioning of bipolar disorder. Peter Kramer (1993; 2005), trained in depth psychology, has so embraced the biochemical explanation that he contends it is no longer necessary or even appropriate to engage in any psychological inquiry with a patient. In spite of those attitudes, all of the participants, as well as Dr. Jamison, have rejected the splitting between medical and psychological camps that is present in so much of the discourse on bipolar disorder. They managed to hold onto their integrations of biochemical and psychological explanations, even as their psychiatrists and the larger society were claiming that the biochemical imbalance is the sole etiological factor. The way the participants found an integrated explanation, albeit imperfect, can be considered the beginning of the establishment of the “depressive position,” as articulated by Melanie Klein (1959/1985).

Resolution

The final section of findings in this chapter presented the participants’ current status in terms of resolving questions about the bipolar diagnosis, their sense of self, societal explanations for bipolar disorder, and other issues addressed in this study. In Western cultures, narratives usually follow the formula of a beginning, a middle, and an end (Denzin & Lincoln, 2000). People usually present their life narrative stories starting with a conflict and ending with its resolution. Further, in identity theory, the final stage is usually referred to as “internalization” (Cross, 1987) or integration (Helms, 1990).

However, after one or many years of having the bipolar diagnosis, participants are still struggling to sort out the conflicting societal messages as well as their internal explanations. Thus, although resolution is part of the desired narrative, it may not be applicable at this time.

Although all of the participants indicated in several ways their efforts to find meaning and create integration, their discussions of their integrations consisted of ongoing processes rather than definitive conclusions. It may well be that finding integration, internalization, or resolution of these complex questions is a lifetime process.

CHAPTER SEVEN

DISCUSSION

I never hear that one is dead
Without the chance of Life
Afresh annihilating me
That mightiest Belief,

Too mighty for the Daily mind
That tilling its abyss,
Had Madness, had it once or twice
The yawning Consciousness,

Beliefs are Bandaged, like the Tongue
When Terror were it told
In any Tone commensurate
Would strike us instant Dead

I do not know the man so bold
He dare in lonely Place
That awful stranger Consciousness
Deliberately face –

(Dickinson, 1890/1960b)

This study investigated how a relatively new diagnosis, bipolar disorder, has been socially constructed in American society, as experienced through people who have been labeled with this diagnosis. The process of social construction involves a continual interchange between societal discourses and individual meaning-making. The societal process was examined as it was filtered through the meaning-making experiences of six participants. Their process of working through the meaning of the diagnosis and finding ways to explain their experience reflects the changes in the societal discourse around bipolar disorder over the last forty or fifty years and its current fluctuating status.

There are two core areas of findings from this study. The first involves the interactive process between societal and individual experience in creating the construct of bipolar disorder. The second involves the many challenges to self and identity that are implicated for someone with a diagnosis of bipolar disorder by the way this particular diagnosis has been defined by the psychiatric community and understood by society. After discussing these two sets of findings, I will propose some possible societal implications of these findings, in an attempt to understand the role bipolar disorder may have in American society today and how it may be constructed as an American institution.

The Interactive Process of Social Construction

The findings were laid out in a chronological developmental process showing the changes over time in how participants created meaning from their life experiences. In each step, participants chose from the available societal explanations and applied them to aspects of their personal experience.

The six participants, identified as European Americans who grew up during the mid to late 20th century, generally in the east coast of the United States, all described challenging childhoods, including experiencing such difficulties as sibling deaths, a parent's death, or being isolated by peers at school. They also spoke of repeated episodes of feeling unheard or unsupported by parents.

In childhood, the participants explained their difficulties by reference to behavior of other people, such as. "my mother was wacked," or "I was so overwhelming unpopular

and disliked ... I was the kid with the cooties.” The external attribution is considered developmentally appropriate in American culture. Further, these are explanations that would have made sense to Americans during that period and were derived from the American lexicon of explanations. None of the participants referred to themselves as survivors of trauma, although some of their stories would qualify today for that label, because there was no particular societal focus on trauma at that time.

Several of the participants described difficult or “crazy” parents; other participants had no label for their parents’ behaviors. Now, looking back through the lens of the bipolar diagnosis, several participants believe a parent manifested symptoms of bipolar disorder then, even though the parent had no mental health diagnosis or was simply labeled as depressed. For example, one participant now believes her mother exhibited bipolar symptoms when the participant was a child, but then the explanation was simply “that’s just mom being industrious.” One participant indicated that in the rural world in which she grew up, a common explanation for women who behaved oddly, including even committing suicide, was menopause: “Any woman from 30 to 60 who did anything strange was going through menopause.” It becomes evident that during the participants’ childhoods there were only a few labels available to explain difficult internal experience or unusual or unpredictable behaviors. The few labels (i.e., depression or menopause) encompassed a vast range of experience. As one participant described the culture from that period:

A hundred years ago you'd have said, "Oh, Aunt Edna, she's just, she's just really, really cranky. That's just who she is." And it would have been OK. Now we say, "You've got a disease. We have to medicate you."

In adolescence, the participants' explanations were still primarily focused on external causes of discomfort. Yet the participants also started creating internal explanations, such as labeling themselves as depressed. They tended to view their depression as caused by other people or circumstances. For example, one participant stated: "when I attributed anything to anything, it was ... I'm sad because nobody likes me and nobody likes me because I'm ugly and ... I can't play sports and I can't make friends" By late adolescence, almost all of the participants had called themselves seriously depressed.

Only one participant did not consider herself depressed in adolescence. Her childhood situation was that she had lost an infant brother when she was four and then her mother when she was ten. She started drinking at age twelve and was a full-blown alcoholic within a few years. Her self-label during adolescence and for many years afterwards was that of an emotionally numb alcoholic. She said, "Alcoholics ... never fit in. That's one of the reasons they drink."

The self-labels of depression or alcoholism, which the participants used in adolescence, were well-accepted terms during that period, as they still are now. The interchangeability between "normal" sadness or dejection and clinical depression was equally present then as now, even though the participants' depression was more intense than the meaning of "depression" in common parlance. Nonetheless, when participants

indicated they were depressed, it was a statement easily understood by others in the culture.

Several of the participants indicated that, looking back, they believe that as children they were extremely sensitive or "moody." Some described periods of elevated mood, euphoria, and expansiveness, terms from the current American discourse that were not available 30 or 40 years ago. Although the words like euphoria, irritability, expansiveness, or emotional sensitivity existed, there was no organizing framework or category within which to place these experiences. Without societal categories providing options of possible labels, these moments of extreme irritability or euphoria were treated as experiences but not singled out as remarkable or signs of anything else.

By adulthood, four of the six participants had attempted suicide. In adulthood all but one participant (the person who self-identified as an alcoholic) had received a label of clinical depression from a psychiatrist. In addition to the depression diagnosis, one participant was also diagnosed as having an anxiety disorder, borderline personality disorder, and co-dependency. Again, these were all common labels at that time.

Eventually all of the participants received diagnoses of bipolar disorder. Three were diagnosed in their forties; two were diagnosed between 25 and 30; one was diagnosed in her 50's. When interviewed, time since diagnosis ranged from one to two years to 15 years. Participants' initial reactions to the diagnosis were negative. Their predominant reaction was to associate bipolar disorder with "crazy" and out-of-control or unpredictable behavior. They felt like they had crossed over the threshold from "normal"

to “mentally ill.” They remembered all of the worst conditions of their relatives with psychiatric and other cognitive disabilities and assumed their lives would follow the same trajectory. Participants’ initial associations of bipolar disorder to mental illness were framed in derogatory language, like “wacked” and “nuts.” This use of language indicates that participants had introjected the negative societal prejudices about bipolar disorder without ever interrogating these associations.

Participants’ concern that bipolar disorder means “crazy” may be indicative of the societal discourse around mania. Even though four of the six participants had previously attempted suicide, five had had diagnoses of clinical depression, and one had self-diagnosed as an alcoholic for about thirty years, they never previously worried that they might be “crazy.” This finding suggests that the societal definition of “crazy” in this context meant “manic” or “hypomanic.” Viewed through these participants’ eyes, depression or even attempted suicide were not considered “crazy.”

Fears of becoming unpredictable and of losing control also emerged powerfully when participants faced a bipolar diagnosis. These fears were aroused by the diagnosis, even though nothing in reality had changed from pre- to post-diagnosis. Since there was no common societal term for manic or hypomanic behavior when participants were growing up, bipolar disorder became the container for societal projections about mania, manic behaviors, loss of control, and by extension, craziness, as these projections had been taken in by these participants.

Although there were few labels available in 20th century discourse for painful experience or odd behavior, the advent of the DSM-III and DSM-IV towards the end of the 20th century brought into American psychiatric discourse many more diagnostic options. Thus, instead of “just” depression, choices for “affective disorders” now include dysthymia, major depression, Bipolar I, Bipolar II, cyclothymia, and so forth. Each named disorder has a list of discrete symptoms, distinguishing it from related disorders. There is an implicit hierarchy within these categories. Bipolar I, which incorporates full-blown manic symptoms, is considered by psychiatrists to be the most serious. The hierarchies are implicit and rarely explicit. Even though the listings of disorders in the DSM-IV-TR is designed for use by psychiatrists and other mental health professionals, all of the participants (including the non-health professionals) were well aware of the symptoms lists and the implicit hierarchies. The participants self-diagnosed or hoped for a label “lower” on the implicit “seriousness” hierarchy than Bipolar I.

After participants learned more about the psychiatric definitions of the diagnosis, they entered into a new stage. They became accustomed to having the label and started feeling relief that there was a comprehensive label that incorporated more of their experience. The diagnosis organized into a coherent explanation a series of internal experiences and external behaviors that participants had experienced but not categorized. Unlike the depression diagnosis, the bipolar label explained feelings of expansiveness, irritability, hyperactivity, emotional dysregulation, and high emotional sensitivity. In other words, a variety of discrete experiences that had never been categorized together

were now captured by and contained within the bipolar disorder label. This step indicates that the participants had moved from the general societal discourse, with its associations about how bipolar disorder means “crazy,” into a more narrow discourse, the psychiatric one around the specific DSM-IV-TR diagnostic criteria.

The participants’ relief waned somewhat once they started working through the myriad issues about self and identity that were implicated by the definition and societal meanings of bipolar disorder. Related to identity questions were those involving competing societal explanations about the etiology and manifestation of bipolar disorder. The psychiatric discourse relies on one explanation to the exclusion of others. This explanation is that bipolar disorder is simply a function of a biochemical imbalance, impacted by genetic variables. Although participants acquiesced in the biochemical imbalance definition, they also chose to include other explanations in their understandings of the nature of bipolar disorder. In so doing, they were moving beyond the psychiatric discourse. The participants integrated the biochemical imbalance explanation with other explanatory factors, including personality, character, trauma, attachment, and parental attunement. Although all of these explanations are part of the societal discourse, they tend to be associated with particular discourse communities. One can say that the participants integrated the explanations from the psychiatric discourse community with those of the psychological discourse community as well as the larger society.

There is another discourse community around bipolar disorder, which is the psychiatric disability community. In this community, people with psychiatric disabilities and service providers who work with them have a special language. The term “mental illness” is rarely used; a preferable term is “psychiatric disability.” People who have such diagnoses are called “consumers” or “survivors.” They speak of themselves “in recovery” and there are support groups, websites, organizations, and staff people to help and provide support. None of the participants considered themselves part of this community and only one was even familiar with the language of that subculture. Thus, even though there was another discourse community into which the participants could have engaged, they chose not to or were unaware of it.

The purpose of delineating these steps is to show how individual and societal explanations interrelated in the social construction of the term “bipolar disorder” in the United States, through these participants’ eyes. At each step, participants’ self-understanding was dependent upon the current societal discourse. It is possible the use of language by these participants and others like them impacted upon society, creating a cyclical process.

A social constructionist approach studies the myriad processes involved in the moment-to-moment creation of constructs in a society. Medical sociology distinguishes between the social constructions of illness and diagnosis. The construct of “illness” is understood to be the experience of pain or discomfort. The construct of disease is the socially endorsed categorizing of the disorder (Brown, 1995; Kleinman, 1988b, 1995).

This study investigated both aspects. The “social construction of illness” consists of the participants’ stories of such internal experience as emotional dysregulation, difficulties with parental attunement in childhood, and fears of loss of control. Yet during every step in self-understanding, participants were drawing from the language, labels, and terms available in their society. In social constructionist theory, a construct is developed through language and relationship (Gergen, 1994; Wittgenstein, 1953/2001). Therefore, a more precise statement of this study is that it involves the social construction of the diagnosis rather than of the disorder itself.

Wittgenstein noted that we never really know what another person experiences, so our use of language is just a “game” (Wittgenstein, 1953/2001). Lacan (1968) deepened this understanding by analyzing how we never even know ourselves, since language is a weak substitute for the deep understanding we as humans seek. Stated another way, humans desire to have words for thoughts: “what eludes him ... [is] that *not-known* from which man is perpetually summoned for self-knowledge” (Foucault, 1970, p. 323). Both Foucault and Lacan are pointing out how inadequate language is to express our experience. Thus, a social constructionist analysis must deconstruct language to find the part of the social construction that is either not organized into categories or is simply not put into language at all (the “unsayable”) (Brown, 1995; Derrida, 1967/1997; Rogers, 2006b).

In this study, participants’ physical, sensory, or emotional experiences without organizing labels could not be categorized. For example, participants knew that they had

experiences of expansiveness and intense anger pre-bipolar diagnosis. Yet they had no container in language to organize these experiences. The bipolar diagnosis provided the context for understanding these experiences.

It is likely that this particular process is inapplicable in different cultures in other countries. It may not even be applicable to all subcultures in the United States. It is “local” to this community, since culture is always local and never universal, at least from an anthropological perspective (Geertz, 1983).

I now address the second group of findings: how the definition of bipolar disorder in American society impacted upon the participants’ sense of self and identity and their meaning-making.

Forging Workable Constructions of Self and Identity

The participants faced many challenges to their conceptualizations of self and identity post-bipolar diagnosis. It was difficult to develop a cohesive sense of self as well as an ongoing and continuous sense of self in light of the way bipolar disorder is defined in the psychiatric discourse and understood in society. It was similarly difficult to develop a cohesive explanation for the meaning and etiology of their moods or disorder. The ways the participants worked through and addressed these issues may reveal certain fault lines in societal understandings of moods, mania, and bipolar disorder.

Identity Coherence

The participants sought to establish an identity coherence by synthesizing what Erikson called “the various selves that make up our composite self” (Erikson, 1968, p. 217) or what James (1950) called the “Empirical Self,” which is all those experiences that a person knows of as “me.” The participants had to create a new sense of “me” after the diagnosis, one that would include the various selves they claimed with the bipolar disorder label. The participants had many, often divergent, selves to integrate, so it was difficult to feel a “stability of self,” as one participant explained. The disparate selves included the self before the diagnosis, when the participants may have thought of themselves as depressed but never “crazy” or unpredictable. With the bipolar diagnosis, they experienced, usually alternately, selves that were depressed or had “elevated moods,” as the psychiatric discourse taught them to say. Some of their elevated experience felt foreign or “not-me.” They worried about having crazy, out of control, or unpredictable selves, which also felt like foreign selves. They experienced a medicated self, which seemed to be another “not-me” self. They had a somatic self that seemed to be driving certain feelings and behaviors, but it was difficult to describe or isolate this physiological self, which also felt outside of conscious awareness and control. They also experienced a self that watched these other selves from an objective distance; this self could be called an “observing ego.”

The participants had other ways to describe the different selves they wanted to integrate into a cohesive sense of self. One participant described some of his selves, which he called “parts” and “pieces”:

I’m a professional, and I’m also somebody who takes medication. ... [These are] both parts [of me] I go back and forth between wondering if, uh, my own experience is due to my, you know, mood fluctuations that are driven by some internal chemistry or whether it’s part of my, you know, pastIf I locate it from an attachment-trauma paradigm, interacting with a Bipolar II piece. These are all my, all my pieces.

Each of these selves is also related to a different explanation of bipolar disorder (e.g., biochemical or early disruption in attachment). This participant sees himself as both a professional (a psychologist) and as someone who takes medication; someone with a chemical imbalance but also someone who had childhood trauma. He claims these “pieces” as all part of him, but he still feels that he goes “back and forth” between the selves and their related explanations.

However articulated, the participants did not experience their different selves as dialogic selves, which are conceptualized as selves in dialogue or conversation with one another, as Bakhtin (1981) and Hermans (2002) visualized the interplay among selves. The participants experienced their selves more as contradictory or irreconcilable selves, more as opposite sides of a magnet, as one participant described it. Opposite sides of a magnet do not interact; either one side or the other is active at any one time. The participants’ difficulty in integrating these seemingly opposite selves is consistent with the analysis of Halbertal and Koran (2006), who suggest that for someone who has “a multiplicity of compelling, ultimately irreconcilable voices, the notion of identity

synthesis is an oxymoron” (Halbertal & Koren, 2006, p. 57). Halbertal and Koren believe it is infeasible to synthesize identities that are as opposed as a gay or lesbian self with an Orthodox Jewish self. Yet the selves of a person with a bipolar diagnosis are even more disparate than those identities.

Even if it is an oxymoron to consider such a synthesis, the participants desired it. As one participant noted, “I’ve always been aware of sort of struggling to maintain a sort of easy sense of self, uh, given how I feel.” The desire for an integrated sense of self, even in light of the difficulty achieving it, is captured by Erikson (1963), who suggests that the tension for those who cannot achieve an ego integration is “despair.” He also suggested that the search for integration is based upon the desire for “order and meaning” (Erikson, 1963, p. 268). The participants needed to find a meaning to their lives with bipolar disorder; their efforts to create a cohesive self were based on that desire.

The biggest challenge for participants to integration of these selves is that some significant parts of their experience felt “not-me.” These were selves that were sometimes known by the participants, but still felt foreign and not part of self. These usually involved a lack of conscious control over bodily sensations, feelings, or behaviors. “Not-me” selves include experiences that became labeled as manic or hypomanic behavior, like the times when Darlene was yelling at family members and feeling like she could not stop yelling. She described some of those “not-me” moments as follows:

It’s like you’re on a treadmill and you’re running so fast that you can’t stop. ... For me, it’s, it’s the manic, um, racing feeling that, that just mind-racing thing that I just can’t stop.

I call this the “treadmill self.” Other parts of participants’ selves that felt “not-me” were their medicated selves and the biochemical self that was first called “unbalanced” and then supposedly became balanced with medication. The biochemical self may be related to the treadmill self, but the participants did not organize these selves into a containing category of “somatic” self.

On the other hand, participants experienced some selves as the best or happiest “me.” These often involved experiences when the participants were happy, elated, expansive, and energetic. I call this the “expansive self.” The participants loved and valued highly the expansive self. The psychiatric discourse has not previously addressed the pleasure in the “expansive self” Yet these participants and the people who wrote memoirs of bipolar disorder described how they valued this self. Jamison’s (2004) recent book about “exuberance” reflects the joys of the expansive self. The participants were willing to discard the treadmill self, as it was uncomfortable, but the loss of the expansive self was viewed as abhorrent.

The psychiatric community pathologizes both the treadmill and the expansive selves as simply problematic byproducts of mania or hypomania. However, the psychiatric definition does more than just pathologize the expansive self. The bipolar definition labels these experiences as fraudulent, inauthentic, or false and seeks to nullify them. The pathologizing of hypomania or mania by the psychiatric discourse results in the evisceration of the expansive self. As a result, the participants were somewhat ashamed to admit how pleasant the expansive self feels. Even more, it felt to the

participants that the bipolar disorder label, along with the current chemical imbalance explanation, seems to erase all personal history that was experienced with the expansive self. As Rose put it, after getting the bipolar label she was no longer Rose “because that person was, uh, I don’t know, chemicals, or whatever” The societal and psychiatric disowning of this valued part of self was experienced as a devastating loss for the participants.

In exchange for the “treadmill” and “expansive” selves, the psychiatric community offered the “medicated self.” However, that self felt equally foreign to the participants. They felt manipulated by an outside force; medicated life did not feel real to them. Although the psychiatric messages to participants were that they should dispense with the expansive and treadmill selves and feel grateful for the medicated self, this exchange felt unsatisfying. One participant described the expansive self as follows:

I like the wind on my face. And I like singing songs. And I like the fact that I can ... act silly and not be embarrassed and ... I like having unconventional thoughts. And I like to be able to pray to my God in a way that is sincere and spiritual to me but isn’t necessarily within the confines of my religion. I like all of that.

She then explained how she dreaded the medicated self: “If he slaps another pill in me, it will be gone. That is my dilemma. How much do I tell him? Because he sees black and white, manic-depressive.” They participants believed that with the medicated self, the expansive self “will be gone.” As a result, the very self that the participants most disliked or feared is the only self that the psychiatric community offered. And the self that the participants most valued was rejected by the psychiatric community.

Another reason participants experienced difficulty accepting the medicated self is that they believed it allowed them only limited affective experience. As one participant put it, “If I can just, if I can just make myself be right in this narrow window of mood—, I, I, I absolutely do not give myself slack to be depressed or elated.” To many participants, the medicated self meant an emotionally limited self.

Another factor complicating the challenge of identity coherence involved adverse reactions to medications. The medicated self was even more foreign and “not-me” when the medications went awry and caused negative reactions. Titrating medication to the correct dosage is always a time-consuming process. All of the participants described situations when their medications or the dosages were not correct. These experiences definitely did not feel like a welcome self. One participant described that feeling:

I had never, ever, ever, ever been there before. And it was so scary because I was, could not control it. I could not use any part of the tools I have as a human being to control any of it. I couldn't rationalize my way out of it. I couldn't understand it. I couldn't see half of it. All I knew is that somebody had taken the shell of who I am and hit a hammer and broke it. And there I was, just a pile of pieces. And I didn't have enough glue to put it together. Nor did they know which piece went where.

Thus, the participants had to face the divergence between their evaluation of which selves felt like “me” versus “not-me” and how their psychiatrists assigned the categories. By taking medication, the participants acquiesced to some extent in the psychiatric organization of their life experience. With the psychiatric definition, they had to re-conceptualize their experience, moving aspects of their core self into pathology (e.g., the expansive self) and bringing foreign selves into the core (e.g., the medicated

self). This was a work in progress at the time of the interviews. One participant was considering terminating her medication in order to experience a “true” self without manipulation by substances (whether alcohol or medications). Others grappled with making peace with their various self experiences.

The participants’ “depressed self” was also deemed pathological by their psychiatrists, the DSM-IV-TR, and by society. However, most participants did not mind the pathologizing of the “depressed self” as much. This might be understood in two ways. One is that the psychiatric discourse does not view the “depressed self” as false in the same way it views manic behaviors. Secondly, several of the participants disliked their “depressed selves,” so they were in agreement with the pathologizing of depression. In fact, some participants were relieved to relinquish the depressed self, like the treadmill self.

On the other hand, some participants felt quite comfortable with the “depressed self,” even though depression can be painful and debilitating. It felt comfortable and known. They identified with the depressed self and were as unwilling to relinquish it as to lose the “expansive self.” The “depressed self,” even though unpleasant, was rarely felt as a foreign self to any participant. Although painful, the depressed self felt particularly real and authentic, as in the Emily Dickinson poem, “I like a look of Agony, Because I know it’s true ...” (Dickinson, 1890/1960a).

The task faced by the participants was to create their own sense of “me” or of self, even if it included selves that were painful or even rejected by society and their

psychiatrists. They also had to determine which parts of their history to claim as self and which parts to reject as “not-me.” This is consistent with Erikson’s suggestion that the development of identity necessarily involves discarding “divergent” selves (Erikson, 1959). For participants, one of the “not-me” selves that was hard to acknowledge and address was the out-of-control, “crazy” self, a self that was more feared than experienced.

The Out-of-Control Self

The participants were afraid of losing control, acting unpredictably, or becoming “crazy.” When initially diagnosed, they thought the diagnosis meant that these events would now happen. Participants described few actual experiences of losing control; most of the examples participants offered involved loss of control resulting from adverse medication reactions. However, it seems they addressed the fear of loss of control in their dreams and metaphors. The “out-of-control self” was one that was inordinately difficult to integrate into a cohesive self since it was a self rarely acknowledged or welcomed. One of the participants described the need for control over moods this way: “Maybe I, maybe that’s part of this whole mood swing, that I get to play out some kind of, you know, obsessive c—, controlling, uh, way of trying to cope with, with some of that.” In other words, one aspect of the identity challenge involves obsessively trying to maintain control over self and moods.

One way to understand how participants forged their own sense of self is based on the ideas of the identity theorist Gary Gregg (1991). He proposes that the term “self” should be conceptualized as including the “not-me,” or the parts of self that have been

disowned, cast off, and projected into others. He states, “The self thus constituted does not consist of a conglomeration of attributes scaleable as more or less Me, but of a system of Me/Not-Me oppositions” (Gregg, 1991, p. 119). This approach can be applied to the participants’ experience. What is most “not-me” to the participants is being out of control, whether caused by medication, chemical imbalances, somatic arousal, or other reasons. Participants were somewhat aware of their fear of losing control, but rarely, if ever, of actually losing control. They feared their own craziness and unpredictability, but saw those qualities only in their parents. By locating these qualities in their parents, the participants were able to disown them in themselves. Thus, the selves of these participants did consist of “Me/Not-Me oppositions,” as conceptualized by Gregg. The oppositions involved personal responsibility and control (me) versus out-of-control, unpredictable, or “crazy” behavior (parents).

Selfsameness

A separate identity challenge involved the goal of experiencing “selfsameness,” or a continuous sense of self across different self experiences (Erikson, 1959). For participants, it is the sense that one is the same person when depressed, when expansive, when medicated, from childhood and pre-bipolar diagnosis, and across all the other selves. This was difficult since the definition of bipolar disorder is of a fluctuating self, sometimes “manic,” sometimes “depressed,” and otherwise “mixed.” To some extent the definition of bipolar disorder, as a disorder of fluctuating moods, provided a handle for experiencing some kind of continuity across moods. What was most difficult for the

participants was finding continuity between their unmedicated and medicated selves since the medicated self felt so foreign.

The process of coming to terms with self and identity was related to the participants' development of individualized explanations about bipolar disorder.

Explanations

Participants worked with different societal explanations, as part of their process of claiming an identity in which bipolar disorder was included.

Biochemical explanation. The participants all acquiesced in the biochemical imbalance explanation for bipolar disorder. This is consistent with the discourse in the psychiatric community, as well as the larger society. Today few people would question a biochemical imbalance explanation for bipolar disorder, unlike the 1960's, when there were many challenges. Other perspectives are often viewed as so irrelevant that they do not even merit consideration, as documented by Gray Greenberg (2007), in his recounting in *Harper's Magazine* of his experience participating in a pharmacological research study for depression.

There are a few lone voices, such as Colbert's (1995; 1996), a psychologist who questions the chemical-imbalance-in-the-brain theory. His argument is that mania involves out-of-control behavior, but the behavior has a meaning, which is to address the person's internal "woundedness." Although Colbert's is the rare voice challenging the biochemical imbalance explanation, his language is otherwise consistent with American culture, as being "wounded" is part of the mental health discourse about surviving trauma

or victimization. Nonetheless, this did not seem to be an explanation chosen by the participants.

Early life experiences. All of the participants linked their current emotional and behavioral lives in some ways to their childhood and early developmental histories. In addition, they described significant childhood traumas or inadequate emotional attunement with one or both parents. Kevin and Sarah, the two psychologists, presented the most psychologically sophisticated linkages as they conceptualized their life experiences as a complex interplay between genetic predisposition, biochemical imbalances, trauma, inadequate nurturing from their mothers, learning, insecure attachment, and other psychological factors. The linkages by the non-psychologists were not articulated in the same psychologically complex way. Nonetheless, by detailing feelings and episodes from their earlier years, these participants also claimed the relevance of developmental and psychological explanations.

Psychodynamic personality theory makes the connection between early childhood experiences and adult psychological functioning. The psychodynamic paradigm may be particularly suitable as an explanatory framework for participants because it conceptualizes their difficulties as products of their actual experience, difficult though it may have been, rather than the product of an external (or demonic) agent like a biochemical imbalance. In other words, they can experience more personal responsibility for their personalities and behaviors. The psychodynamic understanding of personality may also be a more familiar paradigm, one that pervaded the culture at the time they were

coming into intellectual maturity. Moreover, several of the participants have been in psychodynamically oriented psychotherapy, so this approach is likely familiar, one they would have used for their own self-understanding.

Integration. The participants and bipolar memoir writers all worked to find ways of incorporating different explanations into their personal meaning-making. In other words, they recognized a role for both biochemical and personality factors in explaining their “disorder” and their life experiences. They all claimed that personality impacted their experience and refused to allow a “disease model to fully define” them, as one participant put it.

Even more, they were willing to claim disowned parts as self. While recognizing that having bipolar disorder is not their “fault,” they were able to claim negative aspects of self. Participants made comments like, “maybe I was just a bitch,” when explaining that they would not use bipolar disorder or the chemical imbalance as an excuse for all behavior.

What these participants developed can be framed in a Klein-Bion light. Until getting the diagnosis, their own fears of their aggression, out-of-control affect, and craziness were projected out onto their unpredictable parents and other “crazy” people. Part of their healing process has been to claim some of their own aggression, out-of-control experiences, and negative qualities. At the same time, they are willing to engage in the psychiatric medications world, which views their experience differently from their own perspectives. None of the participants fully endorsed the medical model, yet none

fully rejected it either. They found a way to hold multiple perspectives and work with them.

The participants each developed a self-understanding that included biological and psychological explanations. The psychological community, as well perhaps as the larger society, may be approaching similar resolutions. For example, Fonagy and his colleagues (2002) and Schore (1999; 2003a; 2003b) have proposed integrations of attachment theory and neuropsychological research. Other integrations are being developed in neuropsychology and other psychology literatures. There is starting to be an integration in anthropology (Chisholm, 1992).⁴

Thus, the integration being created by participants, to the extent that it also represents other people, is both mirroring and affecting the changes occurring in the psychiatric, psychological, and societal discourse communities. The process would then be an interactive, iterative process in which each side influences the other. Yet to understand these findings more fully, it is necessary to consider processes occurring in the larger American society.

Implications of these Findings for the Social Construction of Bipolar Disorder

What do these findings suggest about the social construction of bipolar disorder in American society at this time? One way to conceptualize the social construction of bipolar disorder is to think of the Gestalt image of the vase and the faces:

⁴ Integrations of biological understandings by anthropologists have been viewed by some as simply an effort of anthropologists to be taken more seriously by academic psychology (Schwartz, 1992)).



(Wikipedia contributors, September 9, 2007)

If one focuses on the meaning-making of the six participants (the faces), one sees their phenomenological experience and the labels and explanations they have utilized to find meaning in their lives. If one focuses on the society, (the container or the vase), one sees these issues from the perspective of the larger society and the discourse communities within that society. It is difficult to see both parts at once, but it is useful to try.

I will now discuss four areas in which the findings from this study may link to larger societal issues. The linkage will provide some information of the extent to which the participants' individual meaning-making may be reflective of societal conflicts. The first question involves the threshold between "normal" exuberance and "crazy" mania and how this threshold was experienced by the participants and may be defined in society.

The Threshold Between "Exuberance" and "Craziness"

One of the ways participants had difficulty forging a sense of identity involved determining when their behaviors were deemed appropriate or inappropriate by society. The participants did not recognize the boundary line intuitively. Instead, they went to

great lengths to guard against “improper” behaviors, maintaining a consistent hypervigilance. For example, Darlene described her reaction when her daughter repeated a passing comment her daughter’s future father-in-law said about Darlene: “He says you’re wild.”

And I said, [exasperated sigh] “OK. What does that mean?” So, “I don’t know, he just says you’re wild.” And I—, you know, when somebody says that to me, I get nervous. What does that mean? What did I do? What was I doing that caused him to consider me wild? ... I’m in the process of making dinner and I’m thinking to myself, “What did I do? What was I acting like? What did I say? Where were we?” [softly, then sighs]. You know, because I want to know. ...

I reviewed the entire evening in my head a thousand times after she said that, trying to figure out what I did. And I couldn’t think of anything really. So that made me even more nervous. Cause I thought to myself, “I thought I was really well behaved. And he called me “wild.” Oh my God. What am I like when I’m having fun? What is he—? Oh geez, you know. ... It is a pretty constant theme with me.

Darlene’s process of second-guessing herself “a thousand times” was shared by most participants.

To avoid this agonizing, some of the participants recruited other people to help them know when they were acting “too” exuberantly. Psychiatrists, partners, and even a priest engaged in this role. Although Lacan (1968) and identity theorists (e.g., Erikson, 1968) recognize that identity is always developed in relationship with real and imagined “others,” the need for the other was particularly acute for the participants because of the difficulty in making this evaluation themselves.

One way to understand the participants’ hypervigilance about behavior that was “too” exuberant is their sense that clearer guidance was not available. They did not

receive specific guidance for determining what is improper (hypomanic or even manic) behavior and what is acceptable exuberance. They also could not easily make this determination for past and future behaviors. The psychiatrists had told the participants that the history they provided was adequate evidence that they have bipolar disorder. For example, one participant shared how sudden the diagnosis felt to her:

Then all of a sudden, I'm being told manic is dangerous. That it's dangerous to be happy. And I said, bull! I'd rather be happy. I'd rather be manic than to be flat-lined. Than to be some of the people on this earth who have no enthusiasm. Who have no spirit. Who have no sense of beauty in the world.

This participant interpreted her psychiatrist's comments to mean that her lived experience of "enthusiasm," "spirit" and "sense of beauty in the world" were evidence of mania.

After these "sudden" determinations, the participants had to analyze their behaviors based on the rules their psychiatrists set out about proper and improper behavior. They had to determine which experiences from their past belong in the inappropriate category and which are considered "normal." They then needed to develop a comprehensive categorization of these distinctions in order to know if a future behavior might be "over the line." Without a clear taxonomy, they were left to monitor their behaviors continually, as they are doing now.

Anthropological analyses of cultures suggest that every society develops its own delineation of the threshold between "normal" and "abnormal," or appropriate and inappropriate behavior. Benedict applied this general proposition to the categorization of mental illnesses. Basing her analysis on anthropological research, Benedict explained:

No one civilization can possibly utilize in its mores the whole potential range of human behavior. ... Every society, beginning with some slight inclination in one direction or another, carries its preference farther and farther, integrating itself more and more completely upon its chosen basis, and discarding those types of behavior that are uncongenial. ... Normality, in short, within a very wide range, is culturally defined.

(Benedict, 1934/1967, pp. 15-16)
(a more lengthy quotation is in Chapter One)

Thus, from the anthropological perspective, there is no universal “normality.” An example of one mental disorder is depression. This disorder is represented differently across various cultures (Kleinman, 1988b; Kleinman & Good, 1985) and the American construction of depression differs from its manifestation in other cultures. Karp (1996) noted how depression is constructed in America:

... biological, psychological, and social processes are intricately woven together in creating the depression phenomenon. ... A necessary condition for widespread depressive illness is a culturally induced readiness to view emotional pain as a disease requiring medical intervention.

(Karp, 1996, pp. 167, 172)

Thus, even if people in a culture experience sadness or emotional difficulties, those experiences would not be organized as illness unless the society chose to place emotional pain in the category of illness, as is the case in the United States.

Even though each culture establishes its own rules of operation, members of a culture generally perceive the rules of that particular culture as the “truth.” The indoctrination is so complete that one rarely thinks to question basic understandings. As Foucault noted, “the fundamental codes of a culture ... establish for every man, from the very first the empirical orders with which he will be dealing and within which he will be

at home” (Foucault, 1970, p. xx). Humans learn quickly what “normal” and “abnormal” mean.

Using these anthropological perspectives, it seems evident that there is a clear boundary in American culture between “crazy manic” behavior and simply ebullient energetic behavior. However, the boundary between “normal” and “hypomanic” or even a non-psychotic mania seems to be in flux. That fluctuating boundary is difficult to manage for those people who often experience life at that boundary.

Locating Hypomania

The behaviors about which participants sought hypervigilantly to avoid as “too” exuberant are probably considered hypomanic symptoms in the DSM-IV-TR. A hypomanic episode is defined to involve a “persistently elevated, expansive, or irritable mood,” with symptoms such as decreased need for rest, inflated self esteem, and being more talkative than usual (American Psychiatric Association, 2000). The participants were more fearful of manic episodes, where they felt a loss of control over their behaviors or somatic sensations. It seems that the participants’ hypervigilance around hypomania reflects a societal ambivalence about hypomania.

One element of the confusion is that the DSM-IV-TR does not consider hypomania by itself a mental disorder. Hypomania is viewed by the DSM-IV-TR as problematic only in people who have experienced *other* symptoms of a mood or bipolar disorder, such as a major depression, mania, or a mixture of depression and mania. Moreover, in those people, hypomania is a problem only “if the symptoms cause

clinically significant distress or impairment in social, occupational, or other important areas of functioning” (American Psychiatric Association, 2000). In other words, hypomania is fine for most people; it is considered a mental disorder only when certain people have it (people with other symptoms of bipolar disorder) and when it causes significant distress.

The pathologizing of hypomania in people who have had other symptoms of bipolar disorder is probably a function of concerns about mania and not hypomania. It may be that the medical community’s fear is that the mood of someone with clinically diagnosed depression or mania has the potential to move from hypomania into mania, the most feared symptom. Thus, it is possible that the concern about people with other bipolar symptoms having hypomania is simply concern about the slide from hypomania into mania. Even if this is so, the pathologizing of hypomania for only some people still seems to present a societal message that hypomania is acceptable for most – but not all – people.

The Privileging of Hypomania

Hypomania is more than acceptable in much of American society; it is privileged and valued. For example, there are many areas of society where high energy, brilliance, grandiosity, and speed are especially valued. Most politicians, celebrities, and so-called workaholics have at least hypomanic energy. Professional fields that require such high energy include the stock market and politics. John Gartner (2005) makes the case that American society has a hypomanic energy:

Energy, drive, cockeyed optimism, entrepreneurial and religious zeal, Yankee ingenuity, messianism, and arrogance – these traits have long been attributed to an American character. But given how closely they overlap with the hypomanic profile, they might be better understood as expressions of an *American temperament*, shaped in large part by our rich concentration of hypomanic genes.
(Gartner, 2005, p. 11)

Gartner's argument explains this cultural preference on the basis of genes, arguing that the genes of those immigrants and slaves who survived the passage to American were hardier and more hypomanic (Gartner, 2005). Although his biological explanation may be unsupportable, the societal commentary is interesting.

Others have discussed how the American speeded-up society has a kind of hypomanic energy (Gleick, 1999; Honore, 2004; Whybrow, 2005). Honore makes an argument that the American over-scheduled time-keeping is a way of maintaining control over one's fear of loss of control. In a similar vein, Gergen refers to the "saturated self," which is sort of an overwhelmed hypomanic self (Gergen, 1991).

Peter Whybrow (2005) proposes a psychological explanation for mania in American society:

Unwittingly, in our relentless pursuit of happiness we have overshot the target and spawned a manic society with an insatiable appetite for more. ... America's dream of a Utopian social order ... has become mired in a confusing mix of manic desire and depressive discomfort.

(Whybrow, 2005, p. 4)

Whybrow, like Gartner, attributes much of the hypomanic nature of American society to immigrant forbears. He argues that the American society fluctuates between manic and depressive postures, using, for example, the "highs" of the 1990's in terms of technology industry to the "lows" of this decade.

Although Whybrow and others refer to “manic” energy, their descriptions of it are closer to the DSM-IV-TR definition of hypomania. Yet this is more evidence of the societal confusion. “Hypomania” is a medical term from the DSM-IV-TR. “Mania” and its related forms, like “manic” and “maniac” are the terms used in popular discourse.

Various commentators have sought to explain the American preference for hypomanic energy. One set of explanations involves economic factors and their impact on American culture and its psychology. This theory is that American capitalism has created an insatiable consumer hunger. By this theory, the desire to continually obtain and own more has resulted in a hypomanic society that lurches along between periods of hypomanic spending frenzies, like the 1990’s, and recessionistic depression. Again, notice how the word “depression” has a similar psychological and economic meaning.

Some commentators have addressed the psychological impacts of these economic factors. These include a narcissistic hunger and self-focus; a culture of the self (Whybrow, 2005); and an “empty self” that is the American consumer self (Cushman, 1995). Christopher Lasch (1979) referred to American culture as the “culture of narcissism.” He was also addressing the emptiness and malaise of the culture that no longer has a strongly shared moral basis. Another commentator (Karp, 1996) critiqued the self-help focused society. The point of this group of societal analysts is that consumerism, focus on self, empty selves, and hunger all help explain the hypomanic American construction of self.

Another example of the high value placed on hypomania is evident in Dr. Jamison's recent (2004) book extolling the virtues of exuberance. She describes exuberance as "an abounding, ebullient, effervescent emotion. It is kinetic and unrestrained, joyful, irrepressible. ... exuberance leaps, bubbles and overflows, propels its energy" (Jamison, 2004, p. 4). This description seems to meet the DSM-IV-TR definition of hypomania. Jamison makes a clear distinction between exuberance and mania, calling mania "exuberance gone amok" (p. 121). Yet she never elaborates on whether there is a distinction between exuberance and hypomania and, if so, where that distinction might lie.

These examples suggest that in American society hypomania may be a valued personality variable.

The Pathologizing of Hypomania

While hypomania may be privileged in American society, the opposite is also occurring. Efforts are being made to expand the criteria for a bipolar disorder diagnosis, thereby expanding the range of people who are considered mentally disordered. This push to expand the DSM definition of bipolar disorder is coming from a number of psychiatrists who are experts in bipolar disorder. They are urging that the next DSM have several new categories of bipolar disorder, including Bipolar II ½, Bipolar III, Bipolar III ½, and a bipolar spectrum disorder. They argue that there are several patterns of symptoms, some similar to cyclothymia, that are not as serious as Bipolar I or II, but that should be labeled as bipolar disorder. They believe people with those so-called "soft" or

milder symptoms should be medicated (Phelps, 2006a). If these changes were accepted, more behavior that is currently considered “normal” and not “disordered” would be moved into the disordered range.

One of these clinicians, Dr. Akiskal (2006), complained that the prior DSM committee failed to recognize one of these bipolar variants, even though this is a “common clinical phenomenon” (Akiskal, 2006, p. 3). He is equally distressed by those seeking to depathologize bipolar disorder and states: “Although psychologically ill (bipolar) patients are represented in the media as being creative, this is a destigmatization campaign at best and glamorizing madness at worst” (p. 4). He is a well-respected psychiatrist from the International Mood Center at University of California at San Diego. These two statements, published in 2006, show a different picture of hypomania than its valued status in American society. Akiskal wants to enlarge bipolar disorder categories to include people with only these “soft signs” of bipolar disorder. While doing so, he rails against positive projections about bipolar disorder, like the notion of bipolar creativity. His rhetoric suggests that bipolar disorder is truly “madness.” Since he wants to expand bipolar disorder to include those who only have the “soft signs” of bipolar disorder, he is in effect arguing that the label of “madness” should be extended to include a very large group of people.

Akiskal is not alone. There is a collection of popular self-help books about the “soft signs” of bipolar disorder by these authors and others. For example, Phelps has a self-help book called *Why Am I Still Depressed? Recognizing and Managing the Ups and*

Downs of Bipolar II and Soft Bipolar Disorder (Phelps, 2006b) Another self-help book suggests that one may have bipolar disorder if he or she has such “soft signs” as “vivid thoughts and emotions”; “variable periods of energy and productivity”; “good times followed by periods of foggy depression”; and is “strongly affected by stress, relationships, changes of seasons, or losses” (Bunch, 2005). Since this definition is rather broad, it seems to be expanding the population that has pathology. The thrust of this thinking is that many more people should be included on the “other” side of the craziness threshold than are currently placed there.

The contradictions in the two themes discussed above may reflect societal tensions around hypomania. On the one hand, this society values hypomanic energy. On the other hand, the experts are seeking to enlarge the number of people with bipolar disorder so as to include people with milder symptoms of hypomania or depression. At least one of those experts fears that efforts to destigmatize bipolar disorder are effectively “glamorizing madness.” Accordingly, assuming the anthropologists are correct in concluding that each culture develops a clear delineation between what is considered “normal” and what is “abnormal” behavior, the location of hypomania around that boundary seems to be fluctuating in American society.

The Blurry Boundary Involving Bipolar Disorder

The preceding section mainly addressed societal confusion around the hypomania threshold. Yet there is equally complex societal confusion around bipolar disorder. The biggest societal concern about bipolar disorder seems to be about out-of-control mania.

The Emily Dickinson poem at the beginning of this chapter reflects the terror of going mad, that is, of being out of control. The participants themselves had this concern about their own behavior. In Chapter Four, I discussed participants' dreams and metaphors of weather, glass breaking, and car accidents. These all evoke uncontrollable, unpredictable, and irreparable events and seem to reflect the participants' fears of being out of control. With hypomania, the threshold is between "normal" and the label of "mental disorder." With mania, the threshold seems to involve behaviors that are unpredictable, out-of-control, and "crazy."

Like hypomania, bipolar disorder is both privileged and denigrated. One example of its special status is evidenced by the increasing prevalence of the diagnosis of bipolar disorder in children (Moreno et al., 2007). Groopman (April 9, 2007), in a recent *New Yorker* article, discussed the repercussions of the increasing diagnosis of bipolar diagnosis in children. The article suggested that the prevalence of childhood bipolar disorder increased in large part after the publication of a popular book about bipolar disorder in children. The book emphasized the creativity, precociousness, and intelligence of children with bipolar disorder. The book spawned a flurry of articles about childhood bipolar disorder, often emphasizing the bipolar child's creativity. Groopman reports that, in the wake of that book, parents are now eagerly claiming that their children are bipolar, since creativity, intelligence, and precociousness are highly valued qualities in the dominant American culture. This is an example of how the positive, romantic notions about bipolar disorder exist concurrently with fearful projections about the

“maniac” aspects of bipolar disorder. The risk of extending the bipolar disorder diagnosis to include difficult but creative young people is that this group of children now considered “normal” will be cast into the role of people with a serious mental disorder.

Another example of the societal ambivalence around bipolar disorder and the threshold between “normal” and “crazy” behavior is Dr. Jamison’s life. She is both an international expert on bipolar disorder and someone who has received that diagnosis. Arguably, Jamison crossed the threshold to “crazy,” as she admitted in her memoirs (1995) to experiences of out-of-control mania and a serious suicide attempt. Yet she is considered both a celebrity and an expert. Her memoirs were on the bestseller list for years. Most people would not think of Dr. Jamison as having crossed the “madness” threshold. Perhaps being a psychologist, articulate, and successful keeps a person on the “normal” side of the threshold.

Another problem in tracking the threshold is the circularity of thinking that supports the bipolar diagnosis. Unlike most physical conditions, there is no medical test that can determine the presence of bipolar disorder. The diagnosis is determined purely on family reports of behavior and patient reports of internal experience. Based on those self-reports, the psychiatrist concludes that someone has a biochemical imbalance that is making the patient feel and do those things. After that initial determination, many future feelings and behaviors of that patient are explained by or attributed to the biochemical imbalance. In other words, a person crosses the bipolar disorder threshold based on historical reports of certain feelings and behaviors. Once that threshold is crossed, their

exuberance (hypomania), sad times, and many other experiences are viewed differently than before crossing that threshold.

This section has discussed possible societal implications of the findings about participants' difficulties determining when their behaviors are "over the line." The suggestion is that the participants' difficulties may reflect a societal ambivalence. There seems to be an ambivalent and fluctuating societal boundary between so-called "normal" and "hypomaniac" behavior and an even more confusing boundary between "normal" and "crazy manic" behavior. Another area of societal ambivalence involves the "proper" role of the patient.

The Induction into the Role of Patient

For all of the participants, receiving the bipolar diagnosis changed their lives. They entered into a world defined by medications, psychiatric instructions, biochemical imbalance explanations, and other processes that organized their lives as a bipolar patient. Two of the six participants stopped working after the diagnosis; others felt that bipolar disorder came to color every aspect of their lives. This sense of being overtaken by bipolar disorder involves both internal experience and perception of societal perspective. For example, one participant mentioned the internal challenges to the diagnosis:

I feel exhausted to be me sometimes [laughs]. And, it's like, it's like um, during the, during, open my calendar in the beginning of the week and what I have to do for that week. And I figure out how much I'm going to need to get enough sleep. It's going to be hard work for me. ... Sometimes I'm having a rough time. Sometimes I'm down. Sometimes I'm not dressed. Sometimes I just can't quite make it. And the medications I take make me very drowsy and very sleepy and it's very hard to get up in the morning.

Another participant discussed her concerns post 9/11 about societal attitudes towards people with diagnoses of mental illness:

It's the political environment that'll make you paranoid. ... After 9/11 I had this weird thought ... I have a feeling that there's going to be a lot less tolerance for any kind of emotional or other circumstance that explains why people would ever break a law. Because people are going to go, "It's unpatriotic." And that's that

Societal Collusion

One way to think about these experiences is that the participants were being inducted into the role of patient. Sociological labeling and role theories attend to the process by which a society will create a role of "deviance" and then reinforce the newly-labeled deviant behavior. The term "deviant" means someone who violates those cultural requirements about "normal" and "appropriate" behavior (Scheff, 1999). The reinforcement is performed by various societal players. Kleinman (1988a) provides an example of how the patient role is created by medical and psychiatric staff:

The recording of a case in the medical record, a seemingly innocuous means of description, is in fact a profound, ritual act of transformation through which illness is made over into disease, person becomes patient, and professional values are transferred from the practitioner to the "case."

(Kleinman, 1988a, pp. 130-131)

Kleinman refers to this act as a "secular ritual" (p. 131). This is a term from the anthropological literature describing an important action that helps members of the culture feel that the world is as it should be. Kleinman is describing one part of the ritual by which a person becomes a medical or psychiatric patient.

The Emily Dickinson poem at the opening of Chapter One provides a poetic example of how social power is used to take power from someone who crossed the

appropriateness threshold: "... 'Tis the Majority In this, as All, prevail – Assent – and you are sane – Demur – you're straightaway dangerous – And handled with a Chain— (1890/1960c, p. 571). There are personal consequences, set by society, for someone who is “deviant” in this way.

There are several societal institutions that become involved in managing deviant people; these rules affect “different levels of the social order” (Schur, 1980, p. 18), including political institutions and the media. A recent example of the role of both the media and political institutions involves the mass shootings at Virginia Polytechnic University (April 2007). In the wake of the shootings, both President Bush and Virginia Governor Kaine created task forces to investigate violence by people with mental illnesses. At the same time, mental health organizations rushed to defend people with mental illness from the media, after deluges of media reports focused on the mental illness of the perpetrator. To counteract the media's power in portraying people with mental illness as dangerous, mental health advocacy organizations urged the public to separate individual violent acts from mental illness in general. For example, a press release from the United States Psychiatric Rehabilitation Association (USPRA) urged media restraint:

USPRA has become increasingly more concerned that the media's focus on the killer's mental illness will lead the public to believe that all persons with mental illness are potentially violent. Public perceptions that violence is strongly associated with mental illness are fueled by graphic media reports of violent crimes. Studies have shown that it is incredibly rare for someone with a mental illness to commit gross acts of violence In the wake of such a national tragedy receiving world-wide media coverage, USPRA urges all media networks to avoid over generalizations about the link between mental illness and violence.

(United States Psychiatric Rehabilitation Association, 2007)

USPRA's concerns supports the theory about the power of political entities and the media to impact the lives of people who have (or are perceived to have) mental illness.

The media and governmental institutions did impact participants' lives. Their initial reactions to the diagnosis as meaning "crazy" is likely informed by representations in the media of people with mental illness. However, the state had an even larger role in the lives of the four participants who are health professionals (two psychologists, one internist, and one retired nurse-practitioner). They feared the possibility of losing licensure if their behavior were found to be improper. Three of these people felt it necessary to tell their co-workers about having the diagnosis, so that any "inappropriate" behavior could be noticed and addressed by other doctors or staff. One psychologist expressed significant anxiety about this point, explaining how she continues to maintain a clinical supervisor to monitor her behavior. She has felt concerns when completing applications to serve as a provider and other formal paperwork, for fear that having a mental health diagnosis in general, and bipolar disorder specifically, would disqualify her from work as a psychologist. Clearly the power of political institutions was noted by the participants.

Lally (1989) undertook to extend the sociological labeling and role theories by studying how the person in the assigned role experiences the pull into the role. He studied patients in a long-term psychiatric institution and found that his participants moved

through three stages of role engulfment. During each stage, the person increasingly accepted the role of mental patient and relinquished the role of “normal” person.

The participants in this study were living full lives in the community, so to that extent the Lally study does not apply. They also chose not to be part of the psychiatric recovery movement or the psychiatric disability community. Nonetheless, the participants did move through a series of stages, during which they came to claim an identity in which bipolar disorder was highlighted. Their claimed identity was not fully consistent with the role assigned to them, inasmuch as their psychiatrists stipulated that bipolar disorder is caused by a biochemical imbalance. Full engulfment into the role would involve adopting that perspective as the sole truth. Instead, the participants developed their own integrative explanations.

Thus, one can conclude that the participants were partially inducted into and engulfed in the role of person with bipolar disorder, using the taxonomy proposed by Lally.

The Role of Pharmaceutical Companies

Another factor that may be part of the induction process involves the pharmaceutical companies. They sponsor significant research into different mental disorders and develop medications. Once the medications are developed, the pharmaceutical companies have an economic need to sell these products. In recent years, there has been a large marketing campaign to doctors and patients to sell the new medications that treat depression and bipolar disorder. The marketing to doctors of

bipolar medications often emphasizes the serious danger of failing to diagnose bipolar disorder. Through the marketing campaigns, doctors, patients, and society in general have become more aware of bipolar disorder.

Thus, the American social construction of bipolar disorder can perhaps be viewed as a process by which society both induces and pathologizes certain behaviors and experiences. It then locates the extremes in certain segments of society, which in this case are those diagnosed with bipolar disorder. The society then medicates and over-controls those who are so diagnosed.

One of the consequences of being inducted into that role may be a loss of the belief in personal control.

Personal Control

The Metaphor of Demonic Possession

One of the metaphors the participants and memoir writers used for capturing the experience of momentary lapses into out-of-control behavior was that it was like being demonically possessed. These incidents were all associated with the “out-of-control self” or other selves over which they had no personal control, such as the “medicated self” and the “treadmill self.”

The Western construct of demonic possession was initially a religious notion that a foreign and supernatural entity, with evil purposes, has taken over a person’s body without his or her permission. That entity would claim the person’s body as its own, “possess” it, and use it for evil purposes. The “victim” would no longer have control over

his or her body – or be responsible for the evil things that body might do. The idea derives mostly from medieval Christian ideas about the Devil and demons. In Christian theology, Satan or Lucifer, the Devil, had lesser demons who work for him (Morgan & Morgan, 1996). Such a devil may decide to possess a human:

Sensing a weak or injured soul, a demon will grab the opportunity to jump inside the human's shell and take over. Possession is different than being harassed by demons, as the evil spirit actually inhabits its victim's body until it is exorcised.
(Morgan & Morgan, 1996, p. 157)

As discussed in the history section of Chapter One, for centuries one of the explanations in Western culture for mad people was that they were demonically possessed. It is worth noting that in the Middle Ages people accused as witches were often people who did not fit the cultural norms of the time, were odd or different, and often were women.

The demonic association to madness is no longer present in Western society, but ideas of demonic possession remain in cultural consciousness and were evident in the interviews. A recent example from popular culture was in a television program (*Without a Trace*) (CBS, April 2007). In that program a woman with bipolar disorder sought an exorcism because she believed she had evil inside that needed to be expelled. The metaphor of demonic possession is also present in the participants' narratives, but without the religious personification that existed in previous eras. That is, their "demon" is amorphous and unexplored. It is an invisible bad entity called "chemical imbalance," not a concrete, religiously-based devil.

One way of conceptualizing the demonic narrative in Western society today involves having someone or something to blame for unfortunate events. Alon and Omer

(2004; 2006) suggest that the blaming societal narrative is the current incarnation of the demonic notion, relieved of the religious content from earlier centuries. They suggest that the psychological manifestation of this narrative assumes that there is a cause for all suffering. They see the core features of this narrative as hostility, fear, and suspicion (Alon & Omer, 2004, 2006).

Alon and Omer contrast the “demonic narrative” with a “tragic narrative,” one that simply accepts suffering without locating its cause externally. The Buddhist and existential perspectives reflect the “tragic narrative.” The Buddhist perspective is that as humans we always feel divided and fragmented, torn between opposing and conflicting ideas (Rosenbaum, 1999).. This perspective sees suffering as inevitable. There will rarely be a specific cause for a person’s suffering (Alon & Omer, 2004, 2006). The Buddhist prescription is to find happiness as life is right now, with both its positive and negative elements (Das, 1999; Rosenbaum, 1999). All concerns, including depression, can be addressed by both accepting and “letting go of” suffering, including the suffering of depression. (Epstein, 1995, 1998; Kornfield, 1993; Martin, 1999). Or as put most simply by Scott Peck (1978/2003):

Life is difficult.

This is a great truth, one of the greatest truths. It is a great truth because once we truly see this truth, we transcend it. Once we truly know that life is difficult ..., the fact that life is difficult no longer matters.

(Peck, 1978/2003, p. 15)

Alon and Omer (2006) argue that one aspect of the demonic narrative in Western society, carried over from the Middle Ages, is that a specialist is needed to detect and

eradicate the evil. In earlier eras, the priest or religious person was the appropriate expert to exorcise the demon from the person's body. Today the mental health professionals are the experts who can detect and help the client eliminate bad things that have entered a person's psyche, such as internalized voices or traumas inflicted by others.

This societal analysis is consistent with the way the participants experienced the external "biochemicals." Expert psychiatrists and psychologists can diagnose this evil; only the psychiatric experts can eradicate it. This is one way the participants' specific experience can be understood in the context of a possible societal narrative about suffering and blame.

The metaphor of demonic possession was also present in participants' narratives in two other ways: it emerged in participants' negative judgments about their behaviors and in the issue of personal control and responsibility.

Morality

One aspect of the now defunct demonic belief system that may retain some currency in American culture involves questions of morality or the battle between good and evil. Early Christians believed that mad people were possessed by demons because the mad people had sinned or simply were so weak that an evil spirit could possess them:

In Christian divinity, the Holy Ghost and the Devil battled for possession of the individual soul. The marks ... might include despair, anguish, and other disturbance of mind. ... Believers themselves personally experienced madness and despair as indications of sin, diabolical possession, or a lost soul.

(Porter, 2002, pp. 17, 21)

Vestiges of this morality may be evident in the participants' psyche by their

occasional self-judgmental comments, which suggests the continuing cultural impact of this morality from an earlier era. For example, when participants explained why they needed to be hypervigilant about their moods or behavior, they often stated that it helped them evaluate if they were being “good” or “bad.” Their point was how they watched themselves to avoid overly exuberant behavior, but the comments were structured with judgmental overtones. This suggests that the participants perceive themselves in some way as “sinning” or being “bad” when experiencing or acting from hypomania or mania.

The participants also perceived this morality as being present in the larger society, which will judge them for any out-of-control behavior. One participant explained this by contrasting societal views of unipolar depression and bipolar disorder: “Depression you feel bad. People know what it is. ... it’s a mental illness. ... it’s not, you know, a matter of moral weakness.” Even though the dominant societal explanation of bipolar disorder is about imbalanced biochemicals, this participant’s understanding of societal mores seems to be that any inappropriate behavior by someone with bipolar disorder reflects immoral behavior that is not excused by imbalanced chemicals. Further, as another participant stated,

... even though I’m sitting here telling you myself that what you have to do is call it a biochemical illness, and, you know, analogous to diabetes, and then you don’t have to blame yourself ... that doesn’t work for me. ... But I’ll tell you that nobody else thinks that way when they hear about somebody who has it. If somebody is crazy, they are crazy. It’s not that they have craziness.

She believes that the society does not truly buy into the “imbalanced-chemicals-in-the-brain” explanation. She has concluded that people view someone with bipolar disorder as

“crazy,” regardless of politically correct changes in language or explanation.

This finding suggests that the effort to relieve people with bipolar disorder of responsibility for their actions with an imbalanced-chemicals explanation for their behavior has not in fact excused them of a feeling of being “immoral.” It also suggests that society has not fully embraced the exculpatory explanation.

Volitional Control

The demonic possession metaphor may also be relevant today in implicating the question of personal versus external control. The participants have been told by their psychiatrists that their hypomanic and manic experiences, which included their prized “expansive self,” are not “real” experiences but “bad” ones controlled by an external chemical entity. In this sense, they are being told they are not responsible for their actions when under the control of the “evil” imbalanced biochemicals. Historically, a person who was demonically possessed was relieved of responsibility for the evil they performed, since it was an external agent, a demonic entity, who acted through the person, not the person him- or herself. The person was responsible at most for being weak, which allowed the demonic spirit to take possession.

The issue of volitional control was very present for the participants. They are being told that they cannot control the biochemical imbalance in their brains. They also cannot control the supposedly “good” chemicals they are being asked to put into their bodies and brains (medications) to rebalance those “bad” chemicals. At a phenomenological level, the participants may have experienced this battle of chemicals as

a war between good and evil spirits, a war waged in their bodies but not one they can consciously control.

It is particularly interesting that the participants repeatedly chose to claim a personal self that was in control, even if it made mistakes, to a self powerless over “external” brain chemicals. As one participant stated,

I'd like to be able to say, more like, “You know, these were just things that happened in my life, and this is just the way I am.” ... It's not because ... I have a disorder or a problem. It's just, you know, I, I, this is me, you know. I—, I've done these things; I've had ... had these things happen. And this is the way I've responded and that's just the way it is, you know.

Other participants also claimed empowered selves, even ones that were negative, like being a “bitch” or “ornery.” In other words, it is more comforting and identity coherent to think of oneself as “a bitch” than as someone acting under the influence of warring good and evil chemicals over which one has no control.

There is certainly a pull towards blaming an external demonic agency, as Greenberg (2007) noted when decrying the dominance of biochemical explanations and the demise of insight-oriented therapy:

Who can resist this idea that our unhappiness is a deficiency that is in us but not of us, that is visited upon us by dumb luck, that it can be sent packing with a dab of lubricant applied to a cell membrane? ...

Of course, there's no place in the [survey] to express this, to talk about the immeasurable loss that I think we all suffer as science turns to scientism, as bright and ambitious people devote their lives to erasing selfhood in order to cure it of its discontents.

(Greenberg, 2007, pp. 46, 45)

Greenberg, like the participants, would prefer to claim selfhood and power, even if it means acknowledging sadness and loss or, for the participants, being a “bitch.”

Why would it be so important for participants to feel in control of their behavior? This question about volitional control invokes complex philosophical issues about the nature of free will. Most theories of the self postulate that humans have very little conscious control over cognitions, feelings, and somatic experience. From a Lacanian perspective, the idea of conscious volitional control is a fantasy. “Lacan’s position defines the ego as created in alienation, irrevocably split” (Benjamin, 1998, p. 82).

Psychoanalytic, existential, personality, and identity theories all postulate that our conscious selves have very limited control over our experience. Cognitive psychologists also recognize that unconscious processes are a much larger part of human functioning than conscious ones and recent neuropsychological research clearly indicates that our conscious minds control very little of our actual experience (Blackmore, 2006; Damasio, 1994; Dennett, 1991; LeDoux, 2002; Walker, 2000).

Yet at the same time philosophers of consciousness assume there is some free will (Blackmore, 2006), meaning that even though unconscious forces “control” human sensory and cognitive experiences, we each still have volitional control over our thoughts and behaviors. Furthermore, in Western society, we act from the belief system that we *do* have free will, conscious volition, and control over our actions. Self-help books proclaim how in six steps you can overcome addiction, pain, low self-esteem, or overeating. Pop culture abounds with messages like “trust in yourself,” “you are the expert of you,” and

“be all you can be.” This can perhaps be understood from the context of American culture, where the prized selves are what Cushman (1991) called “bounded, masterful, feeling selves” (p. 210). To be “masterful” means that one can control one’s movement through life. It seems that even though the research indicates otherwise, we as Americans want to believe we have control over our actions.

Thus, in some way, this group of people (people with the diagnosis of bipolar disorder) are the repositories of these societal dilemmas about will and identity, including the question of what experiences belong to the individual and are therefore volitional and which ones are somehow external and out of conscious control. They also represent societal confusion around the mind-body distinctions.

The Western Mind-Body Divide

Another reason the chemical imbalance explanation may have felt like demonic possession to the participants is the societal difficulty in bridging the Cartesian mind-body divide. Even with the recent research indicating the continuous nature of consciousness and the integrated relationship between bodily and cognitive functions, researchers and philosophers of consciousness have difficulty even discussing consciousness without resorting to mind-body dualisms (Blackmore, 2006). American English still does not have an easy language to discuss somatic experience. American discourse is starting to articulate some body-mind interactions, like how stress may impact on muscle tension and digestion. But whereas indigestion and muscle tightness can be felt, chemical imbalances in the brain cannot be experienced consciously. The

participant who talked about the “treadmill self” tried valiantly to describe the physical sensations she gets when she is in a manic state:

... there's some kind of snapping. It's just not nor—, it's just not right. ... It's like you're on a treadmill and you're running so fast that you can't stop. For me, it's, it's the manic, um, racing feeling that, that just mind-racing thing that I just can't stop.

These sensations may be due to a chemical imbalance, but there are also somatic, emotional, and cognitive elements. If the bipolar discourse included more of these elements, it might be easier for the participants to claim ownership of these experiences. For example, suppose this participant's psychiatrist had told her that these sensations occurred because the chemical imbalance in her brain increased her adrenalin, which increased her blood pressure, which increased her anxiety, etc. If she understood her bodily changes, she might be able to feel more of a connection between her brain's biochemical imbalance and her phenomenological experience. In other words, the biochemical-imbalance-in-the-brain explanation, without a more comprehensive explanation that integrates mind, body, and emotion, unavoidably creates the sense that a foreign invader (imbalanced biochemicals) is impacting experience.

The mind-body dualism in American discourse by necessity will interfere with identity cohesion in someone with a bipolar diagnosis. How can one experience as “me” that which is construed in American discourse as an external entity (brain biochemicals) which have possessed the person (like a demon or alien)? This is due in part to a lack of comprehensive scientific knowledge at this time of the physiological processes that create the compendium of sensations, feelings, and thoughts of someone in a manic state.

It may be worth contemplating the possibility that another person diagnosed with bipolar disorder might fully endorse the biochemical explanation, with the understanding that chemistry is influenced by both genetics and a lifetime of experience. To do so, however, would require that the person acknowledge how little conscious control he or she has over this bodily experience, a conclusion that might be quite painful.

Jacques Lacan has an altogether different take on the mind-body divide as it may be impacting these participants. Rogers (2007) describes the Lacanian view as follows:

The biochemical findings about Bipolar Disorder do not provide an out from personal responsibility in a Lacanian view. One may choose to take medication to regulate moods, but what is going on in the body reflects something whose manifestations may not ever alter in this way—the medications blunt certain experiences and acts, but do not solve what is at stake.

From a Lacanian perspective, there is no mind-body dualism. In fact, the body has important knowledge that may be unavailable to the conscious mind. Thus, what Western medicine may call symptoms of bipolar disorder would be viewed by Lacan as important communications about that person's unconscious conflicts and issues.

For most Americans, like the participants, the mind-body divide is one that is hard to bridge. It ends up being too challenging to make sense of a condition that is labeled a “mental disorder,” but which causes emotional dysregulation, impacts on cognitions, creates a somatic mind-racing experience of being on a treadmill, and is based on a biochemical imbalance in the brain. In Western philosophical analysis, sorting out who or what is in charge and acting on self is an unresolved question. These people are essentially handed this dilemma to solve by themselves.

Yet whatever solutions they create must take into account societal projections about bipolar disorder.

Changing Societal Projections

Another aspect that seems to be part of the social construction of bipolar disorder is the societal process of projection and introjection, a process that is premised on unconscious communications. These ideas, based on theories developed by Klein (1959/1985), Bion (1959), and others, are that individuals expel from our conscious awareness and project onto others feelings and experiences that are too frightening to contain. Groups have similar processes of locating unacceptable feelings in other groups. The dominant group can achieve equilibrium once its overwhelming affect is projected elsewhere, just as the Israelites could proceed with their lives after the scapegoat was loaded up with their sins each year and sent into the wilderness. In group process, the “loaded up” group becomes a “denigrated other” (Green & Skolnick, 2002). Yet, even though denigrated, the “other” retains tremendous power (Benjamin, 1998).

In American society, the group of mad or crazy people has been “loaded up” to hold a broad range of uncontrollable, unpredictable and bizarre behavior, affect, and thoughts. This allows people without the designation of mental illness to retain the fantasy of being in control, predictable, and “normal.” The connotations of “madness” elicits or evokes the “shadow” or “not-me” aspects of self, ones too terrifying to acknowledge. Someone who is “normal” can keep this terror at bay by locating the madness in people who are crazy.

These processes were very present in participants' experiences. Participants' initial negative reactions to the diagnosis reflected those undigested introjections. Participants were diagnosed with bipolar disorder in adulthood, so they had many years prior to their diagnosis to introject the societal projections and rely on them. Once they were given a diagnosis that meant "crazy" to them, they could no longer place the uncontrollable or unpredictable in others and therefore had to find a way to integrate the "sane" and "crazy" parts of themselves, an integration performed, perhaps, on behalf of the larger society.

Prejudice and stigma are societal processes that organize projections about those groups of denigrated others. Prejudice involves the fears and generalizations about the persons in the group. Stigma is more complex as it addresses both the external prejudice and the individual's internalization (or introjection) of those prejudices and associations (Goffman, 1963). These processes are an integral part of the social construction of a disorder, as they change over time as the societal attitudes towards the disorder change.

All of the participants spoke about societal prejudice and how that impacted their choices of whether, how, and to whom to disclose their diagnosis. Invariably, when they discussed disclosure, feelings of shame emerged. Even imagining disclosure evoked shame. This is evidence of the introjective aspect of stigma. The shame indicated a feeling of being defective or having a "spoiled identity" (Goffman, 1963).

All but one participant had been diagnosed by a psychiatrist with clinical depression before they received the bipolar diagnosis. The participants all indicated that

bipolar disorder is considered more “crazy” than unipolar depression in society today. Yet in 1972 Senator Thomas Eagleton had to abandon running for Vice President due to admitting having been hospitalized previously for depression. This suggests that the construct of depression has changed over the past thirty years such that there is less prejudice about that construct now than earlier. Prejudice, stigma, and societal projections about “madness” remain alive, but “madness” now apparently excludes people who are depressed.

The findings in this study suggest that the societal projections about bipolar disorder may also be changing. These participants all grew up in the 1950’s to 1980’s and may reflect views of middle-aged and older generations about the societal prejudice about bipolar disorder. Younger people diagnosed with bipolar disorder may have introjected less of the negative projections about bipolar disorder. A recent song by a young woman with a diagnosis of bipolar disorder may reflect the change in negative societal projections about the disorder. The song, “Bipolar Girl,” is somewhat flip and lighthearted. It suggests that people in their teens and twenties may no longer view a diagnosis of bipolar disorder with as much shame and horror as it is seen by these older participants. The lyrics are as follows:

Woke up today
In another bed
With a what's his name? I'm outta my head
Mmm, my brain's gettin' worse
I laugh at things that make no sense
Flying high on confidence
Ohh, my head's in reverse

I just don't know
But something tells me
I'm just a bi-polar girl
In a bi-polar world
Just a bi-polar girl
My friends think that I'm disturbed
I'm not ashamed - no one to blame
Moving like a hurricane
I keep on blowing thru this world
Just a bi-polar girl

It's after 10
I'm lost again
I can't remember
Where I've been
Mmm my head's in the ground

My hair's a mess
This dirty dress
Can't believe this emptiness
Like my heart took a train downtown ...

Took the pills, they made me ill
I couldn't sleep at all last night
Lost track of time
In my mind ...
I am coming down

(Lovelis, Enea, & Beers, 2007)

Note how nonchalant this woman sounds about topics that might be shameful for participants (e.g., multiple sexual partners, rapid mood fluctuations). Furthermore, in this case the “blowing” “hurricane” is not some external overpowering force over which the individual has no control; it is the individual herself with all of her subjectivity. This song may reflect how bipolar disorder is becoming less stigmatized in American society, perhaps like depression has become.

I have discussed in this chapter a number of ways that the findings from this study may suggest that the term “bipolar disorder” is constructed in American society today. Perhaps the society is becoming a “bipolar world,” as the author of the song suggests.

SUMMARY AND CONCLUSION

This study investigated the processes by which the construct “bipolar disorder” is being socially constructed in American society, as reflected through the eyes of six people who have received that diagnosis. Those processes involves ongoing interrelationships between societal discourse and individual experiences. The effect of the processes encompass multiple layers of meaning of the construct, including societal meanings around “madness” and “craziness”; individual meanings about internal feelings like sadness and expansiveness; and group meanings about behaviors that may seem odd or unpredictable. These interrelationships were examined through the experiences of six individuals with the bipolar diagnosis..

There are two main sets of findings. The first involves an interactive process between societal and individual experience in the creation and maintenance of the construct of bipolar disorder. The second involves a myriad of challenges to self and identity that result from the way this particular diagnosis has been taken up by the psychiatric community and society. These findings can be understood as reflecting four tensions in the larger society

The first set of findings involves the interactive process between individual and societal experience in participant self-labeling of moods, affect, behavior, and experience. The process of participant meaning-making both before and after receiving the diagnosis of bipolar disorder occurred through a developmental process. At each step of the process, the participants created explanations for their experience and the behavior of

others by choosing from among available labels in the larger societal discourse. As the terms and language changed in society, the explanations of participants similarly evolved.

All of the participants described difficult childhoods, including such experiences as death of a sibling or a parent. Participants also experienced a parent as unpredictable or out of control, yet they had few labels for explaining that parent's behavior. Similarly, participants felt that their parents were not always adequately attuned to participants' emotional needs, yet this too could not be explained easily. As the participants entered adolescence and adulthood, most self-labeled as depressed. Five of the six participants were diagnosed as having clinical depression prior to the bipolar diagnosis. Although they had the depression label for their feelings of sadness and despair, they did not have any comprehensive category in which to organize other divergent feelings, such as intense anger, irritability, happiness, high energy, sadness, low energy, and expansiveness. They did not miss having an organizing label since these were simply seen as different experiences.

When they received the diagnosis of bipolar disorder, the participants initially had negative associations to the label, fearing that this meant that they were "crazy" or that their behaviors would become unpredictable, like their "crazy" parents. Even though five participants had previously received diagnoses of clinical depression, and four of this group had attempted suicide, they did not experience those behaviors as unpredictable or out of control. Their negative associations to the label "bipolar disorder," reflected societal attitudes that mania or manic behaviors are evidence of being "crazy."

Once they became familiar with the psychiatric meaning of bipolar disorder, however, they learned how the definition would encompass divergent experiences like expansiveness and intense anger, which were not previously organized together. They expressed relief at having this new label that provided a comprehensive framework for organizing vast swaths of previously discrete experiences. However, they later realized that the framework was so inclusive that no aspect of self could remain free of the bipolar identity.

The second set of findings addresses the challenges to self and identity that participants experienced with the bipolar disorder label and the impact of societal explanations for bipolar disorder on identity tasks. It was challenging for participants to develop an integrated and cohesive sense of self, since they experienced various, often conflicting selves, such as a “depressed” and an “expansive” self.. What was most challenging was integrating those parts of experience that seemed foreign or “not-me.” One of the experiences often felt to be “not-me” was the “medicated self.”

It was also difficult for participants to experience “selfsameness,” a sense of an ongoing and continuous self. (Erikson, 1959). This would be the sense of being the same person whether depressed, expansive, medicated or relaxed. This was difficult in part because the definition of bipolar disorder is of a self with opposing or “bi-polar” moods. In some ways the definition itself, as a disorder of fluctuating moods, provided a way to think about experiencing continuity across moods. However, the participants found it

most difficult to maintain a continuity of self between their unmedicated and medicated selves, since the medicated self often felt very foreign.

The societal explanations for the etiology of bipolar disorder made these identity tasks even more challenging. The current prevailing explanation is that bipolar disorder is caused by a biochemical imbalance in the brain. By being told that the cause of their divergent feelings and behaviors was a biochemical imbalance over which they have no conscious control, the participants felt like they were being told metaphorically that they had become possessed by an external entity (like a devil). Even though the chemical imbalance explanation essentially relieved the participants of responsibility for their hypomanic or manic behaviors, the participants preferred explanations involving personal choice and responsibility. They preferred a self-understanding in which they had control over their actions, even if they acted badly, like being a “bitch.” Personal responsibility was repeatedly chosen over the reliance on an exculpatory external (biochemical) agent.

The participants developed their own integrations of explanations for bipolar disorder. They integrated the biochemical imbalance explanation with other explanations available in the societal discourse, such as history of trauma or lack of attunement with parents, even though the psychiatric discourse and to some extent society privileges the biochemical imbalance explanation over the other ones.

The participants may be representing other people when they forge their own set of explanations and self-understandings of the meaning of bipolar disorder. As representatives, they are both reflecting and impacting changes taking place in the

societal understanding of bipolar disorder. As psychiatrists and psychologists also create integrative explanations, a mutual, interactive process may be underway. The social construction of bipolar disorder comprises these many layers of meaning and these mutual processes. Language is the medium by which the construction takes place.

There are four areas in which these two sets of findings may link to larger societal issues. The first involves a blurred and fluctuating boundary in American society between “normal” exuberance and “crazy” mania and how this societal confusion affected participants’ meaning-making. The second addresses the process by which society inducts people into the role of patient. The third implicates Western society’s difficulty in recognizing the limitations of volitional control. A related issue is the Western challenge in bridging mind-body dualism. Participants faced this issue when making sense of experiences that are labeled a mental illness, but which have somatic, affective, and cognitive components. The findings also suggest that negative societal projections about bipolar disorder may be shifting.

Limitations of the Research

This investigation proposes a continuous interaction between individual experience and societal discourse as the process for the social construction of bipolar disorder. This proposed process emerged from an in-depth study of six people who were diagnosed in adulthood as having bipolar disorder. The specific developmental process applies to the experience of the six people interviewed. Thus, it is limited by many factors. These include the participants’ personalities, their cultural backgrounds, the

interviewer's personality and cultural background, and the interview process. All of those factors influenced the data that emerged in the interviews. The demographic characteristics of the participants that reflect culturally relevant group identities include the following: they all identify as European Americans who were diagnosed as adults with bipolar disorder; they were born in the mid- to late 20th century in the United States; they currently live on the East Coast of the United States; five of the six participants are women; and four of the participants are health professionals (two are psychologists; one is an internist; and one is a nurse-practitioner, not current working).

Each of these demographic characteristics affects the findings. For example, as people who identify as European Americans, the participants would likely have had different experiences around health and mental health explanations than someone from a minority group. Similarly, the findings reflect more of a woman's experience, since there was only one male participant. Further, the fact that two-thirds of the participants are health professionals may be relevant in several ways. For example, as health professionals they would be more familiar with medical and psychological knowledge than someone without their professional backgrounds. They would also be more familiar with the hierarchies of professional explanations for bipolar disorder, with the biochemical imbalance explanation holding dominance at this time.

Even more relevant is the fact that these participants were well educated, four having obtained graduate professional degrees and the other two having college degrees. Moreover, this was a particularly articulate and thoughtful group of people, qualities I

actively sought with informal recruitment criteria. As a result of their education and verbal abilities, these people were able to think, speak, and report on their experience with a nuanced sophistication. It is also likely that education honed their ability to think abstractly and theoretically. Their education is likely associated with the complexity of their integrative explanations for bipolar disorder, since education is related to the nature of the theories people adopt to view the world, including their own pathologies. I believe these characteristics of the participants helped provide both deep and rich findings, but at the same time these characteristics would limit the generalizability of the findings.

Another limitation is that these participants were unaware of or uninterested in the psychiatric disability world, including its language and its views of pathology and recovery. This characteristic of these participants clearly supports the contention that there are two vastly different mental health worlds in America (Stefan, 2001, 2002).

Further, it is highly unlikely that this group of people could represent the entire universe of people with a diagnosis of bipolar disorder, as that label includes people with quite diverse symptoms and experiences. The goal in this study was to understand some aspects of the impact of bipolar disorder as a label, both on individuals and in society, rather than to record any comprehensive list of symptoms.

Finally, in narrative research, what emerges is always an interaction of the meeting of two people (Josselson, 2005). Thus, the findings are also limited by the particular affective state of each participant at the time of the interview as that person interacted with me as the interviewer and my affective state. The findings are also subject

to factors unconscious to the participants and to me, such as nonverbal communications, the order of the interview, or even the time of day.

Another unique factor of this study is the process of recruitment of the sample. All of the participants were referred by current or former Fielding students from the Washington, DC area, people who have been both friends and student colleagues of the investigator. One person referred three of the six participants. The participants were a former clinical supervisor, a former professional colleague, a friend, and current or former psychotherapy clients of the referring person. Before the referrals were made, the investigator had been discussing this research topic for some time; the referring people were familiar with the research questions and the investigator's interest. It is highly likely that all of these factors influenced the interviews and the findings. For example, the investigator had requested that potential participants be thoughtful and articulate and be people who had considered the meaning of the bipolar diagnosis in their lives. All of the participants fit well within those informal recruitment criteria, a finding that was likely associated with the informal recruitment request.

The nature of narrative research is to obtain a rich picture of a particular phenomenon. No claim is made that findings are generalizable to a larger population. For example, one of the participants described an explanation that was used in the rural community in which she grew up in the mid-20th century: namely, that a woman's behavior that was not easily understood was attributed to her being in menopause. That specific finding may be limited to that small community at that time. However, it is

hoped that the interactive process proposed here for how a mental health construct becomes socially constructed would apply beyond this particular construct in this particular study. This proposed process would include the findings that people organize their experiences with labels or terms available in the culture.

Suggestions for Future Research

There are many potential directions to explore following this study. Additional narrative studies of similar questions but of people with different demographic characteristics would result in other sets of findings that might provide interesting contrasts to these conclusions. Narrative studies of different mental health constructs in American society, such as clinical depression, schizophrenia, or anxiety disorders, might reveal very different findings about the “madness threshold.”

After there is some sense of the landscape of these questions from several in-depth analyses like this one, it would likely be useful to extend the research to larger populations by conducting quantitative studies investigating questions such as prevalence of different meanings of bipolar disorder (or other mental health constructs) across different populations.

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APPENDIX A

INFORMED CONSENT FORM

1. GOAL OF STUDY:

The goal of this study is to learn about how people who have received the diagnosis of Bipolar Disorder make sense of having this diagnosis.

2. RESEARCHER AND SUPERVISING FACULTY MEMBER

Researcher:

Susan G. Goldberg
Doctoral Student, Fielding Graduate University
1317 Rhode Island Ave., NW
Suite 101
Washington, DC 20005
Telephone: (202) 288-6470
E-mail: gsusan@earthlink.net

Supervising Faculty Member:

Ruthellen Josselson, Ph.D.
Faculty Member, School of Psychology
Fielding Graduate University
2112 Santa Barbara Street
Santa Barbara, CA 93105
Telephone (in Maryland): (410) 243-8143
E-mail: rjosselson@fielding.edu

You have been referred to the researcher for possibly participating in this study because you have received the diagnosis of Bipolar Disorder. So that you can make an informed decision about whether to participate in this study, this form describes the purpose, requirements, potential benefits and potential risks of the study to you. This study is being conducted by me, Susan G. Goldberg, a doctoral student at Fielding Graduate Institute, under the supervision of Ruthellen Josselson, Ph.D., a faculty member at Fielding Graduate Institute. The study is part of my doctoral dissertation research.

3. PURPOSE OF STUDY:

I am conducting the study to learn how people with a diagnosis of Bipolar Disorder make sense of the label of bipolar disorder. I am also interested in

people's experiences of telling (or thinking about telling) other people something about having been diagnosed as having bipolar disorder.

4. PROCEDURE:

I will first telephone you to ask a few questions about you and the diagnosis you received. After that initial telephone call, I may ask you to be a participant in the study. I will let you know, by telephone, if I will be asking you to participate in the study.

If you become a study participant, I will meet with you at a mutually convenient time and place for an interview that lasts approximately three hours. We will jointly decide whether to conduct the interview over one or more sessions.

During the interview, I will ask you questions about the story of when you received the diagnosis of Bipolar Disorder, how you think about it, your feelings about having this label, your stories of telling other people about having the disorder, and related issues. I will interview approximately five to eight people.

I will tape record the interview and later prepare a typed transcript of it. My analysis of the findings will involve a review of all of the interview transcripts, looking for common themes emerging from the interviews.

5. POTENTIAL BENEFITS:

There will be no direct benefit to you.

I do hope that when I share the results of this study with other people, this will provide some benefit to persons with a diagnosis of Bipolar Disorder and perhaps other persons with disabilities. By participating in this study, I believe you will be contributing to knowledge and perhaps helping other people with diagnoses of Bipolar Disorder or other diagnoses of mental disorders.

6. POTENTIAL RISKS:

I do not see any risk to you by participating in this research project. Your participation is completely voluntary. If you have concerns or questions that emerge during the interview, I will be glad to discuss them with you during or after the interview. If, after the interview is over, you feel you need assistance as a result of the interview, please contact me and I will provide the names and contact information of local therapists or mental health services.

7. CONFIDENTIALITY:

I will maintain total confidentiality of your name and identifying information. This means that you will not be identified by name, address, or any specific personal information in any written documents or oral presentations. In presenting the results of this study, I will assign you a pseudonym (another name) and change details about your life (such as your gender, age, job, number of children, etc.), in the hope of making you not identifiable at all.

A few other people may hear the tapes of your interviews or see the transcript of your interviews, but only for limited purposes. Members of my dissertation committee and some other Fielding Graduate University students may see your transcript or listen to the tape of your interview only for purposes of assisting me in my analysis. I will ensure that all identifying information is removed before anyone else sees your transcript. I will also ensure that the Fielding Graduate University faculty members or students understand and agree to the need to completely preserve the confidentiality of your interview.

I will also protect your information, tapes, and transcript by using locked file cabinets and password protected computer files.

I intend to retain the data from this study for an unlimited period of time, as I may use it as the basis of further research or longitudinal research at a later time. I will always protect it as described above.

8. YOUR PARTICIPATION

Your participation is completely voluntary. You may discontinue participation in the study at any time without penalty or prejudice. If you withdraw before the completion of the interview, you may also ask that I not use any information collected from you. Also, you need not answer any question that you do not wish to answer. Simply let me know that you would like to skip that question.

9. DISSEMINATION OF STUDY RESULTS

I plan to share the study results broadly, in academic journals and meetings, at national conferences to service providers, researchers, and policy makers, and to consumers and lay people.

10. RESULTS

Unless you tell me not to, I will mail to you a copy of the results of this study when it is completed.

11. CONTACT INFORMATION

If you have any questions about this research or experience any problems, you should contact me or my faculty supervisor. Our names and contract information are at the top of this Informed Consent form.

The Institutional Review Board of Fielding Graduate Institute retains access to all signed informed consent forms.

What you are agreeing to:

I understand that I have a right to privacy and that the researcher of this study will take all reasonable measures to protect the confidentiality of my records. My name and any other information that might identify me will not appear in any presentation or publication resulting from this study. My name and any other information that might identify me will not be available to any person or group other than the researcher of this study and the Institutional Review Board of Fielding Graduate University. I understand the interview transcript (with identifying information removed) may be seen by a few faculty members or students of Fielding Graduate University, but only for the purposes of assisting in the researcher's dissertation or research training. Records may also be reviewed by federal oversight agencies that monitor compliance with the protection of participants.

I have read the previous pages of the consent form. I understand that I am free to ask the researcher additional questions.

I understand that participation in this study is entirely voluntary and I may refuse to participate or may discontinue participation at any time, without penalty. I acknowledge that no promises have been made to me regarding the results of my participation in this study, and I consent to participate in the study. I have been given a copy of this form.

Date

Potential Study Participant (signature)

Name (printed)

Address

Telephone Number

Email Address (optional)

APPENDIX B

INTERVIEW GUIDE Susan G. Goldberg

First question: I am interested in hearing the story of your being diagnosed as having bipolar disorder and what that diagnosis has meant to you since then.

Prompting questions:

- What is the best place for us to begin the story?
- When you first received a mental health diagnosis -- How were you told and what was that experience like for you?
- Did your diagnosis change over time?
- When you first received the label of Bipolar II Disorder, what did you think it meant? How did you feel about the diagnosis? Did you explain your experience in a different way? Did you see yourself as a person with bipolar disorder? How did you make sense of it then?
- What do you call it in your mind? {e.g., disorder, illness, disability}
- What are the symptoms that for you constitute the _____[word they use]
- Would you describe how well the label seems to fit – or not -- with your sense of who you are.
- Do you have a sense of being part of the group of people with mental illness? If so, what is that like? What does it mean to “be” “mentally ill”?
- Tell me about your experiences of having this diagnosis since then.
- Has your sense of who you are -- and the part played by this diagnosis -- changed over time?
- Are there times when having bipolar disorder is more or less in your life? Tell me about these experiences.
- How do you feel about having this diagnosis? How has it affected your life? How has it affected your sense of who you are?

- Have you considered other “explanations” for the origin of your experiences of moods (or of these symptoms) than this particular diagnosis?
- Do you use the term “recovery”? What do you think about that term?
- What are the symptoms that you associate as part of your diagnosis?

[Think about

- disruptions in sense of self
- nightmares
- failed acts (begun but not completed; acts with unintended consequences)
- sense of inexplicable repetition across generations
- look at breakdown
- look at time label first given
- track metaphors
- track slips of the tongue]

Second question: I am also interested in hearing about the circumstances when you have told people something about your having a diagnosis of bipolar disorder and what that experience was like.

If necessary, prompting questions such as:

- When have you told another person -- or thought about telling another person -- about having bipolar disorder? I’m interested in how you thought about it, what you said to that person, and how they reacted.
- I’m interested in other times and situations when you have thought about telling people and how you handled it.
- How did you expect people to react?
- Why is it easier to disclose to some than to others?
- Have your decisions about telling people about your diagnosis changed over time? For example, do you identify yourself in different ways now than before? Tell some people and not others? [Exploration of selective disclosure of person, place, time, and content]. Tell me about that.

APPENDIX C**Demographic Data**

What is your current diagnosis?

Age and date of birth

Gender

Ethnic identity

Where born

Education

Employment

Profession or area of work

What have been your symptoms (of bipolar disorder) initially, changed over time,
and currently

Date of first symptoms

First mental health diagnosis (and date)

Date of first diagnosis of bipolar disorder

Current diagnosis

Which medications being taken now and previously for bipolar disorder

Number and length of hospitalizations, if any