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BIPOLAR DISORDER:

RESPONDING TO CHALLENGES TO IDENTITY

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BIPOLAR DISORDER:

RESPONDING TO CHALLENGES TO IDENTITY

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BIPOLAR DISORDER:

RESPONDING TO CHALLENGES TO IDENTITY

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This qualitative interview study explored the experiences of adults diagnosed with bipolar disorder. Grounded theory methodology was used to analyze transcripts of the interviews conducted. It was found that a central process in the experience of dealing with bipolar disorder is responding to challenges to identity.

For people diagnosed with bipolar disorder, there are many sources of information that may challenge identity. These include symptoms, diagnosis, medications, and psychotherapy. Challenging information may be intrapersonal (observations of own feelings and actions) or interpersonal (observations of others' behaviors and reactions). Experiencing a challenge to identity creates a need to take some action to maintain or reestablish a sense of a coherent identity. This study found two ways that people respond to information that challenges identity. They may discount the information to protect identity or they may consider and use the information to gradually restructure identity. The study examines factors that influence decisions about how to respond to challenging information, strategies for protecting identity, and the process of restructuring identity.

The process of responding to challenges to identity is an iterative process. The actions taken to respond to challenges provide feedback to the process, itself, affecting whether future incoming information will be seen as challenging. Over time, there is usually a shift from more frequently responding by discounting information to protect identity toward more often using information to restructure identity. The restructuring process involves integrating self-views with challenging information, thereby reducing the discrepancy and, therefore, the challenge. This results in a more stable identity, less often challenged by incoming information. Because less energy is then needed to respond to challenges to identity, that energy is more available for getting on with life.

The dissertation then discusses the implications of this model for future research and its implications for clinical practice of psychotherapy.

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Chapter One

INTRODUCTION

What is it like to have a major mental illness that may include intoxicating and delicious highs, despairing and paralyzing lows, intense and rageful irritability, and exquisitely uncomfortable sensitivity? What is it like to have a mental illness that may cause losses of contact with reality and land you in the hospital? What is it like to see yourself doing things that are definitely out of character, things you cannot control? What is it like to have these episodes interspersed with "normal life"? What is it like to live a life in which these kinds of events can happen unpredictably?

The illness is bipolar disorder, also called manic-depressive illness. Out of one hundred adults, one or two, maybe three, have this diagnosis in one of its variations. We know a lot about the symptoms of bipolar disorder; we are learning more and more about its biochemistry; and, during the last several decades, medications to treat its symptoms have appeared with increasing frequency. All of this has been, and is being, extensively researched and documented. What has not been well studied is what it is like to be the person who is experiencing bipolar disorder. This study addresses that question.

Of course, there are many people who know what it is like for one person to have bipolar disorder. These are people who have "been there" themselves, who have received a bipolar diagnosis. Some of them have even written extremely interesting accounts of their experiences (see, for example, Duke & Hochman, 1992; Jamison, 1995; Logan, 1976). Each of these stories, however, is unique, and it is hard to know what of one person's story might apply to another person diagnosed with bipolar disorder.

It was the goal of this study to use the experience of individuals who have "been there" to understand more generally what the experience of bipolar disorder is like. Are there common threads among people's experiences? Are there concepts that might help us understand, and even predict, what process people are likely to go through in dealing with bipolar disorder?

Questions such as these are most fruitfully approached with qualitative research strategies which are aimed at trying to understand what is going on and how it might usefully be explained. For this study, I interviewed people who had been diagnosed with bipolar disorder. I asked about what had happened to them, what they thought of their illness, what they thought about themselves, and how they made sense of it all. The people I spoke with were extremely generous with their thoughts and their time, and told rich and unique stories. Grounded theory methods and a large investment of time allowed me to analyze this material and discover a process that was common to all of these different stories.

This process can be summarized as <u>responding to challenges to identity</u>. I have modeled this process, using diagrams and words, and these results are presented in the chapters that follow. The model is an abstract representation of a real human process that individuals go through in dealing with bipolar disorder. It is a set of concepts that help to clarify the meaning of a sometimes seemingly chaotic experience. Individuals navigate this process differently, resulting in their unique stories, but the underlying pattern of this process is the similar for all.

The remainder of this dissertation develops these ideas. Chapter Two is a review of relevant literature at the time I began the project, showing that this was, indeed, an unexplored area, and discussing research into related concepts. Chapter Three discusses the methods I used for data collection and analysis. Chapter Four presents the core result of the study, the model of the process <u>responding to challenges to identity</u>. Chapters Five through Eight illustrate and discuss in detail the major parts of the model. These chapters are illustrated liberally with the words of the people I interviewed. Chapter Nine provides a brief summary of the findings. And Chapter Ten discusses implications of the model for future research and for clinical practice.

Chapter Two

LITERATURE REVIEW

Before embarking on this research project, I reviewed the work that had been done in the area, fearing that such an interesting subject might already have been thoroughly explored. I found, however, almost no systematic research on the experiential process of dealing with bipolar disorder. I therefore reviewed research in a number of related areas that I thought might shed light on the process I was interested in. This chapter reflects that literature review.

The chapter begins with an overview of bipolar disorder from a biomedical perspective, briefly summarizing current thinking about symptoms, course, treatment, and cause. This is a large body of research which represents an “outsider’s perspective” (Conrad, 1987) on bipolar disorder, rather than reflecting the point of view of those who experience it. Virtually everyone with a bipolar diagnosis, however, is exposed in some way to this perspective of how others view their illness.

The chapter then moves on to look at what qualitative work has been done that might help in understanding the experience of those who have actually received a diagnosis of bipolar disorder. It focuses on studies that have attempted to portray an “insiders’ perspective” (Conrad, 1987), or “personal knowledge” (Peyrot, McMurry, & Hedges, 1987) of what happens. This section begins with studies of patients’ experience of the process of diagnosis, itself. Because this process has not been systematically studied in the area of psychiatric diagnosis, studies of the experience of diagnosis with a physical illness are reviewed. The chapter then covers qualitative studies that have focused on the experiences of people with bipolar disorder. Because this is a very small literature, the review then broadens to cover qualitative research on the experience of dealing with other serious mental illnesses. There is more research in this area, but it is still rather scant, so the review broadens once again to look at a much larger and better-developed literature on the experience of chronic physical illness. In each case, attention is paid to whether and how these studies deal with views of self and views of illness.

There are a number of other influences that I thought might have an impact on the process of making sense of bipolar disorder, and these are then briefly reviewed. One is the potential for others' views of mental illness to have an effect on the person who has received the diagnosis. Last is the little-studied area of unrecognized and unsanctioned grief in mental illness.

Bipolar Disorder: The Biomedical Perspective

Bipolar disorder is considered to be one of the more serious mental illnesses. During episodes of depression or mania, basic functioning is often severely impaired in the most important life domains. A person may act in uncharacteristic ways, and be left to deal later with the devastating interpersonal, financial, and other consequences. Hospitalization may be required, and psychotic symptoms may be experienced. Because bipolar disorder tends to follow a chronic, recurring course, jarring disruptions of one's planned life course may have to be dealt with. At its extreme, through suicide or dangerous behaviors, the illness may prove to be fatal. Yet, between episodes, most people with bipolar disorder are able to function quite well, often in highly responsible or creative positions. They are likely then to reflect on their situation and its meaning, as would anyone with a serious chronic illness.

Diagnosis of Bipolar Disorder

Bipolar disorder or similar syndromes have been observed and described for centuries, the earliest records coming from classical Greece. Goodwin and Jamison (1990) describe the development of the concept: In this century, Kraepelin (1921/1976), in his detailed descriptions of psychiatric disorders, described manic-depressive illness as a recurrent "circular" psychosis involving mania and melancholia. He subsumed virtually all of melancholia under manic-depressive illness, distinguishing this from dementia praecox (later called schizophrenia) by its course and its prognosis. He described manic-depression as having a fluctuating course, with periods of normality alternating with periods of illness. Dementia praecox was seen as following a course of inevitable ongoing decline. Leonhardt (1957/1979) later made a distinction between bipolar and monopolar forms of manic depression, the first including mania, the second depression only. This distinction between bipolar and unipolar depression was introduced into the Diagnostic and Statistical Manual in its third edition (DSM-III) (American Psychiatric Association, 1980). The term "bipolar disorder", rather than "manic-depressive illness", became more common at that time, although there are those in the field who still prefer the earlier term as being more accurate and descriptive (Goodwin & Jamison, 1990).

Bipolar disorder is classified in the current Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994) as a mood disorder. It is important to remember, however, that in addition to mood changes there is a range of significant cognitive, behavioral, and sensory components also involved in the condition. The diagnostic criteria first specify four types of mood episodes, the presence of which may lead to a diagnosis of bipolar disorder. These are: major depressive episode, manic episode, mixed episode, and hypomanic episode.

A major depressive episode is characterized by symptoms of:

- Depressed mood most of the day, nearly every day
- Markedly diminished interest or pleasure in all or most activities, nearly every day
- Significant increase or decrease (when not dieting) in weight
- Sleep disturbances (insomnia, hypersomnia)
- Psychomotor changes (agitation or retardation)
- Low energy level or fatigue
- Inability to concentrate or make decisions
- Recurrent thoughts of death or suicidal ideation

At least five of these symptoms must be present for at least two weeks, always including either depressed mood or loss of interest or pleasure. Symptoms must be severe enough to cause clinically significant distress or impairment in occupational, social, or other important areas of functioning.

A manic episode, on the other hand, is characterized by:

- Abnormally and persistently elevated, expansive, or irritable mood
- Inflated self-esteem or grandiosity
- Decreased need for sleep
- More talkative than usual or pressure to keep talking
- Flight of ideas or racing thoughts
- Distractibility
- Increase in goal-directed activity
- Excessive involvement in pleasurable activities that have a high potential for painful consequences

At least four of these symptoms must be present for at least a week, always including the elevated, expansive, or irritable mood. If mood is only irritable, at least five symptoms are necessary. Symptoms must be severe enough to cause marked impairment in occupational functioning or in usual social activities or relationships with others, necessitate hospitalization, or include psychotic features.

A mixed episode is one in which the criteria are met for both a manic episode and a major depressive episode nearly every day for at least a week. Symptoms must be severe enough to cause marked impairment in occupational functioning or in usual social activities or relationships with others, necessitate hospitalization, or include psychotic features. Mixed episodes are sometimes referred to as “dysphoric mania”.

A hypomanic episode is a milder form of manic episode. It is characterized by the same symptoms as a manic episode, with several exceptions. The mood disturbance is “clearly different from the usual nondepressed mood”, rather than “abnormal”. Symptoms must last at least four days, rather than a week. Symptoms are *not* severe enough to cause marked impairment in social or occupational functioning, or to necessitate hospitalization. Finally, a hypomanic episode does not include psychotic features.

Specific bipolar diagnoses are based on the presence or history of combinations of these four types of episodes. Bipolar disorder in its "classic manic-depressive form" (Akiskal & VanValkenburg, 1994) is called Bipolar I Disorder. Bipolar I typically involves a history of both manic and major depressive episodes. Bipolar I requires the presence of at least one manic episode, and may include depressed, mixed, or hypomanic episodes as well. A more recently recognized variant of bipolar disorder is Bipolar II Disorder. Bipolar II typically involves recurrent depressive and hypomanic episodes. Bipolar II requires the presence or history of at least one major depressive episode and at least one hypomanic episode, but no history of a manic or mixed episode.

Course of Bipolar Disorder

It is estimated that the lifetime prevalence of Bipolar I is about 1% (American Psychiatric Association, 1994; Jamison, 1999). DSM-IV reports the prevalence of Bipolar II at 0.5%, but more recent studies suggest a rate more like 2-3% (Angst, 1998; Jamison, 1999). Onset is usually in early adulthood, most commonly late teens to late twenties (Goodwin & Jamison, 1990). Although some patients experience only a single episode, for most bipolar disorder is a chronic, recurring illness. People with Bipolar I, if untreated, average 8 – 12 major depressive episodes and 4 – 8 manic episodes during a lifetime (Lam et al., 1999). The number of episodes experienced by people with Bipolar II tends to be higher than for Bipolar I. There is evidence that the length of time between episodes decreases as the number of episodes increases (Goodwin & Jamison, 1990). About two-thirds of manic and hypomanic episodes occur just before or just after a depressive episode (American Psychiatric Association, 1994). There is, however, a wide range in patterns of episodes in terms of type, order, and frequency. Cases with more than four episodes per year are termed "rapid cycling".

Onset of bipolar disorder in childhood is a topic of some controversy, but the diagnosis is being made in children much more frequently than a decade or two ago. The symptoms of bipolar disorder in children may look somewhat different than in adults (Papolos & Papolos, 1999), and early bipolar disorder may be mistaken for Attention

Deficit Hyperactivity Disorder (ADHD) (Papolos & Papolos, 1999; Popper, 1996). It is thought that early onset may be associated with a more severe course of the bipolar illness (Goldberg & Keck, 1999).

Suicide is a serious risk in bipolar disorder. Rates of suicide attempts for those with bipolar disorder are reported to be about double those of people with unipolar depression (Chen & Dilsaver, 1996). The risk is increased if there are mixed episodes (Freeman & McElroy, 1999; Zoltan & Pestality, 1999) or concurrent substance abuse (Jamison, 1999).

Issues in Diagnosis

Diagnosis of bipolar disorder is not always clear or easy, and many patients receive other diagnoses lasting months or years before the bipolar diagnosis is arrived at (Lish, Dime-Meenan, Whybrow, Price, & Hirschfeld, 1994). Bipolar II is often mistaken for unipolar depression, as patients may not recognize hypomanic episodes as problems to complain about (Jamison, 1999). Those with Bipolar II may also have received a prior diagnosis of a personality disorder, commonly borderline personality disorder (Goodwin & Jamison, 1990; McWilliams, 1994). Bipolar I patients have sometimes received a previous diagnosis of schizophrenia, especially if psychotic symptoms are observed during an acute manic episode. Some “agitated depressions” may more appropriately be categorized as bipolar mixed states (Koukopoulos & Koulopoulos, 1999), but differentiating between the two can be difficult (Goldberg & Kocsis, 1999). Finally, one-half to two-thirds of bipolar patients have a history of alcohol or other substance abuse (Jamison, 1999; Sonne & Brady, 1999). Although the substance abuse may have been an attempt to self-medicate uncomfortable symptoms or to intensify pleasurable symptoms of bipolar disorder, it may obscure the bipolar diagnosis (Akiskal & VanValkenburg, 1994; Tohen & Zarate, 1999).

Social and Personal Functioning

The social and personal costs of bipolar disorder can be very high. The marked changes in mood, thinking, and behavior during episodes can have immediate and delayed consequences. An episode may include mood lability, financial extravagance, fluctuations in levels of sociability, sexual indiscretions, or violent behavior (Basco & Rush, 1996), for which one may have to "pay later". Major life consequences reported by high percentages of those with the diagnosis include financial difficulties, divorce or relationship difficulties, alcohol or drug abuse, losing jobs or dropping out of school, and injury to self or others (Lish, et al., 1994).

Despite these common problems, most people with bipolar disorder return to a fully functional level between episodes (American Psychiatric Association, 1994). Many, after taking time off during an episode, return to jobs and perform as well as they had previously. Some function at particularly high levels of productivity and creativity (Jamison, 1993). Even during nonsymptomatic periods, however, many people with bipolar disorder are still dealing with implications of the illness. They may be "cleaning up" the results of uncharacteristic behaviors during an episode; they may experience worry or concern about the future course of the illness; they may be actively monitoring possible symptoms or problematic situations to try to avoid or mitigate recurrences. Some people with bipolar disorder do not experience periods of full recovery. According to the DSM-IV, about 20-30% continue to display mood lability and interpersonal or occupational difficulties (American Psychiatric Association, 1994). Other studies estimate even higher percentages with continued psychosocial impairment (Callahan & Bauer, 1999).

Treatment with Medication

There are two phases of medication treatment in bipolar disorder, addressing acute symptoms during a manic or depressive episode, and ongoing maintenance treatment (American Psychiatric Association, 1996). During an acute episode, medication treatment is directed at eliminating disabling symptoms and restoring functioning. This may involve mood-stabilizing, antidepressant, or antipsychotic medications. Hospitalization may be necessary. Electroconvulsive therapy (ECT) is sometimes used when medications are not effective.

Most patients are also offered maintenance (prophylactic) medication aimed at preventing future episodes. The best-known of these is lithium, which was discovered to be effective as a mood stabilizer in 1949, and became generally available in the United States in the 1960s. For many patients, this is highly effective at controlling both manic and depressive episodes, and allows a much more normal life course. Lithium, however, requires fairly intensive medical monitoring. It may have unpleasant side-effects, some of the most complained-about being cognitive confusion and weight gain. It also has turned out to be ineffective in up to 40% of cases (Prien & Potter, 1990), especially those experiencing mixed states (Boland & Keller, 1999; Freeman & McElroy, 1999) and rapid cycling (Dunner, D.L., 1999). In the 1980s, anticonvulsive medications (carbamazepine, valproate) were found to have mood-stabilizing effects, and they are now quite frequently prescribed for bipolar disorder. Current research also suggests that the newer atypical antipsychotics (olanzapine, risperidone) may have mood-stabilizing properties, and may be effective for patients resistant to other medications (Keck, Akiskal, Fawcett, & Schatzberg, 2000). Antidepressants are also used to treat and prevent depression in patients with bipolar disorder. This must be done with care, however, as virtually all of the antidepressants have been associated with an increased risk of manic episodes in bipolar patients (American Psychiatric Association, 1996). It is not uncommon for combinations of two or more of these medications to be used if one alone does not control symptoms.

“Medication compliance” is often seen as a particularly troublesome issue in bipolar disorder. It is reported that most patients being treated for bipolar disorder have “gone off their meds” at least once, often with a recurrence of a mood episode soon following. About 20-50% of patients taking lithium are noncompliant in the first year (Goodwin & Jamison, 1990). Many patients also experiment with dosages to see if they can get along on less. Reasons for this include unacceptable side effects and dislike of medication in general (Callahan & Bauer, 1999). Additional reasons more specific to bipolar disorder are reported to be "denial" of the illness, and missing enjoyable hypomanic highs. Unfortunately, when lithium is discontinued and later restarted, it is sometimes no longer as effective as it was the first time around (Goldberg & Keck, 1999).

Treatment with Psychotherapy

With the strong emphasis on medication treatment, psychotherapy for bipolar disorder has sometimes been virtually ignored. More recently, however, a need for psychotherapy is being acknowledged, and specific treatment approaches are being developed. These include individual therapies (Basco & Rush, 1996; Lam, et al., 1999; Callahan & Bauer, 1999; Jamison, 1991; Miklowitz & Frank, 1999), treatment involving family members (Miklowitz, Goldstein, & Wynne, 1997), and group therapy, both outpatient (Bauer & McBride, 1996), and inpatient (Pollack, 1995c). Virtually everyone advocates psychotherapy coupled with drug therapy. Psychotherapy may deal with medication-related issues (problems not solved by medications, problems actually caused by medications, decisions about taking medications). It may deal with coming to terms with the diagnosis, with making sense of past and future, with monitoring symptoms to try to avoid recurrences, and with the myriad issues human beings face (many of which may be made more complicated in the presence of bipolar disorder.)

Causal Theories

Bipolar disorder may be a spectrum of closely related conditions with multiple and overlapping determinants. There is very strong evidence for a genetic vulnerability for bipolar disorder. The offspring of a parent with bipolar disorder has almost a one in four chance of developing either bipolar disorder or a recurrent major depressive disorder (Rush, et al., 1991, cited in Basco & Rush, 1996). Twin and adoption studies also provide strong support for heritability (American Psychiatric Association, 1994; Torrey, et al., 1994).

The biochemistry of bipolar disorder has been extensively researched (see Goodwin & Jamison, 1990; Young & Joffee, 1997), with indications of neurochemical dysregulation in multiple areas. A definitive mechanism has not been isolated to date, and it is likely that there are multiple processes involved.

Major life events sometimes appear to "trigger" an episode, especially the first or early episodes. After that, the disease appears to take on "a life of its own", with episodes seeming less related to environmental events (Basco & Rush, 1996; Post & Weiss, 1997). One hypothesized explanation for this is "kindling". Early episodes may have an electrophysiological kindling effect, lowering the threshold for relevant brain processes in the future (Post & Weiss, 1997).

Bipolar disorder may also be related to a pre-existing cyclothymic temperament or personality (Akiskal & VanValkenburg, 1994; Goodwin & Jamison, 1990). This may be associated with characteristic early experiences and patterns of defense mechanisms (McWilliams, 1994; Moore & Fine, 1990).

The Evolving Bipolar Spectrum

In addition to Bipolar I and Bipolar II, further categories of "soft bipolar disorder" have been proposed by Akiskal and colleagues (Akiskal & Pinto, 1999). He suggests that there is a continuum of bipolar disorders which are less obvious than "classic manic-depression", may masquerade as other problems, but which may respond to mood-stabilizing medications. He proposes Bipolar III (hypomania triggered by taking antidepressants) and Bipolar IV (late life depressive episode superimposed on a hyperthymic temperament). In between these, he also proposes Bipolar II ½ (short hypomanic episodes with subsyndromal depression, similar to what is categorized in DSM-IV as Cyclothymia) and Bipolar III ½ (bipolar episodes closely associated with substance abuse).

The current study includes interviews only with individuals diagnosed with Bipolar I or II. This section and the previous one, however, reflect the changing ideas and the uncertainty present in the professional knowledge about bipolar disorder.

The Experience of Receiving a Diagnosis

What is it like to receive a diagnosis of a serious mental illness? What processes does this set in motion? These questions have not been systematically researched for bipolar disorder, or even for psychiatric diagnosis in general. A number of studies, however, have focused on this process of diagnosis in chronic physical illness.

One intriguing finding is that the experiences of patients and physicians involved in the same process of diagnosis may be very different. In a qualitative study of the diagnosis of Parkinson's Disease, Pinder (1992) contrasts the experiences of physician and patient. For physicians, diagnosis represented a point of "maximum theoretical coherence", while for patients it was a time of "maximum experiential incoherence". For the physicians, there were feelings of relief at a difficult mystery solved, and a sense of being enabled to get down to the more tangible business of treatment. They thought that their patients were also pleased at having a puzzle solved. The patients, however, saw the predictability of their lives shattered, and reported complex emotional reactions including shock, fatalism, turmoil, and confusion. They considered this a significant turning point in their lives, leading to questioned identities, diminished futures, and ambivalence about treatment.

Diagnosis is sometimes seen as the end of uncertainty (Holohan, 1977), but the uncertainty following diagnosis may actually be greater and more widespread than the uncertainty preceding diagnosis. Cohen (1993), in her study of parents of children receiving diagnoses of serious chronic illnesses, observed a "spread of uncertainty" following diagnosis. One type of uncertainty, diagnostic uncertainty, is relieved by receiving a diagnosis. The diagnosis, however, brings about many new and pervasive uncertainties, which she lists as existential, etiologic, treatment, situational, and biographical uncertainties. Diagnosis thus initiates a process of dealing with multiple unknowns.

The role, power, and authority of physicians in diagnosis appears to be strong and acknowledged, but not absolute or unchallenged. Scrambler and Hopkins (1986) discuss the power of the diagnostic moment for their interviewees with epilepsy. Many expressed an awareness that “a doctor’s utterance... had in an important sense made them into epileptics.” But, because they saw this new status as potentially stigmatizing, many negotiated for “less threatening” alternative diagnoses, using the fact that the doctor could not clearly demonstrate the etiology of their symptoms. The doctor’s pronouncement is seen as life-changing but, at the same time, is not necessarily completely accepted by patients. Hunt, Jordan, and Irwin (1981) also address the impact of the physician’s diagnostic statements, noting that, for the women they interviewed, the physician’s diagnosis was only one of several important inputs for arriving at an explanation of what was wrong with them. Corbin and Strauss (1987), on the other hand, emphasize the impact of “the time of diagnostic announcement, when past and future come crashing into the undesirable or dreaded present.” They suggest this time of shock is followed by an extended “recasting of biography”.

These studies suggest that diagnosis of physical illness is not so much an act as a more complex interaction or process. The communication of the name of the diagnosis seems to be followed by a period of disruption, confusion, or uncertainty. This may be the beginning of processes which are a part of the illness experience and are aimed at resolving this uncomfortable state and substituting meaning for chaos. The wide difference in perspectives between doctor and patient may make it quite difficult for the doctor to comprehend the lived experience of the patient following a serious diagnosis.

Does a similar process take place with psychiatric diagnosis? This has not yet been specifically studied. In a broader study of people taking part in a depression support group, Karp (1992) does make some observations suggesting the importance of diagnosis. Many group members dated themselves from the time of their first diagnosis, and saw this as an “important symbolic benchmark”.

The Experience of Bipolar Disorder

One important purpose of reviewing the literature was to find out what, if anything, had been written about the experience of bipolar disorder from the point of view of individuals who have “been there”. There are a number of very rich personal accounts by individuals who have been diagnosed with bipolar disorder (see, for example, Duke & Hochman, 1992; Jamison, 1995; Logan, 1976). Occasionally, the voice of a person actually diagnosed with a mental illness makes it into a professional journal; a brief article by Lundin (1998) describes his experiences living with bipolar disorder. Family members have also written about bipolar disorder (Berger & Berger, 1991; Steele, 1998), but these accounts focus more on the family experience than on the experience of the person with the bipolar diagnosis. Systematic studies researching the experience of bipolar disorder turn out to be quite rare. There is little to be found in the research literature about views of self or views of illness in bipolar disorder. Lam et al. (1999) also searched, and found that “sense of self in manic depression is an interesting issue which has not been investigated” (p. 70). One lone researcher has focused her qualitative work on the study of the experience of people with bipolar disorder. Her work does touch on views of illness, and is summarized below.

Pollack (1995a, 1995b, 1996) was particularly interested in understanding processes that could help her to design group treatment programs that would be helpful to people hospitalized with bipolar disorder. She interviewed inpatients in a psychiatric hospital about their informational needs and self-management activities related to bipolar disorder. She found that patients desired more information about their diagnosis, about managing the disorder and their daily lives, and about relating to others and to themselves (Pollack, 1995a). She also found (Pollack, 1996) that not all patients were equally desirous of such information. She observed three information-seeking states among her interviewees, which she labeled “information seekers”, “information receivers”, and “information rejectors”. She suggests that these information-seeking states are related to level of acceptance of the bipolar diagnosis, and may shift over time and across situations. Pollack (1995b) proposes a model of information use in bipolar disorder with four phases: 1) “realization of a need” for information, 2) “information-seeking”, 3) “critical juncture in treatment” leading to motivation for self-management, and 4) “self-management”. She suggests this process actually operates in a circular fashion, with self-management bringing about further needs for information. She also found barriers present in all phases, the most common being “denial”.

Pollack thus suggests that view of illness (acceptance vs. denial) may be central in a range of behaviors related to treatment and decisions about self-care. The “phenomenon of how people achieve and sustain an acceptance of the disorder”, however, is an area that she feels still needs to be investigated and understood. Pollack (1995b) also hypothesizes that “valuing of self” is important in decisions leading to self-management, but she does not study this area specifically or elaborate it in her model. This set of grounded theory studies, while looking quite narrowly at views of self and views of illness, is nonetheless suggestive of the importance of these factors in the experience of bipolar disorder.

The Experience of Other Serious Mental Illnesses

Looking at the lived experience of people with serious mental illness in general, rather than just bipolar disorder, reveals a bit more research, but this is still not a well-studied area. Interviewing people with mental illness is apparently not a very appealing prospect for many researchers. Dworkin (1989) studied interviewer preferences for 18 respondent groups, and found that persons with mental illness were rated next to last, below convicted felons, people with AIDS, and cancer patients. Despite this, a number of researchers, some of whom tell us that they, themselves have experienced serious mental illness (Deegan, 1988; Karp, 1996), have taken on this topic.

Davidson and Strauss’s (1992) study focuses specifically on sense of self in “recovery” from severe mental illness. They interviewed people with prolonged psychiatric disorder (schizophrenia, schizoaffective disorder, major affective disorder), and heard repeatedly about the importance of rebuilding an identity. They see "rediscovery and reconstruction of sense of self as active and responsible", as central in their model of the improvement process. The model breaks this into four phases: 1) discovering the possibility of possessing a more active sense of self, 2) "taking stock" of strengths and weaknesses of this self, 3) putting into action some aspects of the self, and 4) using an enhanced sense of self to provide some degree of refuge from one's illness and milieu. As part of the first phase, they discuss several identity-related processes including finding unaffected aspects of self, finding previously unknown aspects of self, and acceptance of illness as an entity separate from the person. It is implied that before the first phase one has somehow lost this possibility of an active self, but the process of this loss and movement toward rebuilding was not studied or included in the model.

Karp (1992, 1994, 1996) has done qualitative research based on interviews of people with depression. He takes a broad look at the "career" of living with depression, and proposes a model with four (sometimes five) stages. These are: 1) "inchoate feelings of distress" (not labeled as depression), 2) coming to the conclusion that "something is really wrong with me", 3) "having a crisis" (which thrusts one into the world of therapeutic experts), 4) "coming to grips with an illness identity", and, for some people, 5) seeing depression as something you can get past (Karp, 1994; 1996). Karp's phases can be seen as a progression of views of illness. He also implies some interaction with views of self. Stage two represents a shift from identifying the problem as in the environment to seeing it as in oneself. Stage three may involve coming to see oneself as "damaged goods". Stage four, he says, involves some "reformulation of identity", but this process is not elaborated. He states that most of his interviewees wanted to define their problem as biochemical, but did not want to define themselves as mentally ill (Karp, 1994).

Estroff and her colleagues (Estroff, 1992; Estroff, Lachicotte, Illingworth, & Johnson, 1991) also examined how people see their illness and how they label themselves. They interviewed people with severe, persistent mental illness, selecting specifically the most impaired who were judged likely to apply for disability benefits. They discovered five “illness-identity accounts”, and looked at how this related to whether people labeled themselves as “mentally ill” (Estroff, et al., 1991). The most common account was termed “medical/clinical”, in which it was “bodily material, such as biochemicals, genes, or the brain, which was imbalanced or malfunctioning”. These people used clinical terminology, and words such as illness, sickness, and symptom. In contrast to Karp’s findings, this group did tend to identify themselves as “mentally ill”. A second group gave “emotional/developmental” accounts, locating the problem in the psyche, with an imbalance or injury to feelings or self-worth. These people did not use clinical terminology, but referred frequently to feelings and relationships with parents. They tended not to identify themselves as “mentally ill”. Some gave a combination account of illness (both medical and emotional), and did identify as mentally ill. People giving two other illness accounts almost never identified themselves as mentally ill. These accounts were “social/situational”, in which the problem is located externally, such as lack of money or a job, and “religious/spiritual”, in which the problem is located in the spiritual realm, sometimes internalized, such as possession.

Chafetz (1996) tested a “life history approach” for interviewing outpatients with severe mental illness (schizophrenia, schizoaffective, bipolar, recurrent depressive disorder). With this approach, she looks very broadly at life patterns, which she summarizes in five stages: 1) process of “coming into the system”, 2) symptom management: “staying out of the hospital”, 3) negotiating treatment regimens, 4) use of environmental supports, and 5) networks in the system. The first stage involves some issues of views of self and views of illness, including “alterations in personal identity”, and a “period of denial or difficulty coming to terms with a life-altering disorder”. The later stages involve managing the illness, and are built on the first stage.

Young and Ensing (1999) interviewed outpatients diagnosed with a severe mental disorder in a study “designed to explore the recovery construct from the consumers’ perspective”. Their model of this process consists of three phases: 1) initiation of the recovery process: “overcoming stuckness”, 2) middle phase: “regaining what was lost and moving forward", 3) later phase: "improving quality of life". In this conceptualization, views of illness are dealt with in phase one, which includes "accepting the illness". Views of self are dealt with in phase two, which includes "learning and self-redefinition".

Lorencz (1991) did multiple interviews with four chronic schizophrenics while they were in the hospital and thinking about discharge. The process that emerged she calls "becoming ordinary", or striving to fit in. She summarizes her findings with the following four phases: 1) extended past – successful management in community, 2) preadmission past – "not making it" in the community, 3) admission to the hospital – "being in boot camp", 4) readiness to return to the community – anticipating mastery. Her model does not include components of views of illness or views of self, except that "positive self-regard" is seen as an indicator of anticipating mastery.

Pettie and Triolo (1999), in an essay with case examples, suggest the importance of two processes in recovery from psychiatric disability. One is a search for identity, following an identity crisis or identity confusion. The other is finding a meaning in the illness. They have not, however, gone on to systematically study these processes.

Most of the models arising from these qualitative studies of the experience of mental illness relate, in one way or another, to views of self and/or views of illness. Some of them take a very broad view of the experience ("careers", "life histories"). Others look at processes quite late in the experience ("recovery"). None really look specifically at the processes of how views of illness develop from the time of diagnosis, or how views of self are affected.

In a different kind of article, Deegan (1988), now a professional in the mental health field, compares her own experience of recovery from schizophrenia with that of a paraplegic man. She finds many similarities. Both were told as teenagers they had "incurable maladies", and experienced denial and rage. Both found that "time did not heal", and they experienced despair, anguish, and "gave up". Both eventually saw the gradual development of a fragile flame of hope, something she says she cannot really explain, which led to a willingness to act. The paradox of recovery, she says, is that "in accepting what we cannot do or be, we begin to discover who we can be and what we can do." This statement from someone who has "been there" points to an intertwining of views of self and views of illness. Deegan's article also suggests that dealing with a mental illness may, in many ways, be similar to dealing with a physical illness.

The Experience of Chronic Physical Illness

Although the literature on experiencing mental illness is fairly sparse, there is a much more fully developed literature on experiencing chronic physical illness. Grounded theories on chronic illness have not been extended to mental illness [see reviews by Charmaz (2000) and Conrad (1987)], but it is sometimes suggested that the experiences may be similar. Deegan's (1988) personal account points in this direction. When Kleinman (1981) discusses the understanding of individual illness meanings as crucial in effective treatment, he includes both mental and physical illness. A recent book on the treatment of bipolar disorder (Basco & Rush, 1996) actually grew out of the experiences of one of the authors (Basco) in designing treatment programs for insulin-dependent diabetics. She tells us in the preface to the book that she saw many similarities between bipolar disorder and diabetes, "such as the chronic nature of the illness, the need for daily medication management, the importance of symptom monitoring and early intervention, the difficulty that patients experience in following treatment recommendations, and the psychological adjustment to a chronic illness" (Basco & Rush, 1996, p. xiii).

Qualitative studies of the experience of chronic physical illness look at the people who have the illnesses, and thus focus very little on symptoms, and very much on people's thoughts and feelings about the meaning of their illness, about themselves, about treatment decisions, about living their lives. This is based on a distinction between the concepts of disease and illness (Conrad, 1987; Kleinman & Seeman, 2000; Charmaz, 2000). As Kleinman puts it, the term disease refers to a "practitioner's construction of patient complaints in the technical terminology of a particular healing system", whereas illness is a much more "experience-near" category, focused on personal and social meanings and experiences (Kleinman & Seeman, 2000, p. 231). Some of these studies of the illness experience divide that experience into a number of chronological stages or phases. Often one or more of these phases involves issues of how self or illness are viewed. Other studies have focused more specifically on issues concerning views of self and views of illness. This section of the literature review begins with studies that focus on views of illness, then moves on to those involving identity or views of self. As will be seen, these are not always easily separable.

Views of Illness

How do people arrive at their views of their illnesses? Qualitative studies suggest that this is a much more complicated process than simply hearing a diagnostic statement and accepting it. Constructing an illness explanation appears to be a dynamic interactive process, which begins before the first diagnostic consultation and continues for at least some months thereafter (Hunt, et al, 1989). Hunt and her colleagues found that the women they interviewed came to their first medical consultation with some fairly elaborate ideas about what was wrong. Sources of these ideas included family, friends, previous observations and experiences. In most cases, "the physicians' diagnoses... were not simply accepted or rejected by patients as explanations for their symptoms, but rather were transformed and incorporated, in whole or in part, into the illness concepts employed prior to consultation" (Hunt, et al, 1989, p. 950). They found that people seemed to "try on" the physician's explanation and, in most cases, to try out the prescribed treatment regimen, but then began to adapt these to fit with previous ideas and with the demands of their daily lives. If treatment instructions proved difficult to follow, due to busy schedules or other demands or preferences, patients adjusted the regimen to fit their lives. They then adjusted their illness explanations to fit their treatment decisions. Other influences on illness explanations included ongoing interactions with friends and family, and major life changes (e.g., a new job) which were incorporated as reasons for improvement or relapse. The interaction with the physician, therefore, is only one of many inputs to the process of constructing an illness explanation. The patient judges the adequacy of the explanation, not by how it matches with diagnostic criteria in the medical world, but by its usefulness in everyday life.

Comaroff and McGuire (1981) also found that the naming of an illness by a physician was only one aspect of coming to understand the illness for parents of children diagnosed with leukemia. The central experience for these parents was uncertainty, followed by a search for meaning. Ambiguity resulted from physicians' inability to really explicate etiology or explain the unpredictability of treatment results. Parents searched for an explanation for the onset, trying to figure out both the immediate biological cause, and the "more ultimate cause" (Why us?, Why now?). Although no fault was implied by physicians, parents searched their lives for potential explanations (an x-ray, chemical exposure). Their view of the illness begins to develop with the physician's diagnostic statement, but does not end there.

A distinction between "personal" and "professional" knowledge is made by Peyrot, et al. (1987) in reporting on how people with insulin-dependent diabetes construct conceptualizations of their illness. "Experience becomes the standard against which diagnosis is assessed, and diagnostic accuracy is discounted unless it confirms the manifest reality of the symptoms experienced" (Peyrot, et al., 1987). Views of illness are a function of both professional medical knowledge and personal experiential knowledge.

In interviewing people with epilepsy, Scrambler and Hawkins (1986) found that "'having seizures' was less salient to [their] respondents than 'being' epileptic" (p. 33). Their view of the illness was influenced as much by its psychosocial correlates as by its symptoms. They viewed the illness as highly stigmatizing, and therefore as a source of a kind of "*ontological* (rather than moral) inferiority" (Scrambler & Hawkins, 1986, p. 33).

Charmaz (2000) notes that people can construct explanations for their distress based on many factors other than disease. The effects of "stress" are frequently reported by the media, and people who are overburdened may make sense of their symptoms as stress reactions to their situations. She also cites a study by Weitz (1991) in which interviewees who did not know their positive HIV status came up with other plausible explanations for their symptoms (drug use caused diarrhea and weight loss, the Arizona heat caused night sweats).

When Bury (1982) interviewed people recently diagnosed with rheumatoid arthritis, he found that they felt a “need to *complete* knowledge gained from specialist sources; a need to tie in formal knowledge with the person’s total biography” (p. 174). These patients also began with the physician’s diagnostic information, but when they realized that the medical knowledge was incomplete, that the cause was not known, that treatment was based on a kind of practical trial and error rather than strictly dictated by the diagnosis, they began individual processes of making sense of this incomplete view of illness. Part of this process was figuring out a “cause” (familial transmission, emotional upset, major life events) for the onset of the illness. They also came to see that “the main issue was going to be learning to live with it”, viewing the illness as something to be coped with rather than something to be cured. With this view of illness, medical intervention is seen as important, but limited.

Views of Self

Qualitative researchers in the field of chronic illness have argued that a “medicalized view of suffering” is much too narrow to capture the broader meaning and significance of suffering for those who are ill (Charmaz, 1983). They point to effects beyond the physical, beyond symptoms. Charmaz (1983), who interviewed people with a variety of chronic diseases, proposes that a “loss of self” is actually experienced by many ill persons. She suggests that valued attributes of the self-concept are maintained by empirical validation in everyday life. The self-images reflected during chronic illness may be different from, and incompatible with, the previous positive aspects of identity. She lists four aspects of chronic illness that contribute to these changed self-images and loss of self. These are: leading restricted lives, experiencing social isolation, being discredited, and burdening others. She suggests that this process may be cumulative over time, as persons experience continued losses.

Corbin and Strauss (1987) also speak of a loss of self in the chronically ill. “When people are unable to complete actions enabling them to carry out tasks associated with various aspects of self, then certain aspects of self are, metaphorically speaking, ‘lost’” (p. 264). Not all aspects of self are lost, and the extent of loss is determined by “the number of aspects of self lost, their salience, and the possibility of comeback... What is lost is the conception of wholeness about who one is” (p. 272). They go on to describe a process of “identity reconstitution”, which includes testing of one’s limitations, reestablishing life priorities, giving new salience to intact activities, and receiving validation from others.

A “biographical disruption” is how Bury (1982) describes the results of chronic illness. Symptoms and diagnosis shake one’s taken-for-granted assumptions about the course of one’s life, about possibilities for future and present, about meanings of the past, about current abilities and daily activities: in many ways, about who one is.

A number of researchers discuss the range of potential outcomes for views of self as people with chronic illnesses struggle to reconstitute their identities. Charmaz (1987) observed a hierarchy of identity goals for her interviewees: 1) “supernormal social identity”, 2) “restored self”, 3) “contingent self”, and 4) “salvaged self”. She observed that people often begin by trying to do even more than before their illness, and then gradually revise their identity goals downward as the illness progresses.

Yoshida (1993) interviewed adults with spinal cord injuries (paraplegics), and observed a pattern of changing views of self. She suggests a dynamic process of identity reconstruction that moves back and forth like a pendulum in a process that may take months or years. She observed five “identity views”, which ranged from “the former (nondisabled) self” to “the disabled identity as total self”. Her interviewees tended to begin at one end of the continuum by trying to maintain the former self, then moved to the other end, seeing the disabled identity as total self. This is followed by a reverse in direction to a “supernormal self”, not including all of the former self, but taking on extraordinary activities and refusing help from others. Then there is another reverse in direction to a view of the disabled self as a part of the total self, and finally a shift back to a “middle self”, which acknowledges disability and incorporates nondisabled aspects of self. Yoshida also suggests five processes that seem to influence this pendular movement of self-view. These processes are: 1) “loss” (of the nondisabled self), 2) “sustaining” (aspects of the nondisabled self), 3) “integration” (reclaiming lost aspects of the nondisabled self, along with the initial process of inclusion of the disabled self), 4) “continuity” (of the nondisabled self – actively carrying through aspects of the nondisabled self in the reconstruction process), and 5) “development” (ongoing maturation of the total self and the continuing process of inclusion of the disabled self). Her study is unusual in that it looks at both the process and the potential outcomes of the identity change phenomenon.

Tewksbury and McGaughey (1998) studied identity transformations in persons with HIV disease. They suggest that their interviewees also experienced the kind of bi-directional identity changes proposed by Yoshida (1993). They observed a first response of “catastrophizing”, moving to “minimizing and ignoring”, and then moving to one of three “adaptation outcomes” (“Being HIV Positive”, “Living with HIV”, or “living as a Person with AIDS”). It is interesting to note that, in the results of this study, views of self and views of illness are intimately linked.

Shapiro, Angus, and Davis (1997) also found a close link between views of changes in identity and views of illness. They interviewed cancer patients, and observed a wide variation in perceptions of change in sense of self, from none (“back to normal”) to total (“rebirth”). These differences were related to meanings given to the illness experience (physical disease vs. signal to change), and these meanings, in turn, affected approaches to self-care. Despite the variations, Shapiro et al. found shared characteristics in the *process* of construction of meaning for the experience.

Charmaz, in her more recent work (1991, 1995), suggests a variety of modes that people select for living with chronic illness including ignoring it, minimizing it, struggling against it, reconciling self to it, embracing it, adapting to it (Charmaz, 1995b), incorporating it, or accepting it (Charmaz, 1991). Each of these, she says, involves an interaction between threatened identity and views of illness. An individual may use some or all of these modes at different times. She suggests the potential for movement from ignoring and minimizing to adaptation as people regain a sense of wholeness and identity in the face of loss.

“Denial”, the mode that Pollack (1995a, 1995b, 1996) discusses for bipolar disorder, has also been discussed in relation to chronic physical illness. Charmaz (1991) discusses denial as a “label”, seeing the “construction of ‘denial’” as often based on others’ judgments of ill people’s behavior. Noncompliance with medical regimens is often seen as reflecting denial of illness. Peyrot, et al. (1987), however, in their study of people with diabetes, found that many “noncompliant” interviewees were actually making attempts at “self-regulation” of symptoms, accepting, not denying, that they had an illness. During illness, one’s view of self may remain relatively unaffected if one’s illness is viewed as acute. Leventhal, Idler, and Leventhal (1999) suggest that people ask early on, “is it acute (not me)? Or is it chronic (me)?” Viewing one’s illness as acute, when physicians view it as chronic, may also be taken as denial. Charmaz (1990) suggests that such behavior is also understandable as protecting valued aspects of one’s identity.

In an attempt to develop a more general model of experiencing chronic illness, Morse and Johnson (1991b) have reviewed qualitative studies of this process in a variety of diseases and contexts. In their Illness Constellation Model, they define the illness experience as a four-stage process: 1) “stage of uncertainty”, 2) “stage of disruption”, 3) “stage of striving to regain self” (this includes striving to make sense of the illness, and negotiating to preserve identity), and 4) “stage of regaining wellness”. For them, issues of views of self and views of illness are dealt with in the third stage.

The literature on chronic illness has moved progressively from an “outsider’s” to an “insider’s” perspective (Conrad, 1987). As Charmaz (2000) summarizes this development, “a research literature that began with role structure and deviance [the “sick role”] moved on to patient career and negotiation, then to managing illness and stigma, followed by increased emphasis on self and identity. With each shift, the literature came closer to the experiencing subject” (p. 278).

Both views of self and views of illness are clearly repeated themes in qualitative studies of the experience of chronic illness. As can be seen, the attempt to divide this section of the review into results related to views of illness and those on views of self was not particularly successful, as many studies discuss both and suggest or imply that there is an interaction of some kind between them.

Effects of Others' Views of Mental Illness

Views of illness and views of self are, in one sense, ideas held by individuals, but they can also be seen as developing out of interactional processes involving others. This has already been alluded to in some of the studies reviewed above (Hunt, et al., 1989; Charmaz, 1983). What others think or, more precisely, what others are perceived to think may affect views of one's self or illness.

Mental illnesses are commonly viewed as stigmatizing conditions. In a recent U.S. survey, 65% agreed that "there is still a lot of stigma attached to mental illness"; only 6% disagreed (Borinstein, 1992). Stigma related to mental illness has been fairly extensively studied (see review by Hayward & Bright, 1997). The extent of stigma, and its effect on persons diagnosed with mental illness, however, is still unclear. A variety of types of studies do show negative attitudes toward those with mental illnesses. Some indicate this is decreasing, while others suggest the opposite. Studies of mental patients' views of "the mentally ill" show that their attitudes are just as negative as those of the general public (Hayward & Bright, 1997).

The original proposition of labeling theory (Scheff, 1966), that the mental illness label is actually the key cause of the symptoms, has not been well supported. Some studies, in fact, suggest that acceptance of the mental illness label is associated with more positive functioning (Warner, et al., 1989). A "modified labeling theory" suggests that a mental illness label can have beneficial effects by leading to psychotherapy and drug treatment, but may also have negative effects on psychological and social functioning (Link & Cullen, 1990). As with the other topics reviewed here, however, almost none of the many studies of stigma or labeling attempt to look at the phenomena from the perspective of the person with the stigmatizing condition.

An exception, from the chronic illness literature, is the interview study of people with epilepsy done by Scrambler and Hopkins (1986). They distinguish between “enacted stigma”, instances of discrimination based on perceived difference or unacceptability, and “felt stigma”, the fear of enacted stigma and the sense of shame associated with the diagnosis. They note that felt stigma does not appear to arise from experiences with enacted stigma. While nine out of ten interviewees experienced felt stigma, only one in three could recall any enacted stigma. They suggest that felt stigma was often learned in the family of origin, with parents (trying to be protective) acting as “stigma coaches”. This resulted, for many, in a policy of keeping their diagnosis a secret, thereby decreasing the opportunities for enacted stigma, but also making the salience of felt stigma pervasive and disruptive in their lives.

People’s decisions about disclosure of their stigmatizing conditions reflect their perceptions about what others think. Limandri (1989) has studied this from the discloser’s perspective. Her interviewees also reported shame and felt stigma about their conditions. Disclosure usually followed a kind of cost/benefit analysis, anticipating possible responses, and comparing what they could lose with what they could gain. There was often a testing of the water with a “hint” of some kind before a full disclosure of the stigma-related information. Charmaz (2000) also describes a “calculus of telling”, involving an evaluation of “relationships, resources, control, and especially risks.” When people decide that telling is too risky, this felt stigma may lead to limiting social relations and restricting interpersonal involvements (Charmaz, 1991).

Without the operation of stigma, per se, others’ views may have a discrediting effect on an ill person’s definition of self. This may happen when one compares oneself with the expectations of important others (concerning family role functioning, for example), and comes up short (Charmaz, 1983). It may also happen when comparing oneself to cultural standards of bodily perfection and feeling shame when one obviously does not measure up (Charmaz, 1995b).

Unaddressed questions remain. How do people with mental illnesses perceive others' views of their conditions and of them? Does this affect their views of their illnesses and of themselves? Do people perceive mental illness to be stigmatized in some "special" way, and what effect does that have?

Unrecognized and Unsanctioned Grief

If an experience involves a "loss of self", associated with other major losses such as jobs, relationships, important social roles, or functioning of valued aspects of oneself, one might wonder if grieving would be an important part of the process of dealing with that experience. The process of grieving has been well studied in the context of losing a loved one to death, or anticipating one's own death through illness (Kubler-Ross, 1969; Littlewood, 1992). Charmaz (1987), in her study mentioned earlier, also suggests that people with chronic physical illnesses repeatedly mourn lost aspects of self as they revise their identity goals downward.

For those diagnosed with major mental illnesses, however, this has not been studied. There have been a number of studies of grief in *family members* of people diagnosed with major mental illnesses who are dealing with losses in their relationships (Solomon & Draine, 1996; MacGregor, 1994; Miller, et al., 1991), but none of the grief process in the patients, themselves. Even in non-research mental health literature, the grieving process is rarely mentioned as part of the process of coming to terms with a psychiatric diagnosis. One exception is Virginia LaFond, now a social worker and herself recovered from a major mental illness, who has recognized grieving as an important process in herself and her patients. She notes that "the occurrence of schizophrenia, mood disorder and other mental illnesses have, in general, not been considered apt fodder for grief work" (LaFond, 1998). She goes on to list five major dimensions of loss to which grief would be an appropriate response: 1) the illness itself, 2) losses related to treatment efforts, 3) material losses: residence, income, career, job changes, 4) relationship losses, and 5) loss related to sense of self. She thus relates grieving to both views of illness and views of self. She has also written a self-help book aimed at patients, families, and practitioners (LaFond, 1994), encouraging them to explicitly make use of the grief concept in treatment. She has not, however, systematically researched patients' experiences in this area.

Losses which are not recognized by society, for which there are no mourning rituals, which are grieved in isolation, often accompanied by shame or stigma, have been referred to as disenfranchised, unrecognized, or unsanctioned losses (Doka, 1989; Pine et al., 1990). The disenfranchised grief that results is thought to tend to be frustrated or disrupted (Hocker, 1990). Responses to losses experienced by those diagnosed with mental illnesses would seem to fit in this category of disenfranchised grief, although they remain unrecognized as such even by those who write about this topic. A further complication of examining grief in major mental illness is that its expression may be seen by others simply as further symptomatology of the illness (LaFond, 1998).

Chapter Summary

The literature review made it clear to me that little work had been done on the lived experiences of people diagnosed with bipolar disorder. The area was still clearly open for exploration. Fruitful qualitative research had, however, been done in several related areas, particularly on the experiences of people with chronic physical illnesses. This suggested that qualitative studies of experiences of mental illness might also be quite productive.

Chapter Three

METHOD

The purpose of this study was to come to an understanding of a phenomenon that often appears quite chaotic, the experience of people who have been diagnosed with bipolar disorder. I was interested in explaining commonalities in what seem to be very different and individual experiences. I wanted to be able to characterize important processes people go through in dealing with bipolar disorder, what influences how people respond, and what meaning this has for those who experience it. The goal was to build a theoretical model representing central aspects of this experience, based solidly in the perspectives of people who had been through it. These are the kinds of research purposes to which qualitative methods are especially suited (Maxwell, 1996).

I did not know, when I started, how this model would be structured, what its central concepts would be, or even which parts of people's lives would be most important to look at. I was interested in how the bipolar experience interacts with views of self, and how people come to relate to the illness. There was no clear basis for formulating specific hypotheses to be tested, as this is not an area in which even preliminary research has been done. For all of these reasons, an exploratory qualitative approach to research design and analysis was chosen as most appropriate and most likely to produce useful results.

Participants

Participants were 12 adults diagnosed with bipolar disorder. Their ages ranged from 22 to 62, with a median age of 41. Half were diagnosed Bipolar I, and half Bipolar II. Each was in a stable and functional state at the time of participation in the study. This means they were not in acute depressive or manic episodes, although many were dealing with milder symptoms which they continued to experience between episodes. None were institutionalized or in an inpatient setting at the time they were interviewed for the study. Participants included both males (25 percent) and females (75 percent). Educational levels ranged from less than high school graduation to an almost-completed Ph.D. All were of Caucasian or mixed-Caucasian ethnicity.

All of the participants were on medications to treat their bipolar disorder, but the specific medications varied. Many had tried other medications before arriving at their current combinations. Half had been hospitalized as a result of bipolar disorder and, for those who had been hospitalized, the number of inpatient stays ranged from one to six. Some identified their symptoms as starting in childhood, others later in life. Some had received their "official" bipolar diagnosis fairly recently, some longer ago, the range being a few months to 13 years before they took part in the interview. One-third had attempted suicide and, of those who had not, some had thought about it and made plans. Almost all identified family members who have, or may have, bipolar disorder. At the time of the interview, 60 percent were married, 40 percent single. Sixty percent reported previous divorces, some more than one. All of the participants had been in psychotherapy, but not all were actively in therapy at the time of the interview.

Participants were referred to the study by therapists, psychiatrists, or acquaintances. The referring person (most often a therapist) gave the potential participant a brief written description of the study and an invitation to call me for more information and to arrange an interview appointment (see Appendix A). When potential participants called, I further described the study, answered any questions they had, and set up a time and place for the interview. Written consent to proceed was obtained from the participant at the beginning of the interview (see Consent Form, Appendix B).

The number of participants was determined during the study by observing when stable concepts had emerged from the data with enough information to understand their properties, and the relationships among them. When additional interviews did not add significantly to the developing model, I determined that theoretical saturation had been reached (Strauss & Corbin, 1998), and stopped arranging additional interviews. It was estimated during the planning stages that 10 to 15 interviews would probably be needed, and 12 were completed. In addition, several participants agreed to return for follow-up interviews to further explore their experiences and the concepts emerging in the ongoing analysis.

Data Collection

The major source of data for this study was interviews conducted with people who had received a diagnosis of bipolar disorder. The theoretical model developed and presented in the next chapter is grounded entirely in the data obtained from these interviews. Other sources of data were used to check the validity of the model. These included published accounts by people diagnosed with bipolar disorder, and the written journal of one of the study participants.

The interviews were semi-structured and open-ended, designed to help participants tell their own stories and express their own perspectives of what their experiences with bipolar disorder had been like (see Weiss, 1994; Smith, 1995). I developed an Interview Guide (Appendix C), which I used as a starting point for interviewing for this project. This was not meant to be a rigid prescription for interviewing, but rather a kind of “map” for touching on areas that could be theoretically interesting. I began most interviews by asking participants to think back to when they first considered that they might have bipolar disorder. They then proceeded to tell their stories in whatever way and whatever order they wished. I provided fairly non-directive prompts and acknowledgment as needed. I usually ended with a question about what it had been like to talk about their experiences in the interview.

The interviews varied in length, most running about two hours. As I reviewed the transcripts, I noted that the first hour or so was usually devoted to “telling the story”, and the next hour was spent following up, expanding on, and clarifying things said earlier. During this later part of the interview, many participants also added things they had not thought of earlier, or reflected on their experiences in ways they said were new for them.

It was interesting to note that most interviewees did touch on most of the topic areas I had listed on my “map”. If I was interested in something they did not bring up, I invited them to talk about it later in the interview. One of my goals in the interviews was to maintain enough openness in the format for people to tell me about aspects of experience that I had not expected or anticipated, which could change, enrich, or expand my developing understanding. I listened carefully for these, and everyone told me important things that were “off the map”.

To better understand the sample and the context of their experiences, all participants were also asked a common set of questions about demographic information and about their specific history with bipolar disorder (see Appendix C). These were asked late in the interview, and usually most of them had already been addressed in the course of the previous conversation.

Interviews were conducted in private office space, with the exception of one, with a determined smoker, which was conducted at a picnic table in a park. I audiotaped all interviews, then transcribed them for analysis. Transcribing the tapes myself gave me the opportunity to listen to and reflect upon tone of voice, pacing, vocalizations which could not be transcribed in words, and other nuances that could not be directly documented in a transcript. The twelve interview transcripts averaged 13,000 words, or about 26 single-spaced pages, each.

Follow-up interviews averaged about an hour in length, and were less structured than initial interviews. I began by asking people to reflect on anything they had thought about after our first interview. I then followed up with queries to deepen my understanding of their experiences, and to focus on how these related to my developing concepts.

Other sources of experiential data were published autobiographical accounts, including 11 books and 43 shorter personal stories published on the internet (see Appendix D for list). Some of these were read during the ongoing analysis for comparative purposes. Others were read after the theoretical model had been constructed, as a source of verification for the theory grounded in the interview data.

Analysis

Methodology

Analysis of the interview data was conducted using grounded theory methodology developed by Glaser and Strauss (1967), as amplified by Charmaz (1990, 1995a), Glaser (1978), Strauss (1987), Strauss and Corbin (1998) and others (Chenitz & Swanson, 1986; Coffey & Atkinson, 1996; Miles & Huberman, 1994). These methods provide a structured way of analyzing large amounts of textual data to discover important underlying concepts. Grounded theory analysis is often described as a hierarchy of "coding" procedures. These procedures are systematic ways of selecting and comparing information at different levels, from the concrete, descriptive level to the abstract, conceptual level. They provide ways of exploring, questioning, and thinking about the interview data, leading to the discovery of concepts that help to explain what is going on. The result is a theoretical model, firmly grounded in the data, of a centrally important phenomenon in the area of study. I will briefly describe these procedures, and then discuss how they were used in this study.

Three levels of coding are generally described, referred to by Strauss and Corbin (1998) as open coding, axial coding, and selective coding. These phases of coding begin with specific bits of interview data, and move conceptually upward to a more abstract theoretical representation of a central process.

Open coding begins directly with the transcribed interviews. It is sometimes referred to, more descriptively, as line-by-line coding (Charmaz, 1995a) or substantive coding (Chenitz & Swanson, 1986). Coding at this level looks in fine detail at what interviewees talked about. Each topic is noted and named, resulting in very long lists of potential categories for analysis. These first categories, which may be relatively concrete and specific to individuals, are examined and compared, and then grouped according to something they represent in common. This new concept is named, and parts of the interviews are re-coded, beginning to raise the analysis from a purely descriptive level to a more conceptual level. As this process is repeated, conceptual categories emerge that seem important and are discussed frequently by interviewees. These concepts are examined in more detail to sort out their properties and their range of variation. Thus, a shorter list of key categories begins to emerge, which have not yet been theoretically connected with one another.

The next level of coding, axial coding, is the process of examining these isolated units and relating them with one another at a conceptual level. Hypotheses are formed about how concepts relate, and the interview data is continually “questioned” to test out these ideas. Hypotheses not clearly supported are revised and again checked out in the source data. Important concepts are organized hierarchically into categories and their subcategories. In addition to looking at relationships among these conceptual categories, each category is further examined in detail to “answer questions about the phenomenon such as when, where, why, who, how, and with what consequences, thus giving the concept greater explanatory power” (Strauss & Corbin, 1998).

The final level of analysis, selective coding, is the process of integrating the concepts around a central theme (“core category”), and refining the theoretical model. Diagrams or “conceptual maps” (Maxwell, 1996) are often used to clarify relationships and to check for gaps or logical flaws. The model is evaluated for clarity, parsimony, explanatory power, and how well it encompasses the whole range of interview data. The final model should “fit” the data well, should have “grab”, meaning it speaks to and is relevant in the real world, and it should “work” as a relevant and useful tool to explain, interpret, or predict (Glaser & Strauss, 1967). All concepts and relationships are verified by rechecking the primary data and by comparing with secondary data sources. At this point, the collected individual stories have been, in a sense, rewritten conceptually as one story with a pattern and variations.

Analysis does not take place after the completion of data collection, nor is it a linear step-by-step process. It is rather an ongoing process beginning soon after the first interview is conducted. The process proceeds by “tacking” (Geertz, 1976) back and forth among the levels of coding and between the analysis and the data collection. Categories discovered in early interviews are used in coding later ones. Relationships hypothesized at a later stage are checked out in earlier data. Concepts emerging in earlier interviews are further explored and expanded upon in later interviews. Information about which categories are not yet sufficiently "dense" (Strauss & Corbin, 1998) is used as a basis for further theoretical sampling. There is also a shifting back and forth between inductive and deductive thinking. Tentative hypotheses about concepts and their relationships are drawn from the data. They are then verified through a careful review of both previously collected and new interview data. Revisions are made, as needed, and the process continues.

Research Questions

The research questions in a grounded theory study are neither hypotheses to be tested nor questions to be specifically or narrowly answered. They are, rather, indicators of areas of interest that have not previously been explored. These questions may be used to initially illuminate the data, but they should not pre-structure the results.

The questions raised in the proposal for this project as areas for exploration were the following:

- What is it like to receive a diagnosis of bipolar disorder?
- How do people make sense of this diagnosis?
- How are their self-views affected?
- How do they come to view the diagnosis?

The theoretical model that emerged from this study is a model of a process considerably broader than would be implied by any one of these questions, or even all of them taken together. It is a model of a central process in the experience of bipolar disorder, within which all of the issues raised by the questions are grappled with and resolved by individuals. Not focusing the analysis too narrowly on the original research questions allowed for the discovery of a common process that encompasses them all, and that moves well beyond the initial questions.

The Analysis Process

The analysis process in this study began after the first two interviews. I transcribed them, and began line-by-line coding, looking first at just what people were talking about. And, it turned out, they talked about quite a lot. One participant began, “Ok, well, then you’re pretty much going to hear my life story.” [H1] Clearly, I was going to be hearing about many, many topics and potential categories for coding and analysis. People talked about symptoms and medications, about their childhoods and their futures, about horrible experiences and funny ones, about what they did and when they gave up, about others and themselves. The two initial interviews seemed unique, as did every subsequent one, telling stories different from anyone else’s. It certainly was not initially clear how, or if, a common conceptual model of what was happening could be drawn from this data.

I continued to interview, transcribe, and review my growing lists of codes. I began to group codes that reflected something in common, that were mentioned frequently in the interviews. For example, many people talked about feelings about medications, about hearing their diagnosis, about how others reacted. In each area, I looked for patterns and variations. It seemed that the variations were endless. Some people initially rejected their diagnosis, convinced that it could not be right; others embraced it as validating something they had sensed all along. I was learning a lot about many categories, but overall patterns still seemed elusive.

As I worked at understanding the properties of my developing categories, I began to think about how they might relate to one another. I tried ordering the categories chronologically. It organized the data, which seemed helpful, but it didn’t really explain much. I was looking for something that would organize the data at a more conceptual level. I spent much time with categories involving people’s sense of self, but was not finding patterns in how bipolar disorder affected identity. After a time, I noticed that, whatever the identity outcome, people were telling me about repeated challenges to their identities. I began working with the concept of “challenges to identity”, which seemed to be an overarching concept that encompassed many of the categories I had found previously.

I then proceeded to work in two opposite directions. One was working within this large category of “challenges to identity”, looking at meaningful ways to organize all of the data it included. The other was looking outside the category to answer questions raised by this concept. What do people do, for example, when their identities are challenged? I went back to the interview transcripts to find out. This involved more coding, grouping of codes, and re-coding, as I tried to understand the new category of “responses to challenges to identity”.

As I tried to understand how all of this fit together, I began to draw diagrams, or concept maps, to summarize my thinking. This helped in several ways. It forced me to specify the concepts I was using and their hypothesized relationships. About each concept, I could then ask myself if I had enough information to understand its properties completely, or if I needed to go back to the data for more. This process directed me back to the transcripts to explore, for example, the category of how people decide how to respond to challenges. About each relationship between concepts, I could ask myself if it was clearly supported by the data. The diagrams also allowed me to look for completeness and logical coherence of the model. I realized, for instance, that I needed to add several feedback loops to give a full picture of how the process worked. Finally, I used the diagrams to review the fit of each individual’s story with the developing model. I actively looked for outliers that did not quite fit, and used these to guide me in adjusting the model. The goal was a model that accounted for as much of the variation as possible, not one that just summarized the most common patterns. One thing I needed to rethink in this area was how the process worked for people who had experienced symptoms since childhood.

I now had a model of the process of responding to challenges to identity. Was it “done”? I asked myself a series of evaluative questions. Was the model conceptual, rather than just descriptive? Was it parsimonious, encompassing the greatest number of important categories with the fewest concepts? Did it fit my data? Was it clear and coherent? Did the process I had modeled shed light on the research questions I had originally raised? Did it explain something that was interesting and relevant in the real world inhabited by people with bipolar disorder and those who work with them? Was it useful?

When I was satisfied with the answers to these questions, I took additional steps to reconfirm the last two. I reviewed published autobiographical accounts written by a wide range of people diagnosed with bipolar disorder. I read these with the model in mind, asking myself how the model represented the experiences they described. This informal review helped to verify the fit and relevance of the model for people I had not interviewed. I also discussed the model with a number of therapists who work with clients diagnosed with bipolar disorder. They were able to apply the concepts to particular clients they knew, and to use them to think productively about what might be going on with these individuals. At this point, I had satisfied myself that the theoretical model was completed.

This is a much abbreviated narrative of a process that took place over a year's time. The result of the analysis, the theoretical model developed, is presented in the next chapter.

Chapter Four

RESULTS:
RESPONDING TO CHALLEGES TO IDENTITY

The outcome of this research project is a theoretical model of a process that people go through as they deal with bipolar disorder. The process can be summarized as responding to challenges to identity. This chapter presents the result, beginning with a brief narration of how the model evolved out of the research analysis. A schematic diagram of the model is then presented and explained, representing more precisely the core process of responding to challenges to identity, its component parts, and the relationships among them.

After this presentation of the results, Chapters Five through Eight are devoted to discussing and illustrating in considerable detail each of the major parts of the model, revealing both the common themes and the diversity of experience of those with bipolar disorder. While it is the model, itself, that constitutes the result of this research, these chapters also relate the model to the rich material from which it was built through many quotations drawn from my interviews. They thus provide deeper insight into ways in which the abstract components of the model may be realized in individuals with bipolar disorder. The code in square brackets following each of these quotations is a reference to the participant and transcript page number.

Evolution of the Model

As I began the interviews for this project, I found every person's story to be revealing, absorbing, rich in detail, and seemingly unique. As I proceeded with the coding and analysis processes described in Chapter Three, it was certainly not immediately evident what theme, if any, could unify the diverse experiences I was hearing about. I found, coded, and thought about many extremely interesting concepts in the data. Among the categories I coded were any references to how people viewed themselves. As the analysis proceeded, I found that everyone talked, in one way or another, about ways bipolar disorder affected their views of self.

One woman had brought with her Jamison's (1995) autobiography, *An Unquiet Mind*, and read me a passage that represented how she felt: "Which of the me's is me? The wild, impulsive, chaotic, energetic, and crazy one? Or the shy withdrawn, desperate, suicidal, doomed, and tired one?" [K30] Another participant described a fight with her boyfriend that, in retrospect, represented her first experience of bipolar symptoms. "I didn't know why I was so mad at him, and I wanted to control it. I wanted to not be in this rage, but I couldn't do anything about it... And it was almost like being two separate people at the same time, because I had this one part going, 'You're really overreacting,' and then the other part of me was just so mad I wanted to go out there and kick his butt." [B3] This same woman later experienced her first depressive episode. "I just wanted to curl up in a ball and not be there any more... It just comes out of nowhere... And I've never been a depressive person. I've always been fairly optimistic." [B1] Several people described the difficulty of knowing what they would be like the next day. "Your moods change, and you feel like a different person from one day or one week to the next. Some weeks, when I'm manic, I'll make commitments that the next week I'm too depressed to be able to keep up with." [J19] Some described doing things that seemed like another person, not them. "I knew I was acting kooky... I've always been raised to be very courteous, and I was calling black people 'darkies'. I never would do things like that... And I was being really rude to all the nurses." [M1] It began to seem that, for people with bipolar disorder, experiences that somehow challenged their self-views were very common. Some of the challenges were major and central, some relatively minor and less significant. But the experience of having things happen that threaten identity was described by all.

I then began to look in more detail at just what types of experiences could be challenging to identity for people with bipolar disorder. What soon became evident was that there are myriad sources of such challenges. Many people described observing things about themselves that just didn't seem to fit their self-views. "It's really difficult because you don't have a grasp on what you're doing... You look back at things that you did and go, 'Why the hell did I make that decision?'" [D3] Also very commonly mentioned were experiences involving feedback from significant others which did not square with people's views of themselves. "Even though I knew I wasn't crazy, when people called me that, you know, I felt like it." [H16] Some spoke of their bipolar symptoms. "I couldn't keep from crying, and there was no particular event that day that triggered it." [J12] Some talked about receiving the diagnosis of bipolar disorder. "I was really stunned, and I wasn't really sure I believed him." [K3] Medications were often mentioned in this vein. "I don't like taking meds. I don't like being dependent on this." [P7] Even psychotherapy could be challenging to identity, often "threatening" a previously constructed negative view of self.

This experience of challenge to identity seemed to happen with such frequency and intensity, and in such a wide range of situations, as to be a central aspect of the experience of bipolar disorder. I then returned to the transcripts to explore how people responded to these challenges, and I found that there were two major ways. Sometimes people found a way to push the challenging information away, to avoid having to deal with it. This seemed to protect their identities from the challenge, at least for the time being. At other times, people found ways to take in the challenging information, to consider it and use it in some way. This seemed to lead, often slowly and incrementally, to changes in identity.

People described many ways to keep information away and protect identities. In fact, this was done by everyone at some time, often as the first response to challenge. Some used alcohol or drugs. Some ignored challenging information. One woman visited a psychiatrist at the strong urging of a friend after weeks of manic behavior. "When I first went in and talked with him, I was not honest about what was going on... He asked me, point blank asked me some questions, and I lied to him because I thought, 'Oh, that makes me sound crazy if I say yes to these questions.'" [D1] This strategy staved off the official diagnosis, which she knew would challenge her identity.

Everyone also described ways they had taken in and used challenging information. Many spoke with great pride of ways they had figured out to resolve identity conflicts and to make their lives more coherent. “I’ve learned a great deal this year.” [K5] “It’s definitely been defining, both as far as having pride over conquering it, to the extent that I have, as well as feeling it’s what makes me who I am.” [F33]

No one exclusively protected their previous identity. No one took in every challenging piece of information to use to restructure their identity. With many “strands” of challenging information coming in, people seemed to be faced every time with a new decision about how to respond. There were times when people were pushing most of the challenging information away, and times when they were open to considering and using most of it. At any one time, an individual may be protecting against one strand of information and simultaneously considering another. It seemed important to examine what influenced this decision process, and I again went back to the transcripts to look at this.

As the relationships among these complex processes became more evident, it became clear that responding to challenges to identity was emerging as a central theme in the experience of bipolar disorder. This central process is actually an iterative pattern of component processes, which are navigated in different ways by different people, and in different ways by the same individual at various times. It is an ongoing and dynamic process which, itself, changes over time, as a person responds to many and repeated challenges to identity. I noticed that some people, especially those who had been dealing with their bipolar diagnoses for longer periods of time, seemed to experience fewer challenges to identity. They appeared to have taken in much challenging information, processed it, and gradually and cumulatively restructured some of their views of themselves. As a result, types of information that previously would have been experienced as challenges to identity were no longer seen in that way. When this happened, people no longer had to use so much energy dealing with identity issues, and were more frequently able to get on with their lives.

As this pattern of processes became clearer to me, I began to draw diagrams to attempt to condense and conceptually represent the process and its components. With each diagram, I went back to all of the transcripts to see if each of them really fit the developing model. If not, I adjusted the diagram (and, with it, my concept of the process) until it represented a process common to all of the people I had interviewed. At the same time that I was narrowing my focus to clarify this specific process, I was also expanding my explorations into the details and variations within each of its component parts. The final diagram, representing a conceptual overview of the central process is presented in the next section. Chapters Five through Eight are devoted to the detailed exploration of each component of the process.

Overview of the Model

Responding to Challenges to Identity – Model of a Dynamic Process

The core concept for the model of experiencing bipolar disorder is responding to challenges to identity. People with bipolar disorder experience frequent challenges or threats to their identities. The actions and reactions of others, as well as the behaviors, thoughts, and feelings they observe in themselves, may cause them to question very basic aspects of their views of themselves. This happens with such frequency, intensity, and in such a wide range of situations that it becomes a central theme of experience. Challenges to identity may cause intense discomfort and distress. Beyond that, if pervasive enough, they can be disabling. Some coherence of identity and the resulting sense of predictability of one's own actions is necessary to simply live through a day. Constant threats to identity interfere with the basics of everyday functioning and must be dealt with in order to get on with life.

This turns out to be quite a complex process, a process that comprises a number of complicated sub-processes. Responding to challenges to identity in bipolar disorder is not an orderly, linear series of stages, moved through once and finished. It is, rather, an iterative pattern of processes which can be navigated in many ways. The process is navigated countless times, responding to countless challenges, and not all challenges are handled by an individual in the same way. As a person responds to many challenges, the responses feed back and affect the process, itself. Over months and years, people's preferred way of responding gradually shifts. The eventual result can actually be a reduction in the number and intensity of challenges to identity. Information that previously would have been threatening to people's views of self no longer has this effect, and they are able increasingly to get on with major life tasks and minor daily activities.

A Picture of the Process

A picture is perhaps the best way to get a quick overview of the basic parts of the process and their relationships with each other. A diagram of the model is shown in Figure 1. In the description that follows, underlined words and phrases correspond to labeled parts of the diagram.

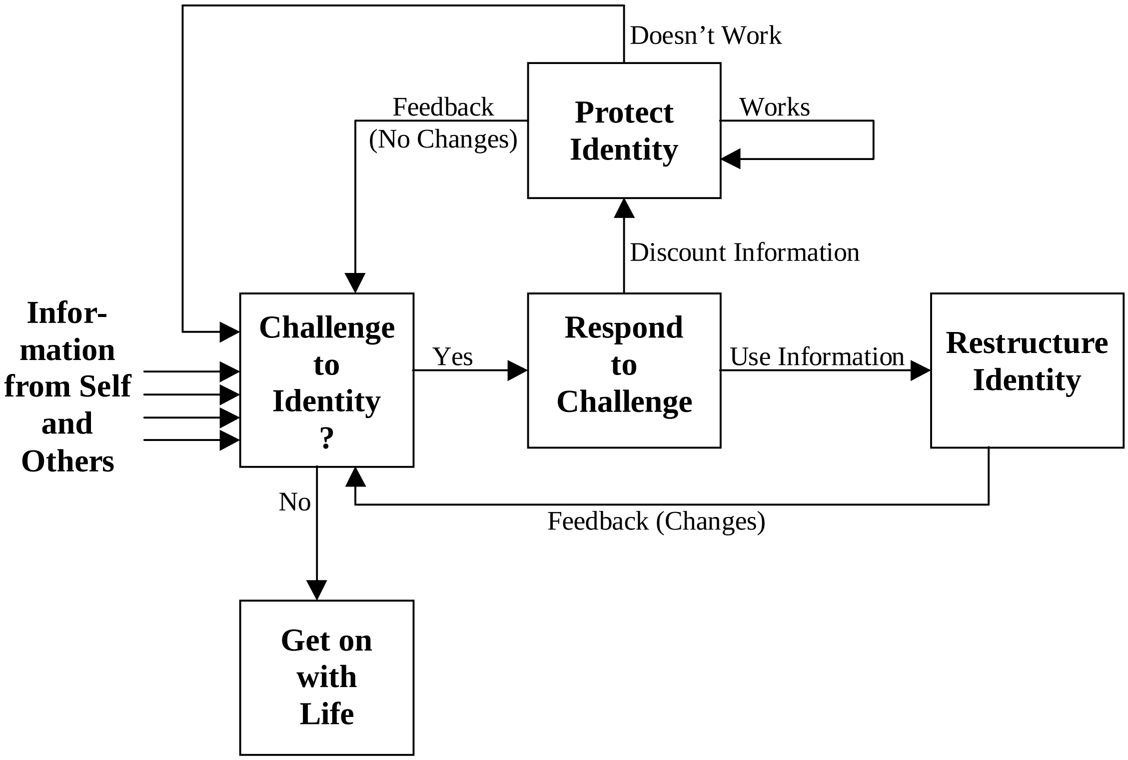

Figure 1: Responding to Challenges to Identity

The process begins with Information from Self and Others. This includes all of the information we are constantly receiving, through any of the senses, by observing ourselves or by noticing the actions of others in relation to ourselves.

As each strand of information comes in, a comparison process takes place. People compare the implications of the information with the way they see themselves, asking, "Is this information a Challenge to my Identity?" Identity is simply a person's view of self, a collection of answers, large and small, to the question, "Who am I?"

The result of the comparison process, Challenge to Identity?, can be No or Yes. If the answer is No, one can Get on with Life, with whatever life tasks one is pursuing at the time. If the answer is Yes, however, a need is created to Respond to the Challenge. The discrepancy must somehow be dealt with in order to produce or maintain a sense of a coherent self.

There are two ways to Respond to a Challenge to identity. One way is to somehow Discount the Information, to push the information away in a manner that is effective enough that one's current view of oneself can be maintained. The purpose of this process is to Protect Identity. This identity protection process then provides Feedback to the comparison process discussed above (Challenge to Identity?), which compares information with current self-views. Since the self-views have been protected, the Feedback consists of No Changes. Therefore, as additional strands of information come in, they will be compared to the same self-view. Whatever was challenging to identity before will continue to be a challenge. If this protective process Works, at least in the short run, a person will tend to continue the same strategy. If the process in some way Doesn't Work completely, then this information, itself, becomes another incoming strand which must be considered and may become a further challenge to identity.

The other way to Respond to a Challenge to identity is to consider and Use the Information. This constitutes a decision to "let the information in", rather than pushing it away. In facing challenging information, an individual must confront the discrepancy between incoming information and identity, and somehow resolve it. The result is to Restructure Identity, perhaps in a tiny way. Cumulative changes over time can result in rebuilding a stable and coherent identity which takes into account the new and challenging information. The identity restructuring process also provides Feedback to the comparison process, Challenge to Identity?. Since identity has shifted, Feedback consists of Changes. Incoming information is now compared with this new version of identity. Since the newer version is more integrated and reconciled with previously challenging information, similar information may now be less challenging. Because of this, the result of the comparison process, Challenge to Identity? will more often be No, allowing the person more frequently to Get on with Life.

Dynamic Aspects of the Process

The process of responding to challenges to identity is a dynamic one, in that the process, itself, changes over time as it is navigated by an individual. The components of the process and their relationships, as shown in Figure 1, do not change. But the paths traced by an individual through the process do shift. Early on, there is much challenging information coming in, and the response to challenge is more likely to be pushing away information to protect identity. Little energy is left for getting on with life. Usually, there is a gradual shift toward responding to challenge by considering the information and restructuring identity. As the resulting tiny changes in identity iteratively feed back into the comparison process, there is a change in what information constitutes a challenge. Some information that would previously have been challenging is no longer a challenge, allowing the person more often to get on with life. Late in the process, the same amount of information comes in, but little of it is challenging to identity. At this point, a person will still occasionally loop through one of the processes of responding to challenge, but most of the time will not need to do this, and will proceed directly to getting on with life.

Discussion and Illustration of Components of the Process

This chapter has been devoted to presenting the result of this study, a theoretical model of the process responding to challenges to identity. Although the model focuses specifically on this process, itself, it is understood that the process for each individual takes place within a wider cultural and social context. This context would be expected to influence the particulars of the information from others that an individual deals with in this process.

The next four chapters explore in detail each of the major parts of the model, looking inside the "boxes and arrows" of the diagram in Figure 1 at the content and mechanisms of the processes involved. This level of detail helps in understanding clearly how the common process of responding to challenges to identity works for people with bipolar disorder, as well as the many variations in how individuals navigate this process.

Chapter 5:	Challenges to Identity
Chapter 6:	Responding to Challenge – Protecting Identity
Chapter 7:	Responding to Challenge – Restructuring Identity
Chapter 8:	Getting on with Life

Table 1: Responding to Challenges to Identity – Components of the Process

Each of these component parts is a process in itself, and a piece of the overall process of responding to challenges to identity. Each component is discussed and, to give a better feel for the meaning to those who have experienced it, illustrated as much as possible using the words of the participants in my interviews. As the content of people's experiences with these sub-processes is explored, the variation among individuals in what they bring to the process, and how they navigate it, can be seen. People with different identities will find different information challenging. They will choose different strategies to protect identity, and will feel this to be necessary at different times. They will use challenging information at different rates, and come to different resolutions of the basic issues in restructuring identity. Despite this tremendous variation, the pattern of the basic underlying process, responding to challenges to identity, is common to all.

Chapter Five

DISCUSSION AND ILLUSTRATION: CHALLENGES TO IDENTITY

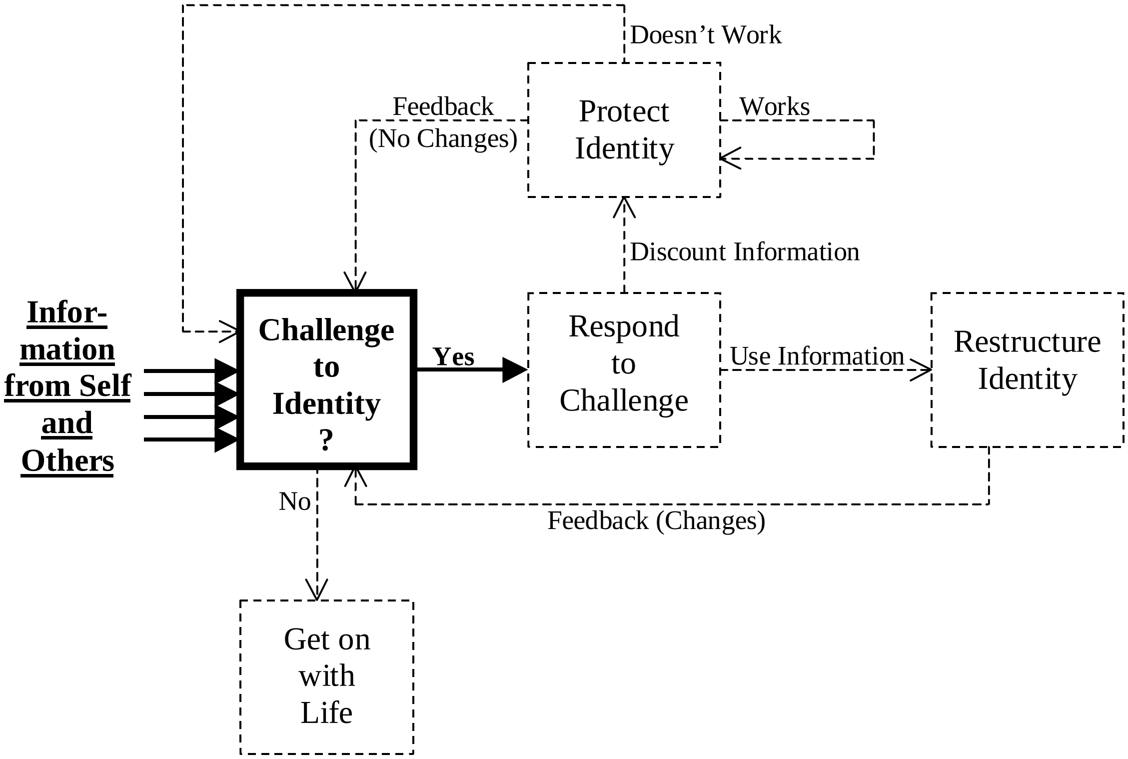

Figure 2: Challenges to Identity

Experiencing bipolar disorder challenges identity. This piece of the process, itself, is not particularly complex. The mechanism is a simple comparison. Incoming information is compared with one's self-views and, if there is a discrepancy, a challenge to identity results. Understanding why this becomes such a central phenomenon in the experience of bipolar disorder, however, requires looking in detail at the content of the potentially challenging information that people with bipolar disorder are likely to have coming in. Most of this chapter is devoted to exploring and illustrating the most common types of challenge to identity. For most people, the most ubiquitous type of challenge is information from self and others related to symptoms. This symptom-related information may have different implications for identity challenge, depending on when in one's life and illness it is experienced. The chapter, therefore, concludes by looking at these different times of challenge. Table 2 summarizes the material to be covered in this chapter.

Types of Challenge to Identity

- Symptoms
    - Very wide range and high intensity of emotional experience
    - Being out of control
    - Actions or behaviors that are "not like me"
    - Not being able to do things one used to do
- Diagnosis
- Medications
- Psychotherapy

Times of Challenge – When Symptoms are Experienced

- Symptoms Experienced in Childhood
- Initial Symptoms Experienced as an Adult
- Challenges After Diagnosis
- Ongoing Challenges

Table 2: Types and Times of Challenge to Identity

Types of Challenge to Identity

In looking at all of the sources of challenge to identity mentioned by participants in this project, I found four major categories of challenging information: symptoms, diagnosis, medications, and psychotherapy. Challenges in any of these categories can reach an individual by either of two routes. The first is intrapersonal, information gained from observation of one's own feelings and actions. The second is interpersonal, information that comes from observing the actions and reactions of others. Each of these types of challenge is discussed and illustrated below, with attention to information coming from both intrapersonal and interpersonal routes.

Symptoms as Challenges to Identity

The nature of the symptoms of bipolar disorder led to identity-challenging experiences for everyone I talked with. Emotional and behavioral manifestations of the illness, whether or not they are seen as "symptoms" at the time, can be extremely jarring to views of self. Others' reactions to these symptoms often further challenge one's self-views. Not all of the identity-challenging experiences of bipolar disorder are related directly to symptoms, but this constitutes the largest and most obvious set of challenges. Because bipolar disorder can have such a complex set of symptoms, the symptom-related challenges to identity can be more easily viewed by organizing them into four areas: the very wide range and high intensity of emotional experience, being out of control, actions or behaviors that are "not like me", and not being able to do things one used to do.

Wide Range and High Intensity of Emotional Experience

The first area of symptom-related challenge is the very wide range and high intensity of emotional experience that people with bipolar disorder contend with. In addition to reaching greater heights and blacker depths than most people, those with bipolar disorder may also find their emotional states much more unpredictable and inconsistent. They may not be able to predict what they will want to do next month or next week or, for some, this afternoon. They may feel like different people at different times, leading to the question, "Which is me?"

"The intensity of feelings I feel, I don't think most people feel," said one participant. "I don't think anybody could ever understand it unless they had it." [H21] "It seemed like, for a long time, it was like either things were overwhelming, I couldn't do anything, I was powerless, or I was like the opposite. You know, I could handle anything, it was wonderful, I could do anything. And I can't remember any times for several years when it wasn't one way or the other." [PF13]

The unpredictability was described in many ways. "They just said it's Bipolar II, hypomanic episodes that can flip into severe depression. And I can relate to those two things. And I can relate to its happening from one hour to the next hour, not just from one day to the next day, or one week to the next week." [G11] "If the depression hits in a very physiological manner, and that's when I don't have any forewarning of it, I'll just be standing in the kitchen and my stomach will just drop, you know, and [snaps fingers] I am depressed. And those typically are extremely intense, so when those hit, you know, I'm very fearful that this is it, this is the big one." [F13] Or, in the other direction: "Sometimes it just startles me. It's amazing, because I'll just suddenly one day realize I've been depressed and I'll wake up one morning and it's just a totally different world, a different person. It's like you turned a corner and suddenly the sun is shining. All of a sudden, today it's totally different..., no difference in situation, no difference in what I was doing from the day before, it's just yesterday everything was dull and bleak and hopeless, and today everything's bright and sunny and cheerful." [J12]

And so, the question: "Which one of me is me? To me, that's the biggest thing that I have trouble figuring out, and I think others that don't have it never think about. When you think about the top of the manic cycle down to the bottom of the depressed cycle, I'm never in the same place, pretty much, even when I'm on a fairly even keel, and it's really difficult to accept and to put out to others." [K16] Speaking about a hypomanic episode: "It was very, very weird. It was almost like having two people in the same body and you didn't know how to merge them, so that the reasonable one could take over, you know, most of the time, and kind of calm the other one down." [B3]

This wide range of emotional experience may evoke reactions from others that challenge identity. Others may only perceive a portion of one's range of experience, or may only approve of a part of that range, resulting in only partial mirroring or validation of the self by others. Since others' views are an important part of the development and maintenance of the self, this incomplete validation may make those processes much more difficult. Others' expectations may also clash with one's own experiences. Others may expect an "average" amount of predictability and consistency, and a person with bipolar disorder may frequently not be able to meet these expectations.

Others may focus only on extreme pieces of experience: "I can remember being asked, 'Why do you dislike yourself so much that you want to kill yourself?' And telling my psychiatrist, 'I don't think I do. Sometimes I'm just fine. And much of the time, I like myself just fine. I just get in these moods where everything's horrible, and I hate myself, and I can't stand it.' So, it was very confusing to me, and created a great amount of guilt, I think, on my part." [J1] "All along, my friends always thought I was really moody, you know, 'Either you're up or you're down, man. There's no in-between for you.'" [P3] Or, others may just perceive the best-functioning aspects of self: "It's funny, because one of the things I've always found really, really peculiar is that other people don't perceive me the way I do. They don't perceive all of this inner turmoil and swinging from one extreme to another. This aunt, in particular, seems to feel that I've always been very 'together', someone who handles their life very well." [J5]

Others' expectations, even minor ones, may be impossible to meet: "I remember my friend and I drove to Dallas. And I remember her saying, 'Would you please sit still? You're making me crazy.' And I was just like, 'Oh god. How am I going to sit still?'" [FF7] One woman, knowing she was not yet able to return to work, had to deal with others' expectations that she be better: "And if I have one good day, then I'm 'well'. Period." [K20] Another spoke of parental expectations she could never meet: "As a child..., I probably felt that inadequacy, and didn't realize that it was inappropriate. So that was something I think would have contributed to low self-esteem..., that sense of failure." [FF14]

And sometimes others don't notice, or don't acknowledge, even quite extreme experiences. Speaking about how parents responded to early depression: "They didn't notice, I don't think. I mean my dad didn't like it when I brought home bad grades, or when I refused to participate in sports, but he would get on me about that, not about hiding in my room. And my mom just never noticed." [P14] And this lack of feedback has consequences: "I remember, for a long time, thinking that I'm the only person who has ever experienced these emotions. And finding out that other people also experienced those emotions was a real eye opener for me." [F27] "I think that what hurt more than people I didn't know discounting what I was going through, or not validating what I was going through, was my family not acknowledging what I was going through." [H8] Family members may not even believe when told: "Sometimes I think he's thinking, 'Oh, it's a bunch of bunk. He's just making it all up.'" [L14]

Being Out of Control

A second area of symptom-related experience is being out of control. Everyone I interviewed described times when their behaviors were out of their control. For most people, choosing one's own actions is a part of enacting identity. When actions seem not to be controlled by oneself, identity may feel severely threatened.

"It's like, I would imagine, being in a car you can't steer. You just feel helpless, because there's just nothing you can do." [B16] "I cried a lot, cried a lot. And I would cry just for no reason. I just remember crying, you know, for hours and not being able to stop." [H1] "I even sometimes think the word 'seizure' when I think about one of those depressed episodes. It's like something, I don't have control of it. It takes control of me." [J4] Expanding on this image, the same person continued later, "I think even people who may think they rationally get it, if they have not experienced it themselves, if they have not experienced not being in control of their emotions, not having their emotions somehow rationally, at least in their mind, coincide with external situations and events that sort of make sense, they just have no basis to understand that this kind of thing can occur, and that you have no more control over it than you do an epileptic seizure." [J13]

Feeling out of control is sometimes only a short step from feeling crazy. "There have been times when I felt like I was going insane, insane in the sense that I was losing control over my ability to control what I was doing." [H16] "I knew that my actions were, were, ah, crazy. They were simply not sane. Things I was choosing to do, I was not making good decisions, I wasn't sleeping and I felt out of control." [D2]

Others may have reactions to these out of control times that further challenge views of self. Some people describe others reacting with fear and avoidance. A common reaction is another person misunderstanding one's motives, often blaming someone for something they cannot control. At the other end of the spectrum, some described others as not noticing, and therefore not being able to provide any connection, when they were having frightening feelings of being out of control. Sometimes others may offer help, which can challenge a self-view of being able to take care of oneself. For some people, out of control experiences are related to episodes of hypomania, and they may be very entertaining and funny. Others' reactions in these instances may actually be actively expressed enjoyment, which may end up reinforcing the out of control behavior.

Feeling blamed can come from specific reactions of others: "And he was just like, 'What is wrong with you?' And that triggered the thought of, 'Oh, my god. There's something wrong with me. I don't know why I'm so mad at him.'" [B3] Or general family attitudes can lead to feeling blamed: "They said, 'No, you're the one with the problem.' They were very adamant about it, you know. I was pretty much the scapegoat of the family." [H10] "'You're feeling sorry for yourself.' That was always the thing my parents told me... That [meant] I was doing this on purpose, I can get out of it if I wanted to, I just want somebody to feel sorry for me... For a long time, I doubted myself. I doubted. Even though I knew, I still would doubt myself because of what was always being thrown at me." [H11] Even interactions with therapists sometimes resulted in a sense of blame: "I think cognitive therapy was real popular at the time, and the idea that you choose how you feel and how you respond to things. And I was kind of getting from certain counselors the message that I felt that bad because I wanted to, because I chose to, which also created a tremendous amount of guilt and frustration." [J2]

Out of control behaviors often result in frightened reactions from others. Speaking about a sudden hypomanic episode: "If I was going to be totally different, unpredictably, then, you know, I'd be dangerous to be around. And, ah, one lady put it as ‘unreliable’, but I think she was understating her feelings about that.” [L7] “Where I used to work..., I would get mad at people and I didn’t hold back... A lot of people were kind of scared of me. Not scared like I was going to beat them up, but they didn’t know when I was going to blow up.” [B19]

Some bipolar symptoms can be enjoyable to others, and their reactions may actually reinforce the symptoms, making them even harder to give up. “I used to really enjoy being the life of the party. I don’t know if I really was, but I thought I was. And, you know, it was really reinforcing. I used to just start talking, and people would be rolling on the floors for like hours.” [PF16] “When I’m able to be hypomanic, I can tell just how people love that, you know. I love being that way for people. I love feeling that myself. I love giving off that for other people.” [H21]

Actions or Behaviors that are “Not Like Me”

A third set of symptom-related experiences are actions or behaviors that are “not like me”. These may not feel out of control, but they feel out of character. Observing oneself acting in ways that are out of character is a direct challenge to one’s view of self.

“I didn’t know what to think. I was like, ‘Hey, who is this person?’ You know, who is this person acting wild and crazy?” [D3] People described many specific examples, large and small, of times their behavior didn’t fit with their usual selves. “I remember he brought me a taco from Taco Bell and I just threw it across the room. I wouldn’t waste food like that. It’s worth good money.” [M10] “When I’m, you know, really manic, I do get really irritated, but I don’t believe that I’m a very irritable person. I don’t believe that I’m the type of person that would just say things to hurt people. Whereas, when I’m extremely manic, that stuff happens.” [H19] “[One time] I got really, really manic. I remember it, but it’s not like it was me. It’s like I was watching somebody else. I just left my house one night... and I just had this idea that I needed to go to Alaska. And I hitchhiked to Alaska. I found myself out there, and it was September, and all I had was summer clothes, and it was getting really cold. It was almost like coming to, although I knew where I was and what I was doing, but it was like

‘Damn, what the hell am I doing here?’ ...That’s not something I would normally do.” [P4]

When someone acts in a way that is “not like them”, others who know them may react with confusion, withdrawal, and anger. Others may also see this behavior as representing who they are, resulting in inaccurate mirroring and a mismatch between others’ views and one’s sense of identity. “When I hear somebody call somebody ‘crazy’ or ‘psychotic’, I feel like they’re calling them that as a whole person. And that’s not right.” [H16] Both pleasant and unpleasant symptoms can be scary to others: “And periodically it would seem like all of a sudden I’d just be reborn, so to speak, and feel like all of a sudden I had gotten over, gotten through all the problems and the difficulties. And it would seem like I would be very understanding and very aware, and everything was very profound. I could see, you know, into everything, and the truth of things would be very clear. And my personal confidence and competence was enhanced. And everything had great meaning for me, very personal meaning, important, significant meaning. And I’d just feel totally different. And I’d share it with people around me, and they’d just think I was off the wall... Well, they probably thought I’d lost it. Even though to me it was extremely positive, to them it might have been a little bit, you know, scary.” [L6] “[My husband and friends] were trying to figure out what to do with me. ‘What do we do with her?’, you know. And I kept telling them, ‘Look at the TV... They’re talking about me. Look, look.’ And they wouldn’t look. They wouldn’t talk, they wouldn’t look.” [C12] The woman whose co-workers were a little scared of her noted, “That always bothered me, because a lot of those people kept the same [opinion] even when I tried to calm down and not be so confrontational or abrasive.” [B19]

Not Being Able to Do Things One Used to Do

The fourth major area of symptom-related experience that may deeply challenge identity consists of times when people are not able to do things they used to do. This may happen temporarily, as during a depressive episode, or it may be ongoing for some who are unable to effectively control symptoms even with medication. People experience this as a loss of an important part of the self, much as people with other chronic illnesses do.

"My reading sometimes is just so poor I can't comprehend a lot. You know, I've been down to reading Sidney Sheldon novels just to pass the time, and I consider myself an extremely bright person. And it's frightening, absolutely frightening, that I might have to become a whole different person, that what I do for a living is read *People Magazine*. Sitting by the mailbox every week till my *People* shows up and that's the span of my living." [K1] "I'm afraid, on some level I'm afraid it means I can't do [the work] I've chosen to do. I'm afraid I might crack up and hurt somebody." [P25] "It still happens where my memory is just shot. And that's real aggravating because, with the kind of work I used to do, everything was deadline driven, and so you had to just be on top of everything right there every day, or you were hosed. Um, and honestly, I don't think I could do that ever [again], I just don't think I could do that." [N7] "It just kind of cuts into your activities and your fun and your work, and just tears little holes in your life as you go." [B26]

This sense of loss or lack can be further reinforced by others' reactions. Others may now provide no mirroring for important parts of the self. There may simply be no validation from others for central parts of identity. One woman, who was not working, talked about missing the input and feedback from her colleagues. Being alone at home, she was beginning to wonder whether that competent "work" part of herself really still existed.

Diagnosis as a Challenge to Identity

Receiving an official diagnosis of bipolar disorder provides a new lens through with to view one's current self, one's past experiences, and future possibilities. What is seen through this lens may be very different from one's previous images of self, resulting in central challenges to identity. The lens of diagnosis may also be used by others, affecting their views of the person who has been diagnosed with bipolar disorder. When others' views of one are discrepant from one's self-views, identity is likely to be challenged.

On receiving an official diagnosis, everyone I talked with considered whether or not they thought this diagnosis "fit". Some felt it did not, and the suggestion was a direct assault on identity. "I never thought I was manic. The depression was very clear... I thought 'bipolar' meant when you were manic you went out and bought everything you could see, you went to the mall, or you went to Vegas and came home with a tattooed husband. That was my understanding, and I never did that." [K2] Others experienced the diagnosis as validating and helping to explain experiences that had previously been challenges to identity. "I guess it just kind of confirmed, you know, and just something to say to my parents, 'There is something wrong with me; I'm not just doing this because I want to get into an argument; I'm not doing this just because I feel sorry for myself...' To me, it was something I could say, 'Here, this is for real.'" [H13]

Whether they felt the diagnosis was a mistake or a relief, most struggled with the idea of seeing themselves as "mentally ill". Some described an internal stigma that affected their views of self. Others described realizing that a chronic mental illness is "for life", and this began to challenge their views of future possible selves. "I was deeply sad, you know, deeply sad. First, I wanted to deny it. I'd say, 'Not me. There's no way. I mean depression is one thing, but that's a serious mental illness,' ...People have transient depressions. They go away. A little bit of anxiety or panic attacks, they go away. Bipolar illness does not go away... You're stuck with it, you know. It's like if you're a diabetic. It's there for life." [D9]

Being seen by others as "mentally ill", "manic depressive", "bipolar", or "crazy" was something everyone had experienced, anticipated, or worried about. This challenges identities in a variety of ways. Most perceived a stigma attached to their illness, and had observed or suspected that some others thought worse of them because of their diagnosis. Some described being feared and avoided by others. A common concern was being discounted, not taken seriously by others because of the diagnosis. Some described friends who said they "understood", but clearly were uncomfortable. Some feared that others would no longer see them as desirable as a life partner, or as able to be independent.

The stigma of mental illness was perceived in many ways. “You have enough people tell you you’re crazy, pretty soon you start believing it. It’s like going to the hospital, having to see psychiatrists, pretty soon you start believing that, well, yeah, I don’t have quite what it takes to deal with things, like other people do.” [M10] “It’s sort of like it’s ok to be depressed. It’s not ok to be manic. Because, if you’re manic, then they’ll lock you up, or put a straight-jacket on you, or something... It’s when I start ranting and raving, calling people names, and being kooky – then they take me to the hospital.” [M21] “People even now still think I’m crazy in [my hometown]. I know that they’ll say stuff because I’ve heard stuff, and it’s very hurtful.” [H8] “What are they going to hear when they hear ‘manic depressive’? Of course, what do they think of? You know, ‘This person’s just off the wall.’” [H23]

Comments made about other people also can convey the stigma: “I remember hearing friends make fun of people who were insane, or drive past the state mental institution and make fun of the people in there.” [J8] “We had Thanksgiving with... family, and they would just throw out these words, ‘Oh, Uncle Larry, he was just crazy.’ ...And, as a matter of fact, he was crazy. He, like, would show up every five years, and nobody would know where he was in between times. And they finally declared him dead, because he never came back again. And, for the first time, I sat there and I thought, ‘You know, you’re offending me, because I think he was manic depressive.’ I didn’t say that, but that’s offensive to me. That means I’m crazy, too.” [K7]

People are sometimes avoided by others who know their diagnosis. “I’m afraid they won’t want anything to do with me because I’m crazy. That’s a real fear for me... And there have been people who have actively avoided me, too. I don’t know why. Maybe they thought I was annoying. I can be pretty annoying. I don’t know it while I’m being annoying, but later I look back...” [P25] Longtime friends may also withdraw: “Like my church friend, she says, ‘I’ll call you.’ Of course she doesn’t call me... And now she’s gotten to the point where she doesn’t know what to say to me anymore. She’s just kind of looking around like, ‘Yikes, how do I get out of here?’” [K9] So, “resigning myself to a sudden round of polite farewells” [K30] is what this woman found herself doing in the midst of dealing with other difficulties of her illness. Another person noticed, “People kind of withdraw, like it’s catching. And I just go, ‘It’s not contagious. You’re not going to get it.’ So, I don’t know. I can laugh off most things.” [B9] Even close family members may be afraid of the topic: “My mother absolutely did not want to believe that this would be possible, because, I guess, as a parent, she took that personally. And so she just thought, ‘It’s just not true, this diagnosis.’ She still won’t talk about it. I’ll bring it up and she’ll change the subject.” [D14]

It can be hard to feel understood with a mental illness. “There’s a very small group of people who know what you’re talking about when you say ‘bipolar disorder’ or ‘manic depressed’. I’ve seen a lot more blank faces than when I used to tell people I had depression.” [N9] “[Some people] say, ‘Everybody deals with this. Everybody feels...’ I know they’re trying to help me, like, ‘Yeah, I feel this too.’ But no, no you don’t. You don’t.” [H26] “Nobody can understand it, I don’t think, unless they’ve been through it. So, even though they can say, ‘Uh huh, I understand’, they can’t. So, it’s hard.” [K7]

Many worried about being discounted because of their diagnosis: “I don’t want to lose credibility because of it, because people think judgment is impaired or something like that, or that, when I say something creative, it’s, ‘Oh, you know, she’s manic.’ Because creativity is not just mania. Maybe you can be more creative when you’re manic, but it’s not the same thing.” [J8] The diagnosis can even lead to discounting oneself: “Sometimes you do think that way. Sort of like all your achievements mean nothing because of that one time you lost it.” [M22]

“Something I think I’ve always worried about is how could anybody deal with me? How could anybody fall in love with somebody [with bipolar disorder]?” [H17] “And just the fear of, you know, will I ever meet somebody that will understand me, that I’ll truly get along with? And what if I get sick? Will that person stay beside me? At times, when I think about it, I think, ‘Why would anybody want to be married to a bipolar?’, you know, because we can get sick. We can get nuts.” [D22] “I wouldn’t want to go out with somebody that had a disease that I, number one, didn't understand or, number two, was going to cause these deep effects of one day they're happy, and one day they're sad, and one day you don't know what the hell they are. Why would you bother with that?" [K9]

The lens of a bipolar diagnosis was also used by most to look back at their own past actions, as well as those of family members. Many found that this challenged long-held views of self, as they now looked at past behaviors as possibly symptoms of bipolar disorder. "There were a lot of things that I look back and go, 'Oh, ok, that explains it.' Like that fight, you know, that one particular fight that I remember with that boyfriend... And there were other instances like that where I'd look back and think, 'Well, no wonder. No wonder that's how I reacted...' Because I was just a freak. I just had things going on that I couldn't control, and I didn't know [what it was]." [B23] "My mom and dad say they could tell in infancy that I had a very different energy level than other children. And I can see it in home movies when I was a child. It's like you've got a group of kids playing, and then here's this little blur moving through the picture... And when I've looked at lists of symptoms of children with bipolar, I say, 'Hmm, yeah, I had that, and that, and that.'" [J18]

Many people also looked at the behavior patterns of undiagnosed parents and other relatives, reaching conclusions that certain family members also must have had bipolar disorder. This challenged views of family interactions and how they had contributed to identity development. "I believe my mother, looking back on it, also is bipolar. Therefore, she had times that she was irritable and had manic rages, and could be very hard on me and my brother and sister." [J1] "I think about the effect of my mother's depression on me. She wasn't available, she was locked in a bedroom. I basically parented my sister through long periods of time when I was a child, because mom was depressed and dad was at work." [P13] "My mom and my grandmother never talked to me about this stuff happening to them. It wasn't until I was in my late 20s, when I was diagnosed. I talked to my parents, 'Hey mom and dad, I've been diagnosed with bipolar disorder, ah, they used to call it manic depression.' And my mom says, 'Oh, me too.' ...I said, 'I wonder if that's what's wrong with grandma.' 'Oh, yeah, she's had that diagnosis for 30 or 40 years.' Oh, nice to know." [P14]

Medications as Challenges to Identity

Everyone I talked with had been prescribed medications to help control their bipolar symptoms. For some people, just the idea of being on medications, especially for an indefinite period, was challenging to identity. "I don't like taking meds. I don't like being dependent on this... I resent having to rely on them to stay sane." [P7]

Even for those who willingly take medications and acknowledge their effectiveness, the effects may challenge identity. "I think that, by my early 30s, I already had 'me'. I was already my own personality. And lithium certainly worked; as far as the mechanism goes, it worked. But I was a completely different person than I had ever been. So it was almost like waking up the next morning and not being the person you had been your whole life. And so I had a lot of trouble dealing with that... What I found was that I pretty much had no affect. I mean I was very even keel, which I guess was the whole idea. But it wasn't me, it wasn't my personality." [F3] "Well, I was drugged. I mean sometimes I felt like no personality... That is one nice thing being off the [mood stabilizer]. I feel like my moods have returned a little bit in the sense that I'm able to be animated and like a person, like a fun person." [M9] Others described the medications as literally giving them back their selves. "As the medication got better, I felt like, 'This is me.' I really got to say, 'This is who I am.'" [H19] "I'm a different person than I was, even a year or two years ago, because we've finally gotten the combination of things that work." [G2] Many of those who take medications and see changes in their feelings and behavior are challenged by the question, which is me? "How do you know? How do you know if this is really me, or if this is me because I'm on meds? You don't. You don't really know." [D20]

Others' reactions to someone being on medication can add to the challenge: "If I get really uptight and nervous, my friends say, 'Go take your pills.'" [G10] "And there were times when [my husband] would say things like, 'You better go talk to your doctor and get a new medication, because the one you're on isn't working.' He'd make remarks like that about it. So I finally told him he better quit saying stuff like that, because the more often you say it, the more damage it does." [B9] "And probably, when [people at work] hear about my doing certain things, they'll say, 'Not taking enough Prozac this week', or something. I hear it said about other people who are mentally ill." [J9] "And then I met my husband, and he knew nothing about mental illness or depression or antidepressants or anything. And one day he said to me, 'You're not depressed any more. Just don't take those any more.' And I went, 'Ok.'" [N15]

Psychotherapy as a Challenge to Identity

Many people described being in psychotherapy as a deeply supportive and important educational experience, but also as a significant challenge to previously central aspects of identity. Many had long-held negative views of self based on years of symptom-related behavior observed in themselves and reacted to by others. The therapy process often presented other possible interpretations that directly challenged these parts of identity. Although these new interpretations were more positive views of self, some people described periods of tenaciously hanging on to old views they had become accustomed to.

One person credited the therapy process with radically increasing her self-esteem. "I saw him... and he immediately realized that I was bright. And so he gave me books and tapes and reams of material [that challenged negative self-images], very much so. Um, at times [I would argue back], because things are so deeply entrenched." [FF14]

People begin to realize that others' negative views of them, incorporated into identity over the years, might not be right. "I was the fighter, and the realist, really, and that didn't fit in at all. And I'm finally getting credit from myself through [my therapist] for, yeah, I may have a disease, but I was the realist. These things really did happen." [K14] The same person talked about seeing things as being her fault: "It's really hard to get over that. I mean, after 40 years of it or something. But at least I can say, '[My therapist] would say this is ok,'" [K22]

Times of Challenge to Identity – When Symptoms are Experienced

Symptoms as challenges to identity may be qualitatively different, depending on the stage of life and illness at which they are experienced. I look here at four times of life/illness at which symptom-related information may have different implications for identity challenge. These times are characterized by symptoms experienced in childhood, initial symptoms experienced as an adult, symptoms after diagnosis, and ongoing symptoms.

Symptoms Experienced in Childhood

A special kind of challenge is presented by symptoms experienced in childhood. Looking back, some people with bipolar disorder remember behaviors while they were in grade school or "all my life" which they now identify as symptoms. Extreme ranges of mood, unpredictability of affect and behavior, and being out of control are experiences that, later in life, may challenge identities previously formed. When experienced in childhood, they may have the somewhat different effect of making the initial formation of a coherent and stable identity more difficult. These experiences may make it harder for a child trying to figure out, "Who am I?" The reactions of important others may make the process even more difficult. As an identity is formed around these experiences and the reactions of others, it may include some highly negative views of self as sad, bad, inadequate, unpredictable, or crazy. When these people later evaluate incoming information, they may sometimes find negative information to be consistent with their self-views, and positive information to be discrepant, and therefore challenging to identity.

"Something I've been really aware of my whole life is, even if nobody notices that I am different, I've felt like I'm different. I mean, it's a belief of mine that I think I've really reified over the years." [P15] Even if different or confusing, developing identities are taken for granted. "When I was a teenager, I was either really going and engaged and doing a lot of stuff and playing sports, or I was hiding in my closet at home with my black light on. And it really didn't seem remarkable to me, at the time. You know, 'This is how I am.'" [PF2] "So, for me, it was normal. There wasn't any reason to think of it as anything other than normal. And then I think, when I got to be about 16 or 17, I started to realize that maybe I had a little more emotionality than a lot of people." [FF5]

Sometimes, the taken-for-granted self-views developed early in life were quite negative. "I thought I was just a bitch. I really did. I thought I was just mean. And sometimes I would really be so ashamed of myself that I hated myself. You know, why was I like that? Why would I do something like that? I could not understand why I would do that." [C21] "For all my life I was extremely irritable and unhappy and angry. And so if you're that way for that long, you really believe that's who you are. You come to hate yourself. I mean, I did." [H19] "I had very low self-esteem. Very. I mean, low wasn't even a description. It was like not there, you know." [F16]

Important others are not always helpful, and their reactions can reinforce a developing negative identity. "Even though I knew I wasn't crazy, when people called me that, you know, I felt like it." [H16] Sometimes experiences central and obvious to a child are simply not acknowledged, making them difficult to integrate. "I had a mother who wasn't very, um, I don't know how you would say, she just wasn't very emotional and didn't know how to handle it very well, so she would not comfort me at all." [H1] "My parents wouldn't validate that I was any different. I mean, even now... if you asked my mother, 'Was I a normal child?' 'Oh, yes.' ...They didn't want their child to have any, you know. And I think there was a lot of guilt in my mother because mental illness runs in her family." [H12]

Initial Symptoms Experienced as an Adult

If first symptoms occur at a somewhat older age, when a relatively stable and coherent identity has developed, they will be challenging to the extent that they are discrepant from earlier self-views. This may be a very confusing and challenging time, indeed, as no explanation is usually available for what might be happening.

“I thought, I literally thought I was going completely crazy, just completely crazy. Like, ‘What is this? What kind of behavior is that?’ I mean it’s just kind of weird. You know, I was devastated. Because it’s, you know, it was out of control and, of course I just felt tons and tons of guilt.” [N2] “I think from the time I was about 20 on, because this also makes you very emotional, and there were instances that, you know, it was way beyond [what I was used to]. It can make you feel very, very bad about yourself... You can just feel like the lowest form of life on the planet.” [B23]

Challenges After Diagnosis

Symptoms that occur after receiving a diagnosis may or may not be viewed through the lens of the diagnosis. If they are, seeing them as bipolar symptoms may either decrease or increase their challenge to identity. The challenge may be decreased when symptoms have an explanation. “I felt better. I felt better because my feelings had been validated. I wasn’t a bad person, I just had something that needed to be fixed.” [B24] “He put me on Depakote, and I’ve been fairly level since. For the first year, I still had times where I’d be really down, or I’d be too far up, but it didn’t happen very often. And I knew what was going on, so I didn’t let it rattle me as much.” [B7] Challenge may be increased when diagnosis makes interpreting everyday life more confusing. “I was really afraid to feel good for a while, for almost a year after my last manic episode I was afraid to feel good. Every time I’d start feeling a little happy or laughing, I’d go, ‘Oh shit. Might be getting manic again.’” [P16] “The very frustrating thing is you wonder how much you have to worry. So if you’re in a real good mood, or you have a real productive day – oh, oh, does this mean something bad?” [M3] “For months after the depression finally broke, it was like I looked around every little corner for any kind of dark cloud. You know, it was just very frightening.” [F3]

Ongoing Challenges

Even long after diagnosis, when a person is taking the most effective medications they and their psychiatrist have discovered, and after years of psychotherapy, a person may still experience continuing symptoms of bipolar disorder. These symptoms may present a still different kind of challenge to identity for someone who has "done everything I was supposed to". Symptoms at this point may be particularly frustrating, challenging to views of future possible selves, and relevant to feelings of loss of parts of self.

"Prozac had just up and quit on me after about 10 years. One day, it just didn't work. I fell into a horrible depression. Ten years it worked, and one day I had to go right to the hospital, practically." [K2] "When you're taking medicine, and you're taking it when you're supposed to, and you're doing pretty much everything you can do to feel good, and it's still not working, I mean, why take it? Why?" [H25]

Continuing symptoms, milder than before but still very noticeable, reminded one person that she still had an illness, and always would. "I'm not cured. I don't think I'll ever be cured. I don't think there's ever going to be a cure, not in my lifetime." [C25] Even when not experiencing symptoms, people may have reminders that they still have to deal with bipolar disorder. "If I run out [of medication]... I kind of panic. It's like, 'Oh god, I've got to go get it or I'm going to start swinging again. And I don't want to do that.' So, it does remind me every day. You get up, you have to take your medicine." [B8]

Chapter Summary

This chapter has focused on the kinds of information that may present particular challenges to identity for people with bipolar disorder. The nature and range of bipolar symptoms, how they are experienced and how others react, is at the forefront of the barrage of challenging information. The label placed on this set of symptoms, the diagnosis and it's implications in society, add further challenges. Finally, the treatments for the illness, both medications and psychotherapy, may, themselves, challenge identity.

Symptoms may be experienced long before diagnosis and, even with good treatment, may continue after diagnosis. Symptom-related information may challenge identity in different ways at different times of life or illness.

Chapter Six

DISCUSSION AND ILLUSTRATION: RESPONDING TO CHALLENGE – PROTECTING IDENTITY

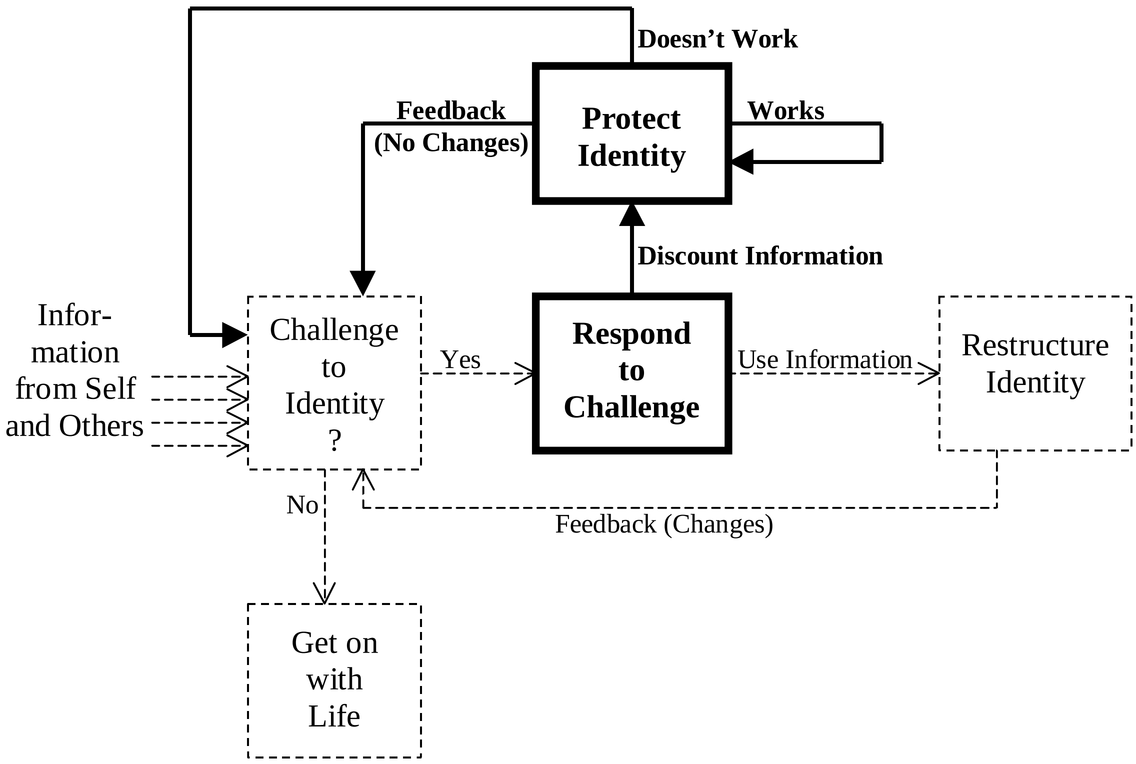

Figure 3: Responding to Challenge – Protecting Identity

Once identity is challenged, a need is created to respond to this challenge. The two major types of response are to discount the challenging information to protect identity or to use the information to restructure identity. Very often the first response attempted when identity is challenged is to push the information away to try to maintain the coherence of one's sense of self.

Protecting identity in this model refers to attempts to maintain whatever is one's current view of self. This might mean one's view of self as a well and functioning person, which would likely be challenged by any symptom-related emotions or behavior, by others' reactions to these, by hearing a diagnosis of bipolar disorder, or by taking medication. The current identity being protected could also be a very negative symptom-based view of self as flaky, unpredictable, unreliable, mean, and bad, which would likely be challenged by diagnosis of an illness as an alternative explanation, by mood-stabilizing medication, or by psychotherapy. Another sort of symptom-based identity that a person might try to protect would be a grandiose sense of self, more common during a manic episode, which would also likely be challenged by any thoughts of diagnosis, mood-stabilizing medication, depressive symptoms, psychotherapy, and reactions of others. Lastly, even well integrated identities, in people who have taken in a lot of previously challenging information and restructured their self-views to include symptoms, diagnosis, past behaviors and future possibilities, may sometimes need protection when circumstances seem overwhelming.

Factors in Deciding to Discount Information
Maintaining coherence, predictability, and control Very threatening information Feeling good – Pleasant manic or hypomanic episodes Feeling bad – Depressive episodes Protective strategies are working Lacking resources to deal with information
Strategies for Protecting Identity
Denying the truth of the information Reinterpreting the information Ignoring the information Keeping the input from forming in the first place Reducing the effect of the information

Table 3: Discounting Information to Protect Identity – Decision and Strategies

This chapter looks first at what leads to a decision to discount information, and then at strategies that people use to protect identity. Table 3 summarizes the material covered in this chapter.

Deciding to Discount Information

Once information is received, compared with identity, and determined to be challenging, a choice point is reached. At this point in the process, a person must decide how to <u>respond to the challenge</u>. This is not a choice made once, but a choice made over and over, sometimes many times in a single day or a single hour. As they receive multiple strands of information from self and others, people with bipolar disorder repeatedly have to decide whether to let the information in or try to keep it out. This decision-making process, although often executed very quickly, appears to be quite complex, involving the potential consideration of many factors.

Individuals seem to weigh the pros and cons of considering versus discounting each piece of information. Many prioritize what information they will consider first, especially at times when they are receiving much challenging information and dealing with all of it would be overwhelming. They consider what resources they have currently available to deal with challenging information, and what resources they have to keep it at bay. Given the constellation of influencing factors, a decision is made for each strand of incoming information. At a particular time, a person may be taking in some information while keeping other information away.

As I talked with people, there seemed to be a set of factors that tended to influence them to discount information in order to protect the self, and another group of factors that would increase the probability that they would take the information in and use it in restructuring the self. The factors that influenced people to <u>discount information</u> in order to protect self-views are: <u>maintaining coherence, predictability, and control</u>; <u>very threatening information</u>; <u>feeling good – pleasant manic or hypomanic episodes</u>; <u>feeling</u>

bad – depressive episodes; protective strategies are working; and lacking resources to deal with information. These factors are discussed below.

Maintaining Coherence, Predictability, and Control

Maintaining a basic level of coherence of identity and a sense of predictability and control in one's life are the fundamental motivators for pushing away challenging information. Daily functioning is rooted in some sense of a coherent self and, if this feels tenuous, further challenging information will be fended off to protect one's ability to continue to function in the world. It is only when a person feels that some sense of coherence can be maintained during the process of change that challenging information is likely to be considered.

Maintaining a negative view of self may be preferable to giving up a sense of oneself as in control. "I look back at the times that I have said something that's hurtful or could be interpreted as hurtful, and I think probably I was just being a bitch. I don't really think that it's the bipolar thing. But, it may also be that if I acknowledge that it was [the bipolar] then I would also have to acknowledge that my control over it is more tenuous than I like to think that it is – which is also a little scary, because I consider myself to be extremely well self-controlled with regard to being bipolar. So, anything that doesn't fit that implies that I'm less well self-controlled than I think I am." [F14]

People are not eager to give up beliefs about themselves that have provided continuity since childhood. "There's the part of me that wants to think that nothing's wrong with me. Because you grow up, and your parents usually treat you like you're special... most parents really love their kids and make them feel special, like there's nothing wrong with them, and nothing ever will be wrong with them. So I guess there's always still that part of you that wants to think that nothing's going to go wrong, and you'll be super-successful, and the world's going to love you, you know." [B7]

Very Threatening Information

Very threatening information is more likely to be pushed away. What constitutes especially threatening information varies considerably among individuals. Many people, however, mentioned that information implying they were “crazy” was particularly threatening to their sense of self. It is hard to reconcile “crazy” with “coherent, predictable, and in control”, so this kind of challenge is often vigorously protected against.

“I had convinced myself that, ‘Well, Prozac is a fairly normal thing to take. Xanax is fairly normal. But, my god, you’re talking about lithium, things like that. I mean only crazy people take that stuff.’ That’s how I thought of it, ‘God, I’m certifiably insane, and this is not a good thing for me.’” [D10] “I think the knowledge was there, but there was also a strong component of denial. Because, actually, ah, manic depressed, I mean, that’s like mentally ill, in an institution, on the street.” [F6] “I went to a family physician because, for some reason, I didn’t like the idea of going to a psychiatrist. Don’t ask me why. I just had a real problem with that.” [F2] One person kept putting off getting information: “And reading that book [*An Unquiet Mind*], first of all, I picked it up for months and months and months, and it scared the hell out of me. I didn’t want to see it.” [K23] One person summed it up in her journal: “bipolar disorder + psychiatrist + lithium = crazy person” [FJ1]

Feeling Good – Pleasant Manic or Hypomanic Episodes

Feeling good is another strong motivator for protecting the current sense of self. Many people describe not wanting to be challenged while experiencing manic or hypomanic symptoms which are pleasant or contribute to productivity. While experiencing euphoria or a sense that “I can do anything”, people are more likely to discount information about the consequences of their behaviors or explanations of their behavior as symptoms of bipolar disorder.

"They could have told me, 'You can't ever get off of [medications]. You can't ever get off of them, or you'll fly into some kind of manic place and it's really an unhappy place to be in. You don't want to do that.' They could have told me that all day, and I would have still, because of the place where I felt so healthy, I would have still gotten off of them." [D19] "One of the things that happens when I'm manic, it's like there's a barrier between me and the world. 'Nothing's going to hurt me, and nothing's going to go wrong.' Pretty grandiose." [PF5] "When things are going really well, you say, 'Well, things are good now. I can just kind of slack off [the meds].' And a lot of people do that. A lot of people do that knowingly when they're in remission, so to speak. A lot of people do it when they're manic, because they just don't think they need it... I asked one of the doctors, 'What happens if I just stop everything?' And they said, 'Well, you can do that.' But they were saying that sarcastically. Of course, that's all I wanted to hear. I didn't care what came beyond the 'you can do that'. You can do that if you want to risk... After the 'you can do that', I stopped listening. And so I [stopped meds] a couple of times, and it got really bad." [G6] "I also have this tendency, when I get sort of hypomanic, to want to stay that way. I mean, it's great, you know, it's fantastic." [PF4]

Feeling Bad – Depressive Episodes

Feeling really horrible might seem like a motivator to find a way to change things, but, for people who do not see their basic personalities as "depressive", it is not a motivator to take in more depression-related information. A large proportion of the people I talked with described strategies, used when they were depressed, to keep others from knowing how bad they felt. This allowed them to avoid large amounts of potentially challenging input resulting from others treating them as depressed. A depressive episode is also a time of considerably lowered internal resources, when dealing with any additional challenges is likely to seem nearly impossible.

"When I'm in [a depression], it's hard for me speak for myself, it's hard for me to let people know that I'm feeling that bad." [J21] "I would mostly use [alcohol] when I was moderately depressed. Because when I'm severely depressed, I don't do anything. I don't move. I'm like frozen." [PF4] "This has been the toughest time. And I think I was actually concerned about my lack of concern this time. I got so depressed, it was just like, 'It doesn't matter.'" [FF12]

Protective Strategies are Working

Having a protective strategy that seems to work, or having a repertoire of such strategies, increases the probability of successfully pushing away threatening information. As long as the strategy protects identity, dealing with challenging information may seem unnecessary.

Alternative explanations may work for a long time: "I knew that I did strange things, but I always considered it to be personality quirks as much as anything." [F1] Drugs or alcohol may work for a while to protect valued parts of identity: "Man, it just makes me feel wonderful, and manic, really. [The drugs I used] trigger my mania, and that's what I was going for." [P9] Speaking of hypomanic episodes: "I sort of romanticize that. It was fun. And I have some good stories that I've picked up from these things that I've done, that I can share with other people. It sort of projects this image of me, or of a part of me, that people seem to admire. So it's kind of hard to let go of that." [PF8]

Lacking Resources to Deal with Information

Not having the resources to take in and use information may contribute to discounting the information. Some people described a time when they simply did not yet have a framework in which to fit certain challenging information. Additionally, if a person lacks the interpersonal support needed to deal with difficult information, they may be more likely to discount it. Finally, a person may have developed ways to take in and process challenging information, but may currently be busy dealing with other material and not have the current capacity to take in more.

"I definitely saw some of that manic behavior earlier. But I didn't know what to call it. I had no framework to put it in." [N1] "I didn't realize at the time. When he first told me [the diagnosis] I didn't realize that you can lead a pretty normal existence. I sat there just going, 'God, it's going to be a death sentence,' you know." [D10] "I don't even know if I'd heard very much about it. I didn't know, like, what it was, really." [H4] "I'm sure it's like any shocking news, I guess. It's difficult to absorb at one time." [F7]

Strategies for Protecting Identity

Once someone has decided to discount information to protect identity, a strategy to accomplish this is needed. The people I talked with described numerous strategies for protecting their identities from challenging information. These can be categorized as five general approaches: denying the truth of the information, reinterpreting the information, ignoring the information, keeping the input from forming in the first place, and reducing the effect of the information. Each of these five approaches represents a process of dealing with information, not a particular behavior. In fact, some behaviors that look outwardly similar may represent differing strategic approaches to dealing with challenging information. All of these strategies are described as "working" – some briefly, some for years. When a strategy works, it will tend to be continued. These strategies are all described by those who have used them, however, as eventually breaking down. When they don't work, the results of the attempt often themselves become challenges to some aspect of identity. Continuing any of these strategies to push away information requires constant ongoing effort. Since they do not result in any changes in identity, challenging information continues to challenge and must be continually dealt with. As a result, these attempted solutions have an unstable quality and require large amounts of energy to maintain over time. The five strategic approaches to protecting identity are discussed below.

Denying the Truth of the Information

Those using this strategy assert, and believe, that the challenging information is wrong. For some people, this was the first strategy used when they received their diagnosis of bipolar disorder. “I wouldn’t accept it at first. I didn’t believe that there was such a thing as bipolar, and that I was manic. I didn’t like that. I didn’t think there was anything wrong with me. I put the blame off on my husband and everybody else. I just thought that I was just too strong to have anything wrong with me.” [C1] “I’m sure I was rifling through my mental files for exceptions. You know, this can’t be true because... I’m very successful at my job; this can’t be true because I have a happy marriage.” [F7] “My thoughts [when I heard the diagnosis] were, ‘Well, I’m not sure that all that stuff back there has any significance or that this bipolar thing has any reality. I’ll just go along with it for a while and see what happens, see if I understand anything about it that has any more meaning, you know, helps me understand better than before.’ And it hasn’t.” [L9]

Denying challenging information is a popular strategy as manic episodes develop. “I ended up in the hospital... Everybody else is weird, I’m fine. And so I’m wondering, ‘Why am I here?’” [M2] “I just feel really criticized and really persecuted, sort of. ‘They don’t know what they’re talking about. Leave me alone, I’m fine. You don’t know what you’re talking about.’ Real defensive. Minimizing, you know, what they’re saying. Excuses to stay the way I am, I guess.” [PF6]

If the strategy is successful, it may lead to behaviors such as discontinuing medications. “At times it’s like, ‘Yeah, I need to deal with this. I have to take [medications] every day as prescribed.’ And then something would happen. I don’t know what, but I’d be like, ‘That guy was wrong. There was something else going on with me. Blah blah blah.’ And talk myself out of it, and I’d stop taking meds. And one explanation is that I really like being hypomanic. I love it. And sort of having the delusion or illusion that I could control my mood, you know, ‘Ok, I’m not going to get really wacky this time.’ And, ah, that doesn’t work.” [PF5] “I really actually didn’t think I needed [medication]. You know, I think I just didn’t believe that it was helping me. I really didn't think anything would happen [when I went off meds]. I think that I just didn't really believe that I had it." [C8]

Reinterpreting the Information

In this strategy, the information is somehow acknowledged, but is discounted by interpreting it to mean something different. Information may be reinterpreted in a positive or a negative way, to fit with the current identity being protected.

"I just view myself as having a highly artistic temperament, and not being average. That's a better word to use than normal. But I wouldn't want to be, because I figure that would be just terribly boring. I get bored so easily that I figure that that would be just a horrible way to live, being bored all the time." [D22] "Even though I was bipolar for a long, long time, and I'd been diagnosed, and I'd taken meds for it, I still had this idea of who I was that was compensatory... I had this idea that, because I was different, I was special. And then I kind of felt compelled to prove it to people – by achievement, by being really funny, by doing a lot of stuff, you know, having an interesting life so I could tell stories about it." [P17] "I was always the boss, so if I didn't like the way something was going, I'd just fire everybody and hire a whole new staff, or whatever. And I thought that was perfectly normal. Now I look back on what I did, and it's just awful." [G3] "There are certainly the times [during hypomanic phases] when I think I'm being highly productive, but I'm being highly productive in a totally esoteric pursuit. Planting tomatoes at midnight is probably not considered productive by most people." [F22]

Sometimes the reinterpretation supports a more negative self-view. "I look back at the times that I have said something that's hurtful or could be interpreted as hurtful, and I think probably I was just being a bitch. I don't really think that it's that bipolar thing." [F14] Another woman talked about her anger, her "fiery side... You cross me and it gets real bad... That's how I am, and maybe that is part of my manic side, you know... but I always thought it was just not being a wimp. And I like that. I like not being a wimp. I hate wimpy people. I think they just get run over too much." [K8]

"You know, it's funny, when I was depressed, I never read about depression much. I thought it was really just my fault. I mean, I knew I needed medicine, but I really think I felt guilty about it, because if I could just snap out of it and be like other people and, you know, I really felt like it was my fault... I did take it as my responsibility. And I just kind of blew off, so medication helped me, well, that was just kind of a happenstance. I didn't put two and two together, because that would have made sense, and I think I would have rather carried that burden and carried that guilt than to have made sense out of the whole deal." [K12]

Ignoring the Information

Sometimes people are able to acknowledge the challenging information, and even know that it is probably correct, but make a choice to discount it by directing their attention elsewhere. "I chose to ignore it for a long time... the fact that I have bipolar disorder... even though I had all this evidence to the contrary." [P10] "I was always afraid of going to the psychiatrist, too. I guess I was a little afraid for a long time. I knew that there was something wrong but, at the same time, I didn't want to get diagnosed." [H12] "I think the knowledge was there, but there was also a strong component of denial. Because, actually, ah, manic depressed, I mean, that's like mentally ill, in an institution, on the street... Even though I had read enough at that time to know that that wasn't necessarily true, that was still very much the perception, really, with any kind of serious 'mental illness'." [F6] "When I start to get manic, how it affects other people doesn't really matter that much. I mean I think about it. I really don't want to hurt anybody, but I do it anyway. I'm really good, when I'm getting manic, at not thinking about consequences." [P11]

One participant re-read a journal she kept around the time of her diagnosis. "I was surprised, though, when I re-read it, about how dispassionate I was about the whole thing. And I think that that was probably... a way to distance yourself from it a little... I would have thought that I would have been a lot more open and verbal about it in here, you know. But, actually, I've always had a problem with tending to conceal things from people who are close to me, and I realized, looking through this, that that includes myself, interestingly enough... But, I was intensely suicidal during this. I mean like that was all I thought about, morning, noon, and night, and it doesn't come through." [FF1]

Keeping the Input from Forming in the First Place

This strategy is used especially for protecting the self from reactions of others. People who have learned that others' reactions are likely to create pain and produce challenges to self-views develop ways to keep this input from forming in the first place. One way to do this is to prevent others from observing anything that might provoke a challenging response.

A number of people described effective masks for hiding their depressions. "When I'm depressed, and I'm really in a situation where people might notice something wrong, I tend to withdraw, keep to myself, do things where other people won't see me." [J5] Another woman described a conversation with a friend: "And he said, 'You can sit at this table and be the life of the party and be the most normal person in the whole world, and everybody loves you, and you've got funny stories, and you can just be dying inside. You can just fake it so well.' And I thought, 'I don't even know I'm faking it sometimes. I guess I'm really good at it.'" [K6]

"When my mood is unstable, I'm a world unto myself. Everything's like inside my head. It happens when I'm depressed and it happens when I'm manic. It's kind of like I feel impermeable. Everything, all the feelings that I'm having and all the experiences I'm having, I'm creating this in my head, and nobody really has access." [PF10] "The first time I went in [the hospital], I talked my way out in 32 hours. I just put on my face, that everything was ok. And I just convinced them that everything was ok. I was so full of shit. [My therapist] calls it my 'game face'." [N20] I commented in one interview that people probably didn't ask about bipolar disorder every day. "No, they don't, because I don't give them that opportunity. I'm good at hiding out." [L20]

"I was totally not willing to tell this psychiatrist, to admit to some things and tell him the truth. It was embarrassing. It's a real humiliating thing. What was embarrassing about it was just not having control over my actions, or I was feeling like I was choosing not to have control, and later found out, well, some of this stuff you can't help. Um, I was hypersexual. I was like seeing several different men. And I would flip from flirting with one man to flirting with the next one to flirting with the next one, just like bonbons or something. And that was pretty bad. Even though I didn't go sleep with this one and sleep with that and sleep all around, I did it enough to realize, when my friend called me on it, ...it's not what normal people do. [And I wouldn't tell] because I thought, 'There's something wrong with me,' and I was going to be labeled some kind of whore or some kind of bad person. I didn't want to be labeled these things." [D7]

Even the most extreme options may be considered. One woman worried that her husband would not be able to accept her diagnosis. (He actually turned out to be very supportive.) "So there was that fear. I was already very depressed at that point, so of course suicide seemed like an even better, um, opportunity, not even option, but a better opportunity at that point." [F8]

Reducing the Effect of the Information

The use of street drugs or alcohol is one way that some people try to reduce the effect of very challenging information. Substances may dull the perception of painful information. The effects of substances may interfere with effectively sorting out important input. "The mood swings were really bad... I just thought it was the drinking and the drugs, because I was also into cocaine." [C18] "In my late teens, early twenties I was doing an awful lot of drugs, so it's hard to like tease it out. You know, why was I staying up for a week at a time? Was that being manic, or was that crack? Or both?" [PF3] "I thought the pills were making me depressed and I had finally gotten to the point where I was taking too many and I was addicted, but, if I got off of them, I would be happy and things would be better in my life. And, of course, they were. And when things do get better, ...you're not supposed to be depressed. And I was still very depressed, nervous. That's when I knew that I hadn't addressed the real underlying problem that caused me to do the other stuff." [G5] The same person says, "I don't know that I’d have ever addressed the manic depressive if I hadn’t got sober and quit taking pain pills.” [G3] “I think I did a lot of [pills and alcohol] because I couldn’t deal with who I was. I do think it was related,” [G13] The function of alcohol was discussed by one woman, who talked about when she was most likely to use it: “Definitely more when I’m depressed... Because it definitely dulls your, I don’t want to say your emotions because I’m not really emotional when I’m depressed, but it fuzzes everything very nicely.” [FF10]

One participant had a different way of reducing the effect of difficult information: “I also did a lot of cutting on myself during my teenage years. It got to the point where I needed to see the blood. I needed to see that I was hurting physically, I guess... I’d much rather feel that than I would feel this... Most of the time when I do it, it’s just to take away emotional pain.” [H4]

Chapter Summary

This chapter has discussed the part of the model that involves responding to challenging information by discounting it in order to protect identity. Something must be done about each strand of incoming challenging information in order to maintain a sense of coherence, predictability, and control. If the information is too threatening or the resources for dealing with it are lacking, then people will find a strategy for keeping the information away. This can work, at least temporarily, to avoid the disruption the information could cause and to maintain a sense of a coherent self. These strategies, however, require continual, repetitive work to keep ongoing challenges at bay. The solutions they represent, therefore, have an unstable quality.

Chapter Seven

DISCUSSION AND ILLUSTRATION: RESPONDING TO CHALLENGE – RESTRUCTURING IDENTITY

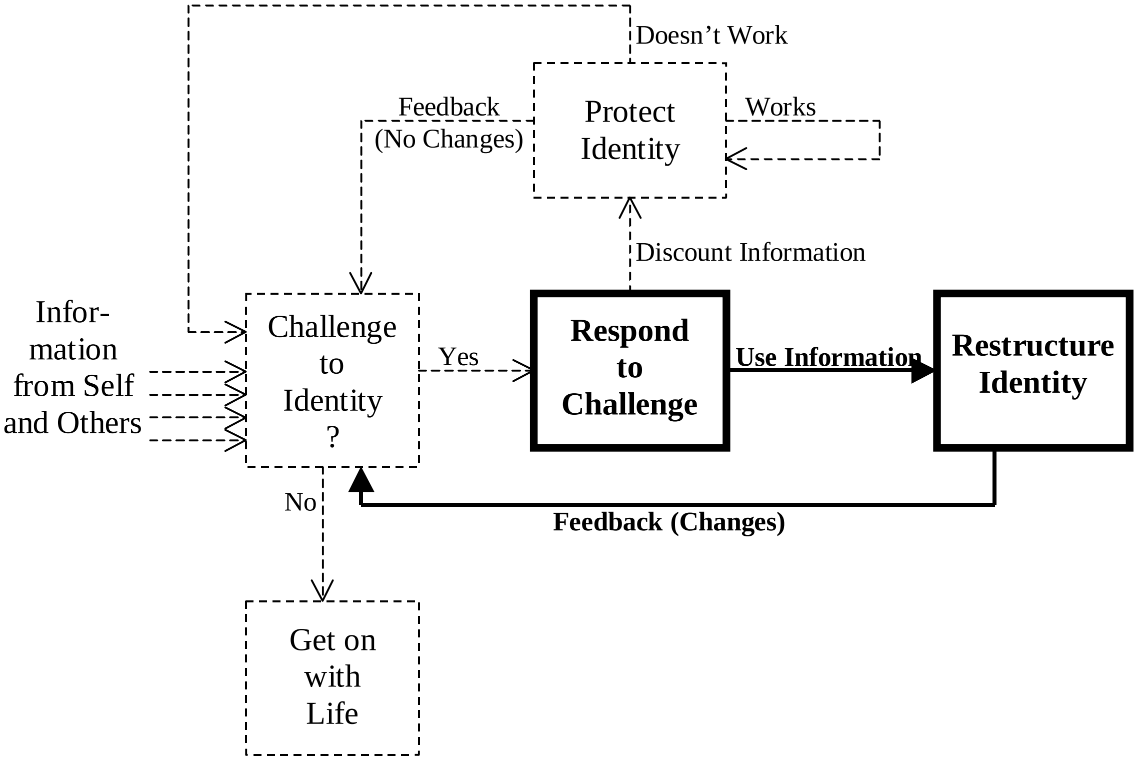

Figure 4: Responding to Challenge – Restructuring Identity

The second of the two types of responses to information that challenges one's view of self is to let the information in and use it to construct a more integrated identity. When a person decides to let in and consider a piece of challenging information, the uncomfortable discrepancy with identity is temporarily maintained. Work must be done to reconcile the discrepancy, and this often involves a reevaluation of aspects of self.

Restructuring identity involves gradual changes in self-views as one processes and integrates information that had previously been challenging to identity. The restructuring process provides feedback to the comparison process that evaluates incoming information. Since the restructuring process has in some way changed identity by integrating or accommodating a particular type of information, the challenge experienced at that sort of information decreases. A lot of energy may initially be required to deal with a piece of information as one explores ways to adjust a self-view, but thereafter that sort of information will be much less challenging. Energy, therefore, does not have to be continually used to respond to that type of challenge, and is available for getting on with life. This way of responding to challenge results in a more integrated identity that is likely to have a much more stable quality than an identity that must be constantly protected from threatening information.

This chapter begins by looking at factors that contribute to making a decision to consider and use challenging information. It then explores the complex set of issues involved in the process of restructuring identity. Table 4 summarizes the material covered in this chapter.

Factors in Deciding to Consider and Use Information

- Protective strategies breaking down
- No protective strategy
- Resources for dealing with information are available
- Remembering really bad experiences
- Commitments to others
- Feeling OK – Being between episodes or experiencing mild symptoms
- Feeling better – Confidence in the restructuring process

Process of Using Information to Restructure Identity

- Observing Self and Coming to Know Self in Relation to Symptoms
  - Patterns of symptoms
  - Getting to know the “middle” self
  - Understanding the results of symptoms
  - Taking a stance – What I consider “me” and “not me”
  - Taking a stance – Relationship with illness
- Dealing with Issues of Control
  - Distinguishing what one can and can’t control
  - Dealing with responsibility, fault, and blame
  - Taking a stance – What I will try to control, and how
- Reevaluating Views of the Past
  - Reinterpreting past actions and behaviors
  - Parents and other relatives with bipolar disorder
  - Taking a stance – Rewriting the story of one’s past
- Presenting Self to Others
  - Telling or not telling
  - Taking a stance – What to present to others

Table 4: Using Information to Restructure Identity – Decision and Process

Deciding to Use Information

As discussed in the previous chapter, the decision about how to respond to challenge is a complex one, involving weighing the pros and cons of using or discounting the information, and the resources available at the time. I discussed earlier a set of factors that tend to lead to decisions to discount information. There is also a set of factors that appear to contribute to a decision to use information to restructure identity. These factors are: protective strategies breaking down; no protective strategy; resources for dealing with information are available; remembering really bad experiences; commitments to others; feeling ok – being between episodes or experiencing mild symptoms; and feeling better – confidence in the restructuring process. When one or more of these factors exists, a person is more likely to consider challenging information, rather than pushing it away. These factors leading to a decision to use information are discussed below.

Protective Strategies Breaking Down

Most people I interviewed described finding ways to discount challenging information that worked for a time, but then broke down. At that point, they found themselves faced with challenging information, but without effective resources to keep it out. These were usually very distressing times of conflict, involving strong motivation to protect identity without the wherewithal to do it effectively. They were times that people may have felt no option but to consider information previously avoided, leading to the beginnings of restructuring identity.

An experiment based on the belief that one does not need medications can backfire. “And by that next Monday, it was, ‘I need to be back on meds.’ I was just terrified, crying, and in his office again, like, ‘I failed. It didn’t work. Now I know I have to do this. I know for sure that I’ll have to stay on meds the rest of my life. I’m afraid. Don’t ever let me do this again.’” [D19] Some protective strategies break down when serious side effects can’t be ignored. “I really realized the things that are affected when my mood spins out of control. It affects my family. It affects my son. It affects my wife. It affects my mom and dad, all my extended family." [PF5]

Sometimes people give up a protective strategy, not fully realizing at the time what it has been protecting. "Well, when I got sober is when I think I figured it out. When I quit drinking and taking pills, and still had this wide fluctuation of moods, and really depressed a lot, and also euphoric a lot. I'd flip back and forth real quickly. I told [my therapist] I thought something was up that we didn't know about, that we had maybe unmasked." [G1]

No Protective Strategy

Sometimes a piece of information will be so sudden, so discrepant from identity, or seem to make itself so obvious, that a person simply has no effective way to discount it, even temporarily. In these situations, people describe feeling very shaken and are likely to consider and use the upsetting information to try to reestablish a coherence of identity that they could not maintain by pushing the information away.

"Well, I fell off my rocker. I ended up in the hospital." [M1] "Something about it was scaring me. But I just knew when I got to that point I couldn't survive any longer if I didn't get help." [H12] "I had [my first] major episode, and my friend – I had ended up on her porch at 4:00 in the morning – looked at me and said, 'Wow, I think you're manic.' And when she said that, it was like, 'Oh, you're exactly right. This is mania! Wow, that's exactly what it is.' It wasn't until then that I had even considered that I might have had some manic or hypomanic episodes." [N1] One woman had a friend who observed her unusual behaviors during her first manic episode, and tried to intervene. An extreme message finally could not be ignored. "You know, she would leave messages and I wouldn't return her calls. It took her actually leaving a message that literally said, 'If you don't call me back by X time, I'm going to get the police, and we're going to come over and break your door in. This is how serious this is. I must hear from you to know that you're ok.' It literally took that message for me to go, 'I think she's worried about me. Wonder why?'" [D7]

Resources for Dealing with Information are Available

People are more likely to consider information when they have begun to develop ways to process and integrate it. Having a framework in which to fit challenging information is often described as especially helpful. A diagnosis of bipolar disorder and knowledge gained about the diagnosis are mentioned by many people as being among their first such organizing frameworks. Further reading can augment this framework. Having the support of a therapist or another person can be an extremely important resource in deciding to consider challenging information.

"I knew I was getting way inordinately pissed off over things that should not have upset me. And then, when [my psychiatrist] said, 'Do you have this? Do you have this symptom? Do you have this symptom?' 'Well, yeah, of course, I always have. Not only I have, but my mother has...' First time I heard the bipolar, the manic side of it. And I've been tremendously relieved." [J18] "By that time I had done enough reading about depression and things of that nature... I was very much book-oriented and read up on things. And, I mean it just immediately sounded right. You know, I knew that it was right." [F2]

"I think it took [my therapist] saying the words. I have, obviously, great respect for this man, and I think it took him saying the words for it really to kind of hammer home that, yeah, that probably was accurate." [F6] "My therapist, he was just... My parents hated my therapist, by the way, because he had no trouble validating my feelings, or pointing out stuff that they needed to do. But, anyway, it was a relief for me. Having him for my therapist was really good because he validated my feelings, which was something that was never really done." [H18] "Journaling... My psychologist encouraged me, 'Write. When you feel your moods changing, write down what are you doing during those periods, or what do you feel like doing, or what do you not do because you don't feel like doing it, or avoid." [F16]

"I started taking the antidepressants, and they worked. And my sister and I talked about it and, 'It's possible. Well, maybe,' you know. And then I started going to the library, and I started looking up all this stuff. And, ‘Ok, maybe this is something that I need to start accepting, that I could possibly have this problem.’” [C5]

Remembering Really Bad Experiences

“I don’t ever want to go through that again.” Many people describe memories of experiences that they are highly motivated not to repeat. These can influence people to process even very challenging information.

“I just had to accept the fact that I have a mental illness, and that was a long time coming. (What led up to that?) Probably the fact that I almost died, and I almost ruined my career, and abandoned my family, and hurt everybody who cares about me. That was a lot.” [P10] “It’s the opportunity to really screw up your life really bad, and pretty quickly. So I think that’s what, that frightens me, of course.” [N23] “When I think back on a lot of the crazy stuff I’ve done, it’s really embarrassing. It is. I’m really embarrassed about a lot of the things I did. So, I don’t want to be embarrassed like that any more, because it’s pretty uncomfortable.” [P18]

“The state hospital, that visit was probably the hardest on me. That episode, that was the worst. That scared me worse than anything. It was a midnight walk down the middle of the street in your nightgown and during a thunderstorm. It lasted about three days. I was completely out of my mind, completely. If ever it was a manic, that was definitely a manic.” [C11] “When I really crater depressively there’s still that fear from long ago. I was suicidal and it was very, very intense. So intense even that I’ve never really forgotten it and I’ve never really forgotten the suicidal ideation. And, um, Virginia Woolf, her suicide note was something like ‘I can’t endure this madness again.’ And that very much sticks in my mind... So that’s frightening.” [F5]

Commitments to Others

Commitments to important people in one’s life can be a factor in considering information that one would ignore if thinking only of oneself. Consciously thinking about these commitments may increase the probability of facing challenging information. “I know I have commitments, that I’m inextricably intertwined with so many people, and that I have to hold up my end of our relationship, and I have to be responsible. I have to treat my family well, if not better than well, and not damage them. I guess it’s a sense of moral commitment. I don’t know what happens, though, when it flips. Well, I know what happens is I refuse to think about those things.” [PF6]

Feeling OK – Being Between Episodes or Experiencing Mild Symptoms

During times between episodes, people describe having less intense motivation to protect identity and more resources to deal with challenging information. During these times, they may explore things that otherwise would be too painful or too difficult.

“My best therapy has been in times of me not being in crisis.” [H26] “When I’m not hypomanic, I look at how I feel about myself when I am hypomanic, how I feel really special, and it’s really embarrassing to me. I mean, nobody else knows about it. But I’m embarrassed at myself, for myself, you know. And I don’t like that. I really don’t.” [PF12] “I haven’t gotten to the point where I can predict when it’s going to happen. I understand some people who are bipolar, with monitoring, may be able to get to that point. But monitoring is hard to do when you’re depressed. I’ve gotten to the point where I just try to... at least monitor when I’m feeling good enough to do so.” [J22]

Feeling Better – Confidence in the Restructuring Process

As people begin to work through the important issues in the process of restructuring identity, a kind of momentum develops. People describe developing a kind of faith in their changing selves, a sense that there is a reason for them to consider challenging information, even if their first reaction is to discount it. People develop a confidence that they are able to use and benefit from this process, even if it is difficult.

One person described her realization that it was important for her to keep looking inside, even though it had initially been difficult. “A lot of people are oblivious. They try this and this and this because they think it's going to make them happy. And they don't realize that the only thing that's going to make them happy is them resolving whatever's inside of them that's making them not like themselves, that's keeping them from looking inside. Most people don't like to dig too deep because it doesn't feel good. 'It's unpleasant. Let's not talk about it.' If you're not going to talk about it, how are you going to resolve it? If you don't resolve it, it's always going to bug you. You just can't bury things." [B17]

"I just feel very lucky that it was caught very early, and that's why I was able to recover so well. I'm still recovering, ongoing. I'm never going to quit." [H10] "Yeah, I'm really into therapy. I'm really into doing a lot of work on myself." [H20]

Process of Using Information to Restructure Identity

Once one has let in challenging information, one is faced with reconciling the discrepancy between this information and one's self-views. This requires work, resulting in a greater sense of coherence in identity. During the process, however, there may be a temporary, but uncomfortable, feeling of lessened coherence and loss of aspects of self. Restructuring identity is a process of uncountable tiny steps which takes place over years and continues throughout life. The people I talked with, however, described times when this process was more intense, times when they experienced observable and satisfying changes. Although, for some, this process began before receiving their bipolar diagnosis, the more intense phase of change usually came after the diagnosis.

Each person described a unique path through this iterative restructuring process. The outcome (or developing) identities were all different. There appear, however, to be a common set of issues that people with bipolar disorder deal with in the process of moving to a more stable, integrated identity. The major issue areas dealt with in the process are <u>observing self and coming to know self in relation to symptoms</u>, <u>dealing with issues of control</u>, <u>reevaluating views of the past</u>, and <u>presenting self to others</u>. How individuals deal with any of these issues may vary considerably, but dealing with each of them appears to be important in coming to terms with the experiences of bipolar disorder.

At times, the process has a quality of observing and getting to know the self. At other times there is a more active exploration process, formulating and trying out various options. And, finally, there are areas in which a person must eventually make a decision or take a stance about self-views and future actions. These are not “steps” in any sequential sense, although some may begin earlier and others begin only after receiving a diagnosis. Observation generally precedes exploration, which precedes taking a stance in a particular area. People may be working in any number of these areas at one time. Many people describe a time of coming to a fairly stable resolution in a particular area, but they may find they need to revisit it if circumstances change in some important way.

The remainder of this chapter is devoted to discussion and illustration of the major issues involved in the process of restructuring identity.

Observing Self and Coming to Know Self in Relation to Symptoms

Patterns of Symptoms

Patterns of feelings and behaviors are often among the first areas of self observation. This may begin before a diagnosis is received, or may come only after years of seemingly unpredictable changes. People begin looking for “cues and clues” that their moods are going to change. As they discover these, they begin to feel that their moods and behaviors are not completely random, and they may gain some sense of predictability. Having a diagnosis may help in making further sense of symptom patterns, as they are able to compare their own experiences with those described for bipolar disorder. Most people I talked with found that the diagnosis helped them make general sense of their symptoms, but they also had to come to understand their own unique patterns, cues, and clues which differed from what they understood to be a typical pattern.

"Now, I can tell you every minute if I'm high or low. I can tell you, manic today, depressed today, ok today. It's much clearer to me. And it's clearer since I've read this book, *An Unquiet Mind*. I've gotten another book on bipolar and read some more about it, since I found out that it doesn't have to cycle the way I thought it did. It's made me understand more about what a cycle feels like. I've learned a great deal this year." [K5] Some cycles are different: "I've really learned my cycles. Like November to April or May is more depressed. Whether or not something severe happens... I'll just get extremely depressed in November... I'm sure it has something to do with the seasonal stuff, the rain – there will be days when it's raining and I won't even get out of bed because I can't. And then it's like from May to October I'll be more manic, having more hypomanic stuff going on." [H6] Looking back, one woman observed cycles long before she was diagnosed: "I knew there was something very odd, and something kind of extreme about my moods. And I knew that when I got depressed, I often had some kind of, I sort of saw it as a bounce back, you know, that almost equaled how deep I had gone. As much as in depression I had been unable to function, I would come back and be overfunctioning. And I sort of got in this cycle. In college and graduate school there were times I would work day and night, and times I would not be able to function at all." [J2]

Patterns within episodes are also observed. Describing hypomania: "Mostly just very high energy... The high energy will sort of continue and increase and increase and increase, and I'll be getting less and less sleep and so forth, until I go into the phase where I get irritable. And then the irritability kind of builds until someone does something, or some situation occurs that triggers anger." [J6] "I think if you're feeling good, you're pretty productive, but it you're feeling too good you're not all that productive at all." [B13]

Some people put considerable energy into discovering cues and clues of impending mood shifts. "For a long time, I kept a warning signs journal I sort of came up with on my own. [It] identified my major warning signs that I'm becoming depressed or manic. I've got like six: euphoria is one, decreased need for sleep, grandiosity, too – I mean I don't think I'm God or anything when I get manic, but I certainly think that I have these special things that maybe I can help the world with... Paranoia is also one of my warning signs. And my depressive warning signs are like I ruminate about my failures, and opportunities I've missed, and things I've screwed up. I have no energy, I get amotivated, I stop caring about things. And I tracked those for about six months." [P12] Another person told me it took "a lot of work. Journaling... My psychologist encouraged me, 'Write. When you feel your moods changing, write down what are you doing during those periods, or what do you feel like doing, or what you do not do because you don't feel like doing it, or avoid.'" [F16]

Different people may identify different cues as relevant. "I can tell because my sleeping habits start changing. I start not being able to sleep at night, and I start sleeping during the day. And my moods, I get agitated easily. Things don't set right with me." [C4] "So I know now, when I go to my pantry and grab for a bottle of fingernail polish, I know by what color I grab what mood is coming on... [I'm] very attuned to that, very attuned. It very rarely catches me by surprise." [F4] "I went to the Estee Lauder counter a couple of days ago and bought this powder compact that is [laughs], it's like shades of blue, and then it fades into purple, and then it fades into this goldy bronze, and it's all glitter... So, you know, that was a pretty good cue – the next couple of days are going to be pretty good. Watching for things like that has really helped. Spending behavior is another big one, if I start wanting to spend money or wanting to write checks... It's a tension that builds up, and it's alleviated when that charge slip clicks or when that check is written. That's a very salient clue, and one that's very easy for me to identify." [F16]

Sometimes cues are difficult to interpret, especially differentiating impending episodes from normal mood changes. "The very frustrating thing is you wonder how much you have to worry. So, if you're in a real good mood, or you have a real productive day – oh, oh, does this mean something bad?" [M3] "I was really afraid to feel good for a while, for almost a year after my last manic episode. Every time I'd start feeling a little happy or laughing, you know, I'd go, 'Oh shit. Might be getting manic again.'" [P17]

Getting to Know the "Middle" Self

Some people describe always having been either high or low, and never having experienced a stable or "middle" self. For these people, being on medication may produce an emotional state that they have never experienced for any significant length of time. This may feel very odd, or even "not me", and requires some time of observation simply to come to know what this aspect of self is like.

"I had lived in a body that didn't just click like most people's. And I used to be envious of people who maintained a more steady, level way of being. I couldn't do it, I couldn't find that. As much as I wanted it or as much as I envied them, I couldn't find it within me to be that way. It still can be a struggle, but it's a lot better." [G2] "My whole life is getting to know myself, you know... I'm trying to learn a whole lifestyle, a whole new life. Because I don't even know me anymore... You try to live in this body. It's not easy. Because I don't even know what I'm doing. I don't drink anymore. I don't smoke anymore. I'm heavier than I used to be. I don't walk the way I walked, I don't talk the way I talked. I don't know me anymore." [C26]

Understanding the Results of Symptoms

Some people try for a long time to protect themselves against information about the results of their symptoms because it can be quite painful to deal with. Many people describe realizing that their actions have hurt others. Others begin to recognize that they have suffered significant losses in their own lives that, in retrospect, they can attribute to symptoms of their bipolar disorder. Others realize that, given their ongoing symptoms, their expectations and hopes for themselves are too high and need to be lowered to be more realistic. Mourning and coming to terms with these real losses is a part of the process of restructuring identity. Some people also identify gains that have come as a result of their symptoms, and are able to recognize and appreciate these.

"I feel like I've really lost a lot. And there's nothing you can do about that... I have no more savings. My disability pay is very low, not enough to survive on... And the pressure of having to get back to work, whether or not you're ready, is awful. And I happen to be in a career which is a commission-paying career, so I need to be pretty up. There's so much self-esteem and everything tied up in that." [K17] "I had done a lot of good things in my career. But I could never maintain them. After I'd get something done, I'd screw it up." [G1]

"It's cut off my social life. I've lost a lot of friends over the years by just, when I'm in a good mood, having my barriers low, and letting people very much into my life and getting very close, and even getting to the point where I'm almost letting people take advantage of me. And then I get manic and irritable and angry, and I snap back and push people away and just break off the relationship." [J20] " I don't have a lot of friendships, real true friendships, because I don't trust people and just because people don't understand." [H23] The closest relationships are often affected: "There's losses as a result of my illness. It damaged my relationship with my daughter..." [D24]

Bipolar disorder affects whether many people have children. "A big part of why I was not happy [about the diagnosis] was, you know, at some point I would like to have children. And the more crap I have to take to keep my brain chemistry even, the less likely the chance that I will get to have my own children... And then people are always like, 'Well, you can adopt.' And I'm like, 'Who's going to let me adopt?' With this disease, who's going to let me do that?" [N10] "I think it has a lot to do with why I never had children... Looking back, I recognize that in my manic episodes was when I was having a lot of sexual activity, a lot of sexual partners. And, because of that, I think I had multiple infections, which affected my fertility. So, between the combination of factors of affected fertility and waiting until late in life, I've had no children." [J21]

One person described looking in the mirror during her first major depressive episode and feeling a real loss of self: "What I saw was a stranger – it's as if [her name] has never existed or has moved out. There just wasn't anything there – no life, no soul, no person." [FJ2]

Many people realize they need to lower their goals and their expectations of themselves. "It has totally changed my future in a lot of ways... Wondering how long you can stay stable, what kind of jobs can you take now, because how much stress can you really handle without it making you sick? And I've been incredibly successful in very high stress, high performance kind of jobs. Well, honestly, I really can't do that kind of work any more. I mean I could try, and I might last a year, or I might last 30 minutes." [N23] "I got a lot of things done during that period [before being diagnosed]. And now, I don't get as many grand things done. I don't pull off as many home runs, but I hit a lot of singles and doubles. I just keep plugging. I just want to aim for some sort of stability, and have enough money to pay my bills." [G4]

Despite losses, many people also come to appreciate gains as a result of their experiences. "I'm not sure I could have done some of the things I've done were it not for just the sheer guts of going out and doing it. And I don't know where that would come from if I wasn't bipolar." [G12] "If I know the mania's impending, I'll go ahead and start making a list of things that I need to get done, because I know that I'll be able to do a lot during that time." [F17] "I feel incredibly fortunate that I've had this experience. I think that it's really given a richness to my life, and a fullness that I wouldn't have had otherwise... you know, the whole idea of looking at it as a gift. Who can say, or how few people can say, that they have these incredible mood swings, and get through them, and that it contributes all kinds of different things to your makeup. I feel very fortunate." [F18]

Taking a Stance – What I Consider "Me" and "Not Me"

As people sort through observations about self and symptoms, and as they consider what they value about themselves, they make decisions about what they will and will not claim as parts of themselves. People do this in different ways. Some see their symptoms as not parts of their real selves, but as something else taking over. Others see some, but not all, symptoms as being a real part of who they are. Some people say, "It's all me." From the point of view of a stable identity, it is less important what people claim as "me" than that they come to have a picture of what is and isn't part of the self.

"I think you know yourself a lot better than a lot of people know themselves, because you're so aware, all the time, of what's going on with you... Sometimes it makes it more difficult because you feel like you're not yourself. When you get really angry or irritable, or really depressed, or even really super-happy, you know that's not really you." [B14] "I don't like parts of me, obviously... I get tempted to blame it [on the bipolar disorder], but I have to catch myself. It's like, 'No, this is something that I need to work on.'" [H20] "I probably obsessed with it in the beginning. Oh, is this the real me or the manic me or the depressive me or whatever. Whereas now, it's just me." [F15]

"Even though I didn't really acknowledge it more comprehensively until the last year, my mood is part of who I am. It's partially constituted my relationships with others, who I've become, how I do things. I don't ever want to be manic again, or depressed again, but that's not realistic. But, to have it taken away would be like losing my self, or a big chunk of it. It would. I can't imagine that happening." [P16] "It's definitely been defining, both as far as having pride over conquering it, to the extent that I have, as well as feeling it's what makes me who I am." [F33] "I think it is all me, regardless of whether I'm intensely manic or incredibly depressed. Because at this point in my life, it's impossible to say, 'I would have been this way, had my mother been normal, or, you know.' So, it is all me, I think. I can't really look at it in any other way." [FF12] "Well, I understood a long time ago, this is me. I'm not getting over it. I hope to get it under control." [J5]

Taking a Stance – Relationship with Illness

After receiving a diagnosis of bipolar disorder, people seem to go through a process of deciding what they think is the nature of this thing they have been diagnosed with, and what will be their relationship to it. For many people, receiving a diagnosis allows them to begin to make a shift from seeing symptoms as reflecting a flawed character to seeing them as the result of a different biochemistry. For some, the result is viewing bipolar disorder as a physical illness, no different than other "medical" illnesses, to be treated with the best medications that science currently has to offer. For others, the illness is viewed as having a biochemical component, but not as completely separable from personality. Some see bipolarity as a part of their character, an essential aspect of who they are, which is not something to be treated or cured. Others note that, even if symptoms originated in biochemistry, the results of those symptoms over time, including interactions with others, have contributed in very basic ways to the formation of their characters. These people would suggest that medications may help to ameliorate current symptoms, but that other long term effects of having lived with bipolar disorder have to be integrated or dealt with in other ways. One of these ways would be in psychotherapy.

Some people are very clear about emphasizing the biochemistry. “As far as I’m concerned, I’m convinced it has a physical basis and that it’s not different than having diabetes or heart disease or something, and should not be stigmatized any more than having heart disease or diabetes.” [J12] “I explain it as a chemical imbalance in my body that other people don’t have... I see it as a chemical imbalance, being addressed by my medication. I don’t see myself as being less capable, or less bright than other people. I consider myself as being much smarter than most people, just because I’m such an arrogant cuss. I don’t see it as a deficiency.” [G8] “My first therapist really just helped me to understand that... ‘It’s not like you’re any different than anybody else. It’s just that your brain chemicals are not working right, so when we give you medication to make it work right, then you’re like anybody else.’ That’s just really helped me feel better about myself, and that I’m not really different.” [H16]

Other people emphasize interaction between the biological and the psychological aspects. “It’s also taught me the importance of, well, I’ve always known this, but not many people know this, that the physiological and the psychological are both urgently important.” [K5] “I think, especially since we didn’t know it, and didn’t treat it, until so late in my life, there’s been so much, psychologically and behaviorally, that has built up as a result of it, that I don’t think medication can help me cope with all of the problems at this point. I think there are certain self-esteem issues, with just having been different than other people, control issues, with not having been in control of my emotions, with having been in a household where things sometimes got out control.” [J15] “I think that if you have traumatic events that still affect and shape you, and of course they will, when you're an adult, and I just happen to believe that things like that will affect things like your body chemistry, because of the emotions that they cause, and that causes your brain to release or emit certain chemicals and, so, I think that definitely adds to it." [B12]

The words people choose to describe themselves in relation to bipolar disorder may tell a lot. "I really own up to the fact that something about it being bipolar, and not just depression, makes me accept it more as a disease... I cannot tell you why, but I finally am saying, 'I have a disease.' Maybe it's because you can say, 'I'm depressed,' and everybody gets depressed, but that doesn't mean you have depression. But you can't say, 'Oh, I'm bipolar' unless you really are bipolar, you know." [K14] "I say, 'I'm bipolar.' Kind of like, 'If you have a problem with it, you better let me know now.' To me it's not an embarrassment, it's not shameful, it's just part of who I am and they can like it or leave it." [B24] "If you say, 'I'm bipolar,' that's saying you are the illness. I used to say, 'I'm bipolar,' and I may still say that sometimes. But I try to say, 'I have bipolar illness,' that I have a bipolar illness instead of saying that I am the disease. I don't want to be a disease, you know. But I have it, and I can't get around that." [D25] "I consider myself a person who's diagnosed with bipolar disorder: 'a person with...' I have bipolar disorder and it's something I deal with, but it's not who I am." [H23]

And some look beyond themselves for a full understanding of their relationship to the illness. "What is dysfunctional where I'm living now, and the way I'm trying to function now, in a high tech job in the western industrial world, I sort of think part of my disorder is created by the society I live in. It might be easier to cope with it, say, if I lived in a small town where human relationships were stronger and longer lasting, more extended family, where maybe individual differences in personality were a little more tolerated, things like that. I think, particularly in the high tech world, we all have to fit a certain mold. We all have to be the interchangeable computer chips that we work with, and be available 24 hours a day, seven days a week, and expected to be able to function at the same level continually." [J10]

Dealing with Issues of Control

Distinguishing What One Can and Can't Control

Figuring out what one can and cannot control is both an observational and experimental process. As people come to know their patterns and rhythms, they may find that they can use early cues and clues to intervene and control behaviors they previously saw as out of their control. They may also find that there are some behaviors and mood shifts that they cannot find a way to anticipate or affect. And some behaviors that they had previously assumed were volitional and in their control may come to be seen as less so than previously thought.

"I don't have control over, you know, when I can't concentrate. The biggest thing with me is reading and concentrating and comprehending. When I'm trying to read something and I can see the words but they don't make any sense, I don't have control over that. I can't stop it when I have extreme emotional pain. But I do have the choice to call somebody." [H14] "I even sometimes think the word 'seizure' when I think about one of those depressed episodes. It's like something, I don't have control of it. It takes control of me." [J4] "I was feeling like I was choosing... and later found out, well, some of this stuff you can't help." [D7]

"I can at least fight it, and maybe make it a shorter duration, or make it not as severe. I think you can influence it. I don't think you can control it." [B17] "I am always very much aware that it's a very short distance to being out of control. And I'm also very much aware, or I try to remind myself constantly, not to get too full of myself for being able to control it as well as I do, because I don't want to kid myself to think that I'm going to be able to control every situation." [FF7] "I just think you're closer to that emotional line than other people are. And I think it takes less to push you over it." [B27]

"I think you have a little [control], like the environment you put yourself in can influence it. And I think what you actually physically are doing can influence it. I think the people you're around can also influence it. Like if I'm real down, I'm not going to subject myself to rejection. There's a lot of rejection in sales. So if I'm really feeling down..., I'd rather just do research." [B16]

Sometimes thinking about the potentially most extreme behaviors helped in understanding issues of control. One person described a time, when very depressed, of coming to the realization about suicide that "...it was my decision. I remember that being a real epiphany, almost, to me. It really is my decision. Now why I would have thought otherwise, who knows? But I remember that very distinctly. And I remember that being a real turning point as far as taking charge of things... [If that was my decision], maybe other things could be." [F30]

Dealing with Responsibility, Fault, and Blame

When behaviors feel out of control, or when someone is not sure what behaviors they control, responsibility is a difficult concept to apply. When people cannot control behaviors, but feel they should be able to do so, they may assign themselves blame or fault for the consequences. As people with bipolar disorder become able to distinguish what they can and cannot control, there seems to be a tendency to take on responsibility for the consequences, but to give up blaming themselves in a moral sense.

"I feel like I have more control over myself when I accept responsibility for what I do. The big manic episodes I've had as an adult have been because I stopped taking my meds, and that was a conscious choice on my part. So even though I may have been spinning out of control, I made the initial decision to get to that place where I spin out of control. And it's my behavior..." [P19] "One thing that I've had to try to conquer a little is to be able to use it as an excuse when it's convenient... Because, you know, I could just go off on somebody, and say, 'Oh well, I'm just manic. It's not my fault', or whatever." [F14] "I've caught myself sometimes giving responsibility to the bipolar when maybe I should take responsibility. Of course, I get very hard on myself. Maybe sometimes I give [blame] to myself that I shouldn't... I do that a lot, actually. I do have very high expectations." [H20]

Taking a Stance – What I Will Try to Control, and How

Based on what they have figured out about what they can control and what they value in themselves, people with bipolar disorder begin to make decisions about what in their lives they will try to control, and how they will do it. This stance about control is a stance about identity – how a person will try to be in the world. For many, this involves monitoring certain early cues and clues of impending mood shifts so they can take action to prevent unwanted behaviors or to make desired behaviors more likely. For things that they have learned they cannot change, it may mean coming up with strategies to "ride it out" with as little damage or discomfort as possible. Sometimes it means deciding ahead of time that, when they observe certain early warning signs, they will ask for help with something they cannot control on their own. This is a way in which some people are able to take responsibility even for behaviors they could not control without help. For virtually everyone, taking a stance about what to try to control also involves making decisions about medications.

"I exercise a lot of environmental control with [the mania], things like when I feel a really bad spell coming on (or good, actually – I hate to admit it), I'll go ahead and put the checkbook away, put the credit cards away, stay off the internet, things of that nature." [F4] "[If I] might be getting manic again... there are things I can do. I can stop and center myself. I've got lots of little tricks. I can just be quiet for a little while. If my mind can't be quiet, then I'll write something. I'll do a gratitude list, things I'm grateful for. I'll write down a list of people who care about me. All kinds of little things like that. And that tends to calm me down." [P17] "When you're down, chocolate helps. Or just... talking to [my office mate] for a little while will elevate my mood and will make me feel better. Or, if I feel like I'm too happy and I'm afraid I'm going to crash – I can be real happy and then in a few hours I'll come way down – I just focus on work. I just concentrate on what I need to do, so that I can be on more of an even keel, and I'm not doing anything that's emotion-related... It's bad if I go out and do cold calls if I'm feeling down... If I get a lot of rejection that day or anything like that, then it just makes it three times worse." [B12]

"If it's the depressive thing, I kind of liken it to preparing for a storm. I gather my supplies and resources that I'm going to need to get me through that time, and then just kind of batten down the hatches and wait for it to hit. If I have the clues, I know it's going to hit and I'm just going to have to ride it out, that it's not the end of the world. I actually do try and exercise some control over my environment, weird little things like making sure that the bills are current... Things I know would bother me if I didn't. Make sure my email's caught up, all those little weird things that would bug me or that I would be able to pin my lack of self-worth on during that period." [F17]

Asking for help at certain times is of pivotal importance for some people in keeping the control they want. "[I ask myself,] 'Can I do something about it?' And if I can't, if I can't control what's going on, I need to call somebody. That's something that I do have a choice over. I can call somebody... My biggest thing that I have to do for myself is, right when it starts, to call somebody. Because, if I don't, I'll be out for weeks or months." [H14] "I can see it coming on. I can feel it and [my husband] can feel it... Now, if I felt it coming on, I'd call [my psychiatrist]. I would definitely do something about it, because I don't want to go back into a hospital. I wouldn't let it get that far ahead." [C7] "I told [my husband] what to look for. You know, 'Call [my therapist] if I do X, Y, or Z.'" [F12] "I told [my boss], 'Hey look, I didn't tell you this up front, but I have bipolar disorder..., and I'd appreciate it if you think I'm acting strange that you let me know, and I'll not [work] for a while. I'll go see my shrink.' He said, 'Oh, ok,' and he's never really mentioned it again. I think he would tell me. So that's worked out pretty well." [P25]

Taking a stance on what one will try to control is not a decision made once and lived with, but a decision faced over and over: "I come to those little points almost every day. Ok, is what I'm going to do now, is that the right thing to do? Taking into consideration my family, my profession, my religious ethics, my friendships, is this the right thing to do? Or, do I not want to think about this, just do what I want to do? I mean that happens every day several times." [PF7]

A very important part of a person's stance on what to try to control is coming to a decision about medications. Medications must be prescribed by a doctor, but it is the person with bipolar disorder who actually makes the decision about whether to take them and which are acceptable. What symptoms a person wishes to control, and what side effects are seen as tolerable, are important contributors to this decision. A very large percentage of people with bipolar disorder stop taking their prescribed medications at some point. After finding out what happens, they may return to seek the same or different medications. This can be seen as seeking a drug regimen that fits identity, which is quite different from the common view of this behavior as "medication noncompliance". If a person has not made a decision to try to control a certain symptom or behavior, then taking medication may actually pose a challenge to identity. This is particularly true for those who experience enjoyable and productive hypomanic episodes. For those who consider their hypomanic behaviors to be valued parts of their identities, a decision to take a mood stabilizer which controls the desired hypomanias, along with the horrible depressions and dangerous manias, can be a difficult one, indeed.

"I reacted very well to the medication... But I remember at first really missing the manic phases. It's like, how am I going to get anything done?" [M3] "The problem with meds is to get a person under control and keep him under control without being totally in a veg state. I'm not willing, I'd rather be manic than be just vegged out and just sitting around, you know. A lot of the drugs that you take to bring you down from the mania can make you real lethargic, and that's not very much fun." [G2]

Taking a stance on medication can involve difficult decision making. "[When on lithium,] I remember I would look at myself in the mirror and I'd be very much aware that it wasn't me in the mirror. It was some other person. I missed, which I felt guilty about, I missed the manic phases intensely. You're able to get so much done. It's so wonderful. You can get your whole house cleaned in a night... The person that I had grown up with, that I had always been, I guess really my best friend, was gone. And it was very difficult to deal with that aspect. I also read a lot that [lithium] thwarts creativity, and I really do feel very strongly that that's true. I've always drawn and painted. I could do the technical part of it. I could sit down with a canvas and paint, but there was no inspiration and no fire to do it. It was a very mechanical enterprise. So I missed the companionship, I guess, that artistic pursuits gave me." [F11] After several years on lithium, this person found a different medication solution that was a better fit for her: "I went to my physician, and he said that it was still fairly controversial, but they were treating some bipolars with Prozac. It seemed they could manage the mania phases fairly well, but it was the depressive phases that were really a problem. And so I went on Prozac at that time, and am still on that, and it seems to work really well. It doesn't seem to exacerbate the mania, which is one of the main concerns with that. But the depressions don't seem to be really severe as often as they were previously." [F4]

For some, the medication decision is very clear: "In the Kay Jamison book, and I've heard other people describe, too, that they would go off their meds just to have some mania. I'm so not interested in doing that. I mean that doesn't even sound good for a moment... because the mania scares me, you know." [N17] Sometimes the stance includes both medication and psychotherapy. "I believe without good therapy and without good medication that I'm screwed. I might not even be alive today, because I would have made somebody mad enough to shoot me, or I would have had an accident because of my driving, my erratic driving, or I would have drunk myself to death, or taken one too many pills, or whatever." [G8] "I couldn't live without either one [medication or psychotherapy]. I would not be alive without either one, that I assure you... I would be dead without either one, without question." [K6]

Reevaluating Views of the Past

Reinterpreting Past Actions and Behaviors

More than one person I talked with told me that, once they received the diagnosis of bipolar disorder and understood what it meant, they said to themselves, "Well, that explains a lot..." Through the lens of bipolar disorder, behavior patterns that had not previously made much sense now had some reason. Behaviors that had been explained in negative ways now had other possible interpretations. To the extent that who one was determines who one is, reevaluating one's past has a direct impact on current identity.

Many things take on a new interpretation: "...the way I did things, or my mood swings. I'd gotten to just spending so much money and going into debt and just going on a whim. The first time I got into a sexual relationship, how I just wanted it all... There was a lot of stuff like that that just began to make sense to me." [H4] "The things that I did... during some of my manic phases, I look back on now, knowing what they were, you know. You didn't sleep, and you were so focused that you blocked everything out. Anybody got in your way, you just told them to piss off and get out of your way. You were going to get it done, and you did, and you ran over a lot of people in the process." [G4] "[My ex-husband] remembers me just losing it with my kid, and him having to get in the middle of it and, you know, it wouldn't stop me from losing my temper." [C4] "I realized that there had probably been a lot of times when, unknowingly, I had alienated someone or been a little rough on them, you know. Not really meaning to be." [B24] Another person, looking back on times that were probably manic periods, remembered "...some times in college when I was probably more promiscuous than I would normally be." [M8]

For some, childhood experiences that had always seemed odd now made sense. "When I look back, I always knew I was different. I always felt different. Some things that I felt and experienced, my friends never did. And I was, 'Am I weird?' I'd become real passionate about whatever it was I was doing... I spent a lot of time in an imaginary world, daydreaming. I would daydream a lot about this great singer... 'This is what I want to do. I want to be that person. I want to be Garland!' ...I had this imagination that was something that Stephen King would want to have. The other kids didn't have this. They didn't imagine. They didn't see ghosts. I saw them." [D21] "I think that there were signs all along, little things, signs all along, that I had bipolar illness, or was susceptible to that, somehow." [D6]

Thinking about past interactions with others, many people realize that they have accumulated a reservoir of self-views, often negative, based on or supported by others earlier reactions to their symptomatic behaviors. As they reevaluate the meanings of their own past behaviors, they may also begin to question the validity and accuracy of others' reactions, as well as the pieces of their identity based on these reactions.

Parents and Other Relatives with Bipolar Disorder

Some of the people I talked with had a parent or other close relative (or several) diagnosed with bipolar disorder. More common were those who, after coming to an understanding of their own diagnoses, began remembering and thinking about the behavior patterns of certain undiagnosed relatives, coming to the conclusion that they very probably also had bipolar disorder. Thinking of parents in this way can affect current identity in a number of ways. Some people found that integrating information about their own bipolar disorder was helped by seeing it as a kind of family trait. Others began to look at how their childhood development had been affected not only by their own symptoms and the reactions to them, but also by their parent's symptoms and related limitations.

"I knew that my grandmother and my mother had always had interesting personalities. I'd seen pictures of my grandmother, for example, one week in a flapper costume and the next week in church doing the pentecostal church-type goings-on, you know, which I thought was peculiar – but when you're a child you don't really question things like that." [F1] "My mom was always really moody... She could hide in her room for days or she would be the life of the party. One or the other. And I knew that my grandmother, even when I was a little kid, my grandmother had really severe manic depression – she could become psychotic – and she lived with us... And I think, in a way, that gives me an understanding of it. In another way, it made it harder for me to recognize my own symptoms. Because, you know, this was family, this is how family acts, this is how your emotions go, this is how your activities go – it's up and down, up and down. So I really didn't think anything of it." [PF2] "Stories I heard from [my grandmother] about her family, when I think back on them now, they were a pretty peculiar bunch." [P13] "I'm trying to go back a little bit. I guess it helps some to know that there was a family history of it, some parallels." [K20]

Speaking of her mother, one person said, "I'm absolutely convinced she's bipolar. I believe to the core of my being that the day I attempted suicide, she was in hypomania, and was very irritable and got enraged over something I did, and I was depressed. And her rage triggered my suicide attempt. So I think just her being older, more dominant position in the family, and having these problems overshadowed mine. I don't think anyone knew. I think if I was depressed and she was manic, her mania was going to get noticed. If I was manic and running around, ...I was just being a kid." [J5]

Taking a Stance – Rewriting the Story of One's Past

No one can change the actual events of the past, but there are, nonetheless, real decisions to be made about one's past. One's story of the past leads up to one's story of the present, so how one decides to view the past deeply affects current identity.

After reevaluating their own and others' past actions, people with bipolar disorder make choices about whether to continue living in accordance with the story they formed as events unfolded, or to rewrite that story based on their current understandings. A new story may include less self-blame for actions now seen as symptoms of illness. It may include fewer negative self-images based on others' reactions to earlier symptoms. Things previously seen as permanent parts of one's personality may now be viewed as choices. Grandiose images of self may be somewhat deflated, leading to more realistic goals. Some traits related to bipolar disorder may be embraced as important contributors to currently valued parts of self. Family life and parents' actions, previously viewed as "just the way things were", may be seen to be deeply affected by a parent's illness. One's reactions to this may come to be seen as necessary protective maneuvers, rather than as problems with oneself.

The stance taken about the past will be closely related to restructuring work done on coming to know self in relation to symptoms and dealing with issues of control.

However the story of the past is rewritten, it will certainly affect the present and the future.

Presenting Self to Others

Telling or Not Telling

What we tell people is a way of presenting who we are. Everyone I talked with had pondered the question of whether to tell other people about their symptoms or diagnosis. If they told, what should they tell, and when, and to whom? Both telling and not telling can be problematic for identity. Being known makes possible other people's responses which reinforce identity. Telling increases what others know, but, if others become focused on the diagnosis, they may end up missing other important aspects of a person's identity. Not telling hides a part of self. Most people agreed that telling, under the right circumstances, can make relationships closer and help consolidate identity.

People figure out ways to decide who they will tell. "It's kind of like you learn who to trust. I don't just tell anybody... But most of the time I kind of know... If they mention stuff about people they know who've had mental illness, or how they'll talk about people with disabilities, I always listen to that very carefully, especially about people with mental illness. Just see how they feel about it, and what their experiences have been... So, it has to be a pretty compassionate... person." [H7] "There has to be a certain level of closeness, I think. If I've known somebody for a while, and I trust them, and have had some level of sharing our lives with each other, I'll talk about it, if it comes up. I don't insert it, you know. It's not like a label I wear. I'm not like carrying the banner for rights for the mentally ill or anything. But, not too many people know, really." [P15] "I remember my parents telling me to be careful about who knew about it, telling me I would never be able to get life insurance since I had attempted suicide and would be considered a bad risk." [J8]

Telling at work may involve different issues. "I don't broadcast it or anything. You don't want the people who work with you closest to be analyzing your every move, you know. Which they probably aren't really, but it's still a concern." [M6] "People I work with, at some point, not right away, but fairly early on, I let them know so that they will be aware when they're working with me that there may be days that I seem more short-tempered or irritable than usual, and that it's probably the mood and not something they have done." [J8]

Telling in a dating situation can be a particular dilemma: "...especially for dating people, who do they see me as? Who do I present? When do you tell them? You don't want to say anything on the second date, because then they're going to run like crazy... Or, do you wait till the tenth, and then you're getting to like each other and they say, 'Gee, I wish you'd told me, so I would have had more of a choice. Now I kind of like you, and I didn't want to like anybody that was sick like this.' Because it's a sickness, you know. Same thing with if you had cancer. When's it fair to tell somebody?" [K16]

People choose different words when they tell. "When I talk about it, it's just 'bipolar disorder'. I do avoid 'manic depressive', because there's still that stigma, I think, and there's still that little thing in my mind that bipolar disorder is somehow more acceptable than manic depressive. I think manic depressive has a much worse connotation associated with it, even though it's one and the same." [F25] "I think I use them interchangeably but, now that I think about it, 'bipolar' seems a little less negative than 'bipolar disorder'." [J9]

Taking a Stance – What to Present to Others

People come to different conclusions about the question of telling. "I don't think it's anything to be ashamed of. And I don't think it's anything that you have to hide. I think if someone acts like there's something really wrong with you or you're a freak or something like that, screw 'em. Who cares?" [B9] "It's become real important for me to become just real open about it. It was really hard for my family at first, because they didn't like me being so open about it." [H7] "I'm not shy about telling people at all, because basically if that wigs them out, or they don't want to be friends with me, or whatever, I really see that as their problem, not mine." [N10]

“If we’re talking about something, I’ll say, ‘Well, you know, I had to go on medication for that’ or ‘I have to take my medication every day or I’ll be a crazy woman.’ You know, if it comes up. But if it doesn’t come up, I don’t say anything about it. I don’t advertise it.” [B9] “You think, ‘Well, I can speak freely about it.’ But I don’t always speak freely about it, because I think that there’s a big section of our society that would label me. I think at first I was more open about talking about it, because I was trying to deal with it, too. And now, unless people are real close to me, I rarely say anything.” [D14]

Chapter Summary

This chapter has discussed the part of the model that involves taking in challenging information and using it to restructure identity. It began by outlining factors that contribute to deciding to consider and use information, rather than discounting it. The remainder of the chapter dealt with a set of issues that are particularly important in restructuring identity for people with bipolar disorder. These issues are related to aspects of self-views that seem to be especially disrupted by bipolar disorder. Their resolution, therefore, is centrally important in getting on with life. How these issues are resolved will vary from one individual to another. What seems to be important is that challenges to identity be considered and reconciled in each of the areas. The process of restructuring that is involved sometimes focuses on observing and getting to know self, sometimes on active exploring and experimenting with options, and, finally, on taking a personal stance on important aspects of identity.

This process of restructuring identity is not, of course, something one moves through, finishes, and is done with. Many people describe a time of intense work, which may span many years. This is followed by a sense of a fairly stable resolution in most areas and much less frequent challenges to identity related to bipolar disorder. Much more energy is then available to get on with life, concentrating on aspects of life that have little directly to do with bipolar disorder.

Because of the nature of bipolar disorder, however, new challenges to the restructured identity are likely to arise. Sometimes previously effective medications do not seem to work as well, resulting in an increase in symptoms. Some people, even with the best combination of medications they can find, still experience some level of bipolar symptoms, and must continue to deal with these. Others notice unexpected symptoms occurring when they are under great stress.

In addition, the continuing social stigma related to mental illness may result in inappropriate reactions from others. Even with close friends, people with bipolar disorder may be left with the impression that they somehow aren’t really understood, resulting in feelings of isolation. And, for those who have had to lower their life goals, reaching an age when they would have accomplished something significant may again challenge identity. So the process modeled here continues, less intensely and as needed, as people encounter newly challenging information.

Chapter Eight

DISCUSSION AND ILLUSTRATION: WHEN THERE IS NOT A CHALLENGE – GETTING ON WITH LIFE

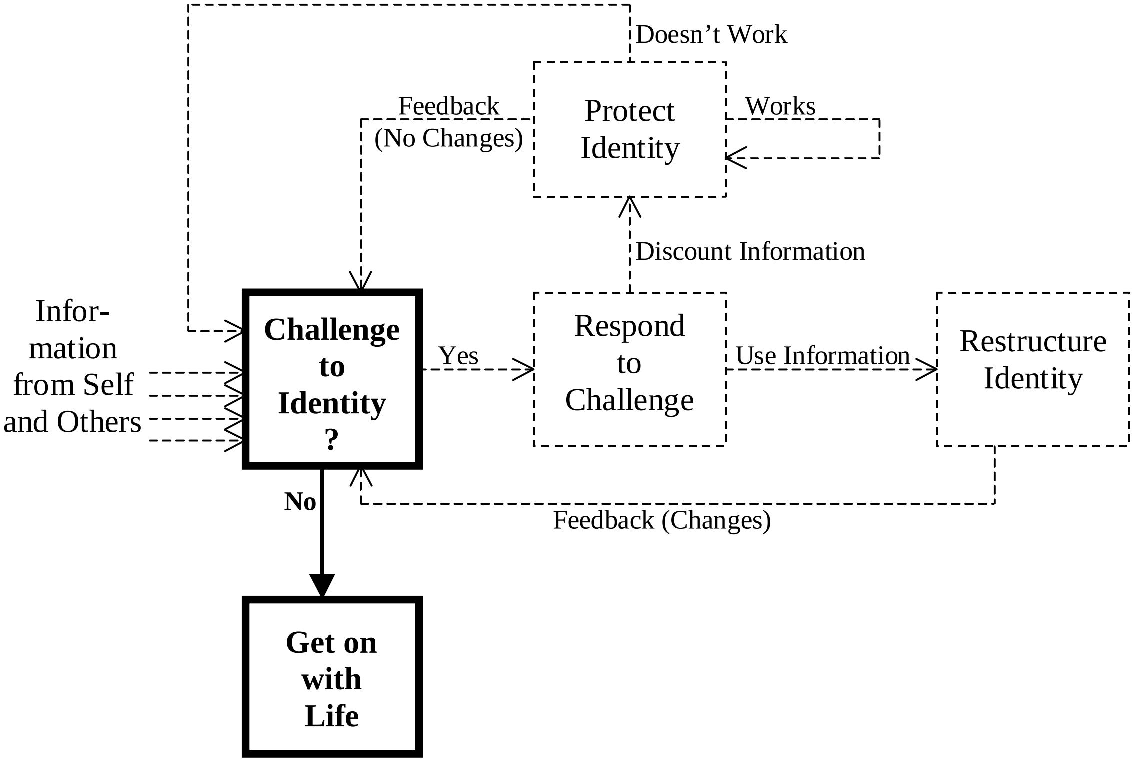

Figure 5: Getting on with Life

Getting on with life is not the central theme of the process described here, but it is probably the central goal of the people interviewed for this study. The process of responding to challenges to identity is, in a sense, something that both gets in the way of and facilitates getting on with life. Bipolar disorder, like other chronic illnesses, can be seen as a "biographical disruption" (Bury, 1982). People form ideas of how and where their lives will go, and these plans may be sidetracked or changed by experiences related to bipolar disorder.

The need to respond to many challenges to identity can take much energy and time, especially when symptoms are unfamiliar and the predominant strategy is to discount new information to protect identity. This may interfere with basic life tasks and delay or derail major life goals. The focus on dealing with bipolar disorder's challenges to identity may go on for months, years, or even decades. That is not to say that the process completely precludes getting on with one's life, but that life tasks are frequently interrupted and disrupted by having to stop and deal with multiple challenges to identity.

For many people, there is a gradual shift from discounting information to considering it and creating a more integrated identity. As people deal with the major issues of restructuring identity (observing and coming to know self in relation to symptoms, dealing with issues of control, reevaluating views of the past, and presenting self to others), information that was previously challenging to identity tends to become much less so. As there are fewer challenges, much less time needs to be spent on the process described here, and more time and energy is available for getting on with one's life.

How this "getting on with life" looks will depend to some extent on the way an individual has restructured identity. The process described here does not determine a particular outcome, and people may deal with the issues of restructuring in very different ways. A more integrated and stable identity results if the important issues have been addressed and discrepancies reconciled. For some people, this means dealing with the disruption in a way that gets them as close as possible to their original life plans. For others, it means rethinking basic expectations of themselves and priorities in life, resulting in very different goals and plans than those they previously held. For most people, major areas of life are likely to be marked by their particular restructuring process.

Career goals may be affected very little or in major ways by experiences with bipolar disorder. "I just know it's there. I'll carry it with me. Big piece of baggage. But it's not going to keep me from doing what I think I want to do or what I think I need to do, because it's not a roadblock. It's just a little bump. You can go over it or around it.

It’s different than a brick wall. If I were really, really nuts, you know, that would be a brick wall.” [B25] “I think I’m going to get an accelerated certification to teach special ed, and maybe work with emotionally disturbed kids. Because, as I say, ‘I’m one of them.’ ...I’m considering it pretty strongly.” [N18]

Getting on with life requires decisions about negotiating relationships with others. “I’ve got my own little very narrow group that’s supportive. And anyone that’s not supportive, I don’t really have a place for them.” [G10] “We have some friends... who were very, very close friends, who didn’t know what to do. Because I had this illness, they didn’t know really how to act. And, while I was sad that we didn’t spend as much time together, at the same time, I really saw that as their problem, that they couldn’t deal with it. I think they just didn’t know how to handle it. And really, I would say, how you handle it is, if you had a friend who found out they were a diabetic, or found out they had any other physical ailment, you just handle it the same way.” [N10]

Understandings are forged with spouses around ongoing issues of bipolar disorder. The woman whose husband used to comment on her medications said, “He doesn’t do that any more. I think I’ve made him realize that that is not even an option. It’s not an option to blame what’s wrong with me because I’m actually working with it, and I’ve taken steps to control it. Therefore, it is not out there for him to attack. He can’t do that. It’s not allowed.” [B18] Spouses find ways to communicate about symptoms. “If I feel like an episode’s coming on... I know that there are certain times when I’ll tell my husband, ‘Well, I think that the next few days are going to be kind of rough.’ And he knows exactly what I mean. So that’s a euphemism born out of companionship, you know.” [F25] Sometimes spouses make contingency plans. “I’d done a lot of reading on what might happen. So I basically said, ‘Ok, this is a psychotic episode.’ Because I knew that, if I went far enough in that direction, I’d not be able to recognize it myself. I’d always depended on myself to be able to monitor... And I said, ‘This is [my therapist’s] number... Watch out for these things. Intervene if necessary.’” [FF6]

Getting on with life does not mean there are no longer fears about what might happen. “The only thing I can think of that we didn’t talk about is fears of the future with bipolars, what might worry them most about the future. It would be suicide, or getting worse, being hospitalized." [D29] "I think the idea of having a psychotic episode bothers me. It's nothing I dwell on or anticipate or anything, but certainly, 'what if', that kind of thing... The thought of being hospitalized terrifies me. But, other than that, [bipolar] is just a part of my life." [F25]

Some people carry with them a sense of some silver lining to their experience. "I guess if you have to have a mental illness, you might as well at least have one that's interesting." [F31] "You definitely feel a stigma. But, in other ways, you think, 'Well, there are a lot of mental health issues to have. At least this is somewhat considered creative...' It's a little more glamorous." [M6] "I'm in pretty good company here. There's a lot of people, famous people, with the same illness, especially in the field that I enjoy most, which is music and arts." [D13]

Many people talk about the effect of bipolar disorder on basic aspects of their identities. "I think it's given me a pretty rich life. It's difficult though to say whether saying it's given me a rich life is a way of making something positive out of something negative, or if it really is true that I've had more experiences and experienced them more fully than people who would not have had this. It would have been nice to have had it without the extremes of feeling suicidal, or the type of mania that makes me irritable. There's a type of mania that just feels good. My concentration is very focused, I have a lot of energy, and I'm very happy and gregarious and so forth. That part feels fun. And I would say I don't even mind a certain amount of mild depression. But it's the extremes that get to be painful. It is hard to say, though. If you like yourself, and this is the way you are, would you change the way you are?" [J15] "It's definitely been defining. It's definitely been defining both as far as having pride over conquering it, to the extent that I have, as well as feeling it's what makes me who I am." [F31] "It's changed my perspective on myself, and I understand myself a lot better now." [D18]

For some people, their experiences have an ongoing effect on their spiritual or philosophical perspectives on life. "I had a real religious sort of awakening while I was in the hospital. It's like I'd been grappling with this whole religious thing all this time...

I hadn't been raised that way at all... I think that it's kind of symbolic, you know. I'm seeing these things as good, these things as evil. This is god, this is the devil. So, in a way it all came clear to me. But yet, it was all convoluted... And it took that to make me say that, 'Yes, I believe in god. Yes, I want to go to church.' Before, I was very much wavering. So, in one way, my perception is it was all because of my choice between god and the devil. And I remember I felt that way at the time, that it was a big, big fight going on between the two forces. Of course, I was overdramatizing... But, it did help me to bring about some sort of conclusion in that way. Something I'd been grappling with." [M23] "Three [episodes] that I recall seemed a lot like spiritual reawakenings, or something like that. It was during a period in my life that I was doing a lot of what I'd call spiritual searching... Certain things about it have stayed with me, and I think all of that work I was doing had a positive long term effect... And maybe [it] made my world view more clear to me. And maybe I forged one that I thought was more acceptable, or maybe it was the first time I forged one at all... I've never really taken to religion very well, organized religion, or used it to give myself a world view. I was looking to work one out that suited me and that seemed based in reality, you know, rather than based on somebody's book." [L6]

Finally, many people seem to get on with life with a desire to use their experiences in some way to help others. "That's partly what brought me here today. You want a perspective of somebody who's been through it. Because of that compassion and understanding, if I can share that and help in some way, make some kind of contribution, however small it is, I want to give it, you know." [D18] "I'm glad [I came]. I feel like I'm also doing a favor for other people, which is good. There's not many things I can afford to do right now. But these kinds of things, I went and gave blood at the blood bank because they're short, that doesn't cost anything. This doesn't cost anything, and I hope it can help people, whether it be shrinks or lay people or people with bipolar." [K27] "I wish I could find a way to really utilize my experiences to help or encourage others in that situation. Which is why I volunteered... for this, because maybe this is the way to do that." [F19]

"The only good thing that comes out of this, for me, is being able to educate people and help people get help. I mean we have lots of people that, either through me or through my family, because they know that I've been sick, that they'll approach one of us and ask questions. I actually did a TV interview for National Depression Screening Week. And I found out from them later that 50 people had come by to get themselves screened for depression, and the only advertising thing they had really done was the interview on TV. And that just made me feel so good, you know, that I'd been able to help out 50 people, whether they were depressed or not. So, anyway, I really like doing that kind of stuff." [N9] "I've gotten really big into advocacy and stuff. I've joined NAMI, National Alliance for the Mentally Ill... And I'm doing a newsletter for them. It's become real important for me to become just real open about it... I know that, being in NAMI, I may have to testify and stuff like that. And there, I'll just have to be comfortable with myself, knowing that whoever hears this may think otherwise." [H7] "I thought, 'How are people ever going to know that normal people they know, and work with, and don't act like lunatics, have mental health problems if nobody ever talks about it?' So, I do." [J8]

Chapter Summary

As people get on with their lives, it is clear that information previously challenging to identity no longer has the same effect. When there are challenges, they are often much less intense. People's sense of identity becomes more stable, and no longer has to be constantly protected against threats. Lives are affected by bipolar disorder, but no longer directed by it. How people have navigated the process responding to challenges to identity will determine what personal stance they have taken about what is "me" or "not me", about what is their relationship with their illness, about what they will try to control, and how, about their sense of their past story, and about what they present to others. As people get on with their lives, they may move beyond responding to reflect on how they can make use of their experiences for their own growth or to help others.

Chapter Nine

SUMMARY OF FINDINGS

In Chapters Four through Eight, I have presented and discussed the findings of this research project. Chapter Four presented the theoretical model of the process responding to challenges to identity. In succeeding chapters, parts of the model were explored, illustrated, and discussed in much more detail. This began by looking at the types of information people with bipolar disorder are likely to be receiving, both from themselves and from others. I discussed what constitute challenges to identity, which information is most likely to be challenging, and implications of the timing of symptoms for challenge. A challenge to identity is extremely uncomfortable and calls for a response to maintain or reestablish a sense of a coherent identity. I then discussed the two ways people respond to challenge, beginning with discounting information to protect identity. When information is too threatening, or resources to deal with it are lacking, people are likely to push it away to maintain a sense of a coherent identity. This sense of identity is retained only with continual protective efforts in response to ongoing challenges. The other way people may respond, when they have the resources and the motivation, is to consider and use information to restructure identity. I discussed this identity restructuring process, which involves gradually dealing with a set of issues specific to bipolar disorder, and gradually making and enacting a set of personal decisions about self, illness, past, and presentation of self to others. This process integrates challenging information and views of self, thereby reducing the challenge. The emerging identity requires less and less protective effort and is, therefore, more stable. As the process continues, people find themselves with more and more time and energy to get on with life. Just how people get on with life will be affected by the many decisions they have made in navigating the process responding to challenges to identity.

As people with bipolar disorder iteratively move through this process, it does not divide itself into neat chunks as I have done here for explanatory purposes. As lived, the process involves continual and simultaneous incoming information, comparisons with identity, need to respond, weighing pros and cons and deciding how to respond, invoking protective strategies to deal with some strands of information, and taking in and using other strands. The ongoing restructuring of identity affects the balance of factors within the process, itself, reducing challenge and, thus, the need for protection of identity. All of this time, one is trying to get on with one's life, to the extent allowed by the challenges and obstacles. Over time, the process becomes less chaotic and demanding, and getting on with life a more real and appealing possibility.

Chapter Ten

IMPLICATIONS OF THE MODEL

This chapter discusses the implications of the model, both for research and for the clinical practice of psychotherapy. It begins by looking back at the literature reviewed in Chapter Two, comparing the results of this study with the findings of previous qualitative studies of mental and physical illness. It then looks at other literature related to the central concept which emerged from this qualitative study. The chapter concludes with a discussion of the implications of the model for the practice of psychotherapy with clients with bipolar disorder.

Research Implications

In grounded theory studies, and in qualitative research in general, the literature reviewed before data collection is "set aside" during the research process. A theoretical model is then built upon concepts emerging from the data itself, and data is not "forced" into categories established by prior research (Glaser, 1978). Once the model is created, however, it is important to go back and see how it compares with previous research findings.

A theoretical model derived from a particular group of people in a particular place is sometimes referred to as a "substantive theory" (Glaser & Strauss, 1967), and it is relevant to a relatively specific substantive area. The model developed in this study is relevant to outpatients with bipolar disorder who are of Caucasian descent and live in a North American cultural setting. A "formal theory" (Glaser & Strauss, 1967) is less specific, and applies to a wider range of settings and problems. A formal theory is derived by observing phenomena of interest under a wide variety of conditions (Strauss & Corbin, 1998). Thus, if aspects of the process reflected in the model <u>responding to</u>

challenges to identity are observed with other groups of people, in other places, and under different conditions, this might point the way toward a more formal theory dealing with how people respond to challenges to identity.

This section begins by comparing the results of this study with the results of the related qualitative research previously reviewed in Chapter Two. I first discuss the structure of the model developed here, and compare it with how theoretical models produced by other qualitative studies have been structured. I then look at the content of the model, discussing points of convergence and areas of difference from these related studies. Next, I look at additional literature, not previously reviewed, which is related to the central construct of this model, responding to challenges to identity, and compare the findings. Because, in a qualitative study, the central construct of the model to be developed cannot be known ahead of time, this last portion of the literature review must be done after the analysis is completed (Charmaz, 1995a). The section then concludes with some thoughts on directions suggested for continuing research in this area.

Comparison with Qualitative Research on the Experience of Illness

Qualitative research on the experience of bipolar disorder, of mental illness more generally, and of chronic physical illness was reviewed in Chapter Two. This section explores the similarities and differences between those reviewed findings and the model developed in this study.

Structure of the Models – Stage Models versus Iterative Models

The structure of the model developed from this study is significantly different from most previous models of the experience of chronic mental or physical illness. These previous models, discussed in Chapter Two, have generally been stage models, naming and describing phases through which people move as they deal with their illnesses (Chafetz, 1996; Davidson & Strauss, 1992; Karp, 1994; Lorencz, 1991; Morse & Johnson, 1991b; Young & Ensing, 1999). Most of these imply unidirectional movement, although some suggest bidirectional movement on what is really a linear series of stages (Tewksbury & McGaughey, 1998; Yoshida, 1993). Almost none discuss mechanisms for how people get from one stage to another. The model developed in this project, on the other hand, is an iterative model of a dynamic process that people engage in as they deal with their illnesses. It addresses directly the mechanism of how people change as they interact with illness and results of illness.

Interestingly, several "stages" are implied by the current model. As people respond to repeated challenges to identity, and as the results of these responses are fed back into the process, the direction of movement, over time, tends to be from protecting identity to increased restructuring of identity, and then to more time spent getting on with life. I could have represented the data from this study as a three stage model of dealing with bipolar disorder. This model would not have been incorrect, but it would have been a very much rougher approximation of the reality of the complex processes people were describing to me. It would have told something about the "what" of the phenomenon, but nothing about the "how". It would have been much less explanatory and much less useful, more descriptive and less theoretical.

The results of this study suggest that future qualitative researchers interested in experiences of illness look beyond organizing their data into chronological stages to try to understand more about the mechanisms and processes that produce these phases. Stating, as some writers do, that stages "overlap", or that people may move back and forth between stages, or repeat a sequence of stages, gives a nod to underlying processes, but actually ferreting out and modeling these processes will increase the explanatory power of these conceptualizations.

Content of the Models

Some of the concepts included in the model responding to challenges to identity are similar to concepts included in the findings of qualitative studies in related areas. These may indicate areas of "emergent fit" (Glaser, 1978) between independently developed models. None of the earlier studies, however, encompasses the whole set of concepts and relationships of the model presented here. The following paragraphs look at previous research in terms of the major concepts of the current model: challenge to identity, responding to challenge – protecting identity, and responding to challenge – restructuring identity.

Challenge to Identity. A number of other qualitative studies have uncovered concepts similar to challenge to identity. Charmaz (1983) describes "loss of self" as a central experience of those with chronic illnesses. She suggests several aspects of the illness experience which contribute to this sense of loss, and these factors could be categorized, in the terms of the current model, as both information from self and information from others. Bury (1982) describes these challenges to identity in illness as "biographical disruptions," but does not discuss in detail the factors bringing about the disruptions. Corbin and Strauss (1987) also speak of losses of aspects of self as a result of chronic illness, and the sources of loss that they describe would be categorized in the current model as information from self. Yoshida (1993) describes a more limited type of loss of the "nondisabled self" in her study of paraplegics. Karp (1992, 1994, 1996) describes a stage of depression in which people come to the conclusion that "something is wrong with me." There seems to be some convergence of findings around the concept of challenges to identity in studies of mental illness and chronic physical illness, although some of the challenges described in earlier research are narrower in scope than the range of challenges found in this study.

Some studies of the experience of receiving a diagnosis of a physical illness suggest that this is a particular challenge to identity. Pinder (1992) suggests that this is the point of "maximum experiential incoherence" for the patient. Corbin and Strauss (1987) describe it as a time of shock "when past and future come crashing into the undesirable or dreaded present." The present study also suggests that receiving a diagnosis (of bipolar disorder) can be a severe challenge to identity, but that this is not necessarily the case for many individuals.

Responding to Challenge – Protecting Identity. This is the concept of the current model which is least emphasized in the findings of past qualitative studies of illness experiences. Pollack (1996) observed that some patients with bipolar disorder were “information rejectors,” and that this was related to non-acceptance of a bipolar diagnosis. This appears to be consistent with the concept of discounting information as a response to challenge to identity. Charmaz (1991, 1995) describes modes people select for living with chronic illness, some of which imply discounting information to protect the self. These include “ignoring” and “minimizing.” Charmaz (1990) also discusses what others refer to as “denial” as a way of protecting valued aspects of identity. Tewksbury and McGaughey (1998) discuss “minimizing and ignoring” as one of the stages of response to a diagnosis of HIV disease. All of these findings suggest, like the current model, that people sometimes discount information to protect their identities, but none of the earlier studies describe this process in much detail.

Responding to Challenge – Restructuring Identity. The concept of restructuring identity in response to losses of illness is discussed frequently in previous studies, although it is treated in a variety of ways. Karp (1992, 1994, 1996) describes a stage of dealing with depression called “coming to grips with an illness identity” which includes some “reformulation of identity.” He does not elaborate on this process, however. Several studies focus specifically on looking at “recovery” from mental illness, which may lead to their emphasis on themes like “reconstruction of sense of self” (Davidson & Strauss, 1992) or “regaining what was lost and moving forward” (Young & Ensing, 1999). Both of these emphasize actively getting on with life, but do not focus on the process of change in identity. There are a number of studies of chronic physical illness which do deal directly with identity change (Charmaz, 1987; Tewksbury & McGaughey, 1998; Yoshida, 1993). These studies focus mainly on specifying different possible identity outcomes after illness, and less on the process of identity change or restructuring. Charmaz also discusses a variety of ways that people may choose to live with illness. These include reconciling, embracing, adapting (Charmaz, 1995b), incorporating, and accepting (Charmaz, 1991), which imply some restructuring of the self in response to challenges. Charmaz is one researcher who discusses both of the types of response to challenge described in my model, responses that involve pushing away challenging information and responses that involve taking it in. Corbin and Strauss (1987) focus more on the process of identity change, discussing “biographical work” which is necessary following the losses of illness. Their analysis covers four major aspects of this change process: “*contextualizing* (incorporating the illness trajectory into the biography); *coming to terms* (arriving at some degree of understanding and acceptance of the biographical consequences of actual or potential failed performances); *identity reconstitution* (reintegration of the identity into a new concept of wholeness around the limitations in performance); and *biographical recasting* (giving new directions to the biography)” (Corbin & Strauss, 1987, p. 265). Like the current model, Corbin and Strauss look at components of the process of restructuring identity in an ongoing illness. Unlike the current model, they do not look at other processes that might compete with the restructuring process.

Summary. There seems to be a clear convergence of findings between the model developed in this study and the findings of earlier qualitative studies of mental and physical illness. Each of the major parts of the current model has been observed, in some form, by other researchers studying related populations. These areas of emergent fit point to the possibility that the iterative model of responding to challenges to identity developed here for people diagnosed with bipolar disorder might be further generalizable to experiences of people with other mental illnesses and/or chronic physical illness.

More specifically, this suggests that looking at sense of identity in the experience of mental illness may be a particularly fruitful area for future research. The process of responding to challenges to identity stood out especially clearly in the stories of people diagnosed with bipolar disorder because it becomes such a pervasive feature of their experience. It would be illuminating to interview people with other psychiatric diagnoses to see if the same sort of process is observed, even if in a less intense form. Previous researchers studying depression and other major mental illnesses have suggested that effects on identity are somehow important. What is striking is that these effects have not been well studied, and the processes involved have not been modeled. This will be an important gap to fill.

Although there does seem to be considerable convergence between the current model and earlier observations, the model presented here includes a wider range of interrelated processes than do previous models. This suggests that responding to challenges to identity is quite complex, and that it will be important to continue to look beyond stages and outcomes to examine in detail the mechanisms and processes involved.

Comparison with Research on Responding to Challenges to Identity

There is a very large body of research dealing with broad issues of identity. This research has addressed the structure of identity, the development of identity, multiple aspects of identity, future and past identities, and so on. More specifically relevant to the central findings of this study, however, is a considerably smaller literature related directly to challenges to identity, and how people respond to them. This section will focus specifically on empirical studies in the area of responding to challenges to identity, and comparing previous findings with the model of this process presented in this dissertation. The research reviewed in this section focuses not on particular populations, such as those with mental or physical illnesses, but on particular processes of responding to information about the self.

Ways of Responding to Challenge

There are several separate but potentially related lines of social psychological research which look at questions of how people respond to information about themselves, what information people will accept or take in, and what information they will reject or avoid. These lines of research all rest on (and test) the premise that taking in information about oneself is not a random process, but is in some way motivated (e.g., Fiske & Taylor, 1991; Kunda, 1990; Sedikides & Strube, 1997; Sorrentino & Higgins, 1986; Taylor, Neter & Wayment, 1995; Weiner, 1986). It is thought that people will go to some effort to get, or to avoid, certain kinds of information about themselves. This general thesis is certainly consistent with the model developed in this study.

There has been disagreement, however, about what motives influence this process. Three possible motives, referred to as “self-enhancement,” “self-assessment,” and “self-verification,” have been fairly extensively studied, and will be reviewed here. The self-enhancement perspective argues that people are primarily motivated to get information about themselves that is positive, that will enhance their images of themselves. The self-assessment perspective holds that people seek accurate or realistic information about themselves, regardless of its valence. The self-verification position holds that people seek information that confirms or verifies what they already think about themselves. Considerable empirical evidence has been generated for each of these three. Researchers have attempted to show that people differentially notice, select, process, accept, remember, and actively set up their environments to get, certain types of feedback or input.

Self-Enhancement. Proponents of the self-enhancement perspective would predict that, in order to promote their own self-esteem, and to gain the confidence and self-efficacy necessary to deal with life circumstances, people will seek to develop or maintain positive images of themselves (Taylor & Brown, 1988; Tesser, 1988). The valence of information is more important than its accuracy. Positive input about the self is sought; negative input is avoided. A self-enhancing style is biased toward getting positive, flattering information. There has been a tremendous amount and variety of research looking at the self-enhancement motive (for reviews, see Brown & Dutton, 1995; Fiske & Taylor, 1991; Ruehlman, West, & Pasahow, 1985; Sedikides & Strube, 1997; Taylor & Brown, 1988).

Studies have looked at memory and cognitive processing, finding that positive information about the self is remembered better and processed more efficiently (e.g., Kuiper & MacDonald, 1982). Research in many different areas has demonstrated the “above-average effect” (e.g., Larwood, 1978; Svenson, 1981). Most people rate themselves and their attributes as above average (often far above average), although it is statistically not possible for this to actually be the case. Studies of causal attributions have demonstrated a “self-serving bias” (e.g., Green & Gross, 1979). Successes tend to be attributed to oneself, while failures are attributed to someone else. Studies of social comparison processes have shown that people often make “downward” rather than “upward” comparisons, casting a positive light on themselves by comparing themselves with people in worse circumstances or of lower ability (e.g., Tesser, 1988; Wood & Taylor, 1991). All of these approaches demonstrate a positive, self-enhancing bias in deciding what information to take in.

Self-Assessment. The self-assessment perspective holds that people want accurate information about themselves and their abilities in order to select goals and activities that fit their skill levels, to deal with the environment in an effective way, and to make appropriate decisions and plans. Therefore, it is predicted that people will seek accurate information even if it could be negative or unflattering (Festinger, 1954; Trope, 1979, 1986). The accuracy of information is more important than its valence. A self-assessing style seeks new information, especially in areas where people are uncertain about their abilities or other aspects of themselves.

Studies of self-assessment have focused on the concept of diagnosticity. A task is termed “diagnostic” if it can provide useful information about a person's abilities. Specifically, a very diagnostic task is one on which people with high ability levels get quite different results than people with low ability. Subjects in self-assessment studies are generally presented with tasks of varying degrees of diagnosticity, among which they can choose. The dependent measure is the degree to which they choose diagnostic over nondiagnostic tasks. Subjects choosing more diagnostic tasks are considered to be self-assessing.

Self-assessment research results (reviewed by Fiske & Taylor, 1991; Sedikides & Strube, 1997; Trope, 1986) show that people find high-diagnosticity tests more attractive than low-diagnosticity tests (e.g., Strube, Lott, Le-Xuan-Hy, Oxenberg, & Deichmann, 1986; Trope, 1979). They choose to take high-diagnosticity tests rather than low-diagnosticity tests (e.g., Buckert, Meyer & Schmalt, 1979; Strube, et. al, 1986). When given the opportunity, they actively construct high-diagnosticity tests to measure themselves (e.g., Trope, 1979; Trope & Ben-Yair, 1982). These findings indicate a self-assessing search for accurate information about the self.

Self-Verification. Proponents of the self-verification perspective hold that, in order to maintain predictability and control in intrapsychic and interpersonal arenas, people will maintain the stability of their self-concepts by seeking confirmatory information. It is predicted that people will self-verify even if the results are painful. Thus, if someone's self-concept is negative, they will still seek consistent and unflattering, rather than positive, feedback (Swann, 1987, 1990; Swann, Wenzlaff, Krull, & Pelham, 1992).

In a typical study of self-verification, after performing a task or completing a questionnaire about themselves, subjects are presented with various feedback opportunities from which to choose (knowing which will be positive, which negative). The dependent measure is the degree to which the subjects select feedback consistent with their existing self-conceptions. Subjects selecting consistent feedback are considered to be self-verifying.

This perspective has been tested by Swann and his colleagues in an extensive series of experiments. (For reviews, see Sedikides & Strube, 1997; Swann, 1987, 1990). Results suggest a variety of self-verification strategies. People may actively attempt to create a “self-confirmatory opportunity structure” by manipulating their interpersonal environments. Several ways of doing this have been demonstrated: “they may strategically choose interaction partners and social settings, they may display identity cues, and they may adopt interaction strategies that evoke self-confirmatory responses” (Swann, 1987). When a self-confirmatory opportunity structure cannot be constructed, people still may find ways to see more self-confirming evidence than actually exists. Strategies for doing this have been shown to include preferential attention to self-verifying feedback, selective encoding and recall of such feedback, and interpreting feedback in a way that supports self-confirmation (e.g., questioning the validity of non-confirming feedback). A number of studies have attempted to demonstrate self-verification in depressed subjects (Giesler, Josephs, & Swann, 1996; Swann, Wenzlaff, Krull, & Pelham, 1992; Swann, Wenzlaff, & Tafarodi, 1992). These studies provided evidence that, when offered a choice of feedback opportunities, depressed subjects chose to receive negative feedback much more frequently than nondepressed subjects. The authors suggest that, because depressed people have negative self-views, these choices demonstrate self-verification.

Integrative Models? All of the research cited above was done in narrow and controlled situations, and discussions of the findings tend to "advocate" for one motive to the exclusion of the others. Evidence supporting each of these different ways of responding to information about the self has seemed convincing. The current study differs from these in its open and exploratory qualitative methodology and in its finding that people do not always respond to information about the self in one particular way. In the terminology of the current model, taking in challenging information to restructure identity can be seen as self-assessment. Discounting information to protect identity can be seen as self-verification. The people I interviewed clearly and vigorously self-verified some of the time, but not all of the time. They also clearly and courageously self-assessed some of the time, but not at all times. Self-enhancement does not correspond directly to a particular part of the model, but the data demonstrate that people's responses to challenging information sometimes involved self-enhancement, and sometimes did not. When people talked about discounting information because it was just too painful or because it challenged grandiose self-conceptions, they were describing self-enhancement. On the other hand, when they talked about resisting positive feedback because it did not fit their self-images, or accepting and integrating painful information about themselves, they were clearly describing times when they were not self-enhancing. Depending on what would be enhancing for a particular individual's identity, self-enhancement could take place either by discounting challenging information or by taking it in.

This suggests the importance of somehow integrating the research about different motives which result in different responses to challenging information. It suggests that perhaps we need to look much more closely at the circumstances under which people respond to challenges in different ways. There have recently been some attempts to speculate about how the three motives might interact. Interestingly, even “advocates” for other motives have suggested that self-enhancement somehow takes precedence. Sedikides and Strube (1995, 1997) suggest direct (“candid”) and indirect (“tactical”) self-enhancement. When brute self-aggrandizement is not feasible, attempts at tactical self-enhancement may be made via self-assessment or self-verification. Swann and colleagues (Swann, 1990; Swann, Hixon, Stein-Seroussi, & Gilbert, 1990; Swann & Schroeder, 1995) hold that self-enhancement is an emotional-level response requiring less cognitive processing than self-verification or self-assessment. It would therefore be expected to take precedence when cognitive resources are limited. (Given sufficient resources, however, they would predict self-verification.) Trope (1986) suggests that the reason people risk the short-term potential cost of self-assessment is for the anticipated long-term gain in self image. Finn and Tonsager (1992) found that self-assessment (receiving feedback of unknown valence about MMPI-2 results) did result in increased self-esteem.

Factors Affecting How People Respond to Challenge

Some empirical studies have begun specifically to address factors that might affect how people respond to information about the self. Studies have begun to examine individual difference variables, conditions, and situational variables that might affect the activation or relative strength of various motives.

First, it has been pointed out that a specific response to information is not always called for (Taylor, Neter, & Wayment, 1995; Weiner, 1986). At times when a response is felt to be irrelevant, none of the three motives need be activated. Some evidence indicates that response to information about the self is most relevant under conditions of recent failure or future threat (Taylor, et al., 1995). People do not seem to feel as much need to actively respond in situations of comfort and competence (Weiner, 1986). This is consistent with predictions of the current model, that people will tend to get on with life when information is not challenging to identity.

People’s beliefs about themselves, or aspects of themselves, may influence the response process. Dunning (1995) looked at the effect of people’s beliefs about the malleability of traits they possess, and how important they consider those traits. His research provides evidence that when people believe a trait can be changed, they are more likely to self-assess with regard to that trait. They are particularly interested in accurate feedback for traits they see as important. This is consistent with the finding of the current study that people were more likely to take in challenging information when they were between mood episodes than when they were either manic or depressed. It is likely that emotional symptoms seemed more malleable at these times, and less malleable during acute episodes.

Swann and Pelham (Pelham, 1991; Pelham & Swann, 1994) have done a number of studies examining the effects of the firmness of people's beliefs. They found people more likely to self-verify in relation to aspects of themselves about which they felt quite sure. Complementing these findings, a number of researchers (Sedikides, 1993; Trope, 1979; Trope & Ben-Yair, 1982) have found that when people are unsure about an aspect of their abilities, they are more likely to self-assess with respect to that ability. This parallels findings of the current study that people were much less likely to take in challenging information about manic symptoms, for instance, if they were quite sure this was part of their personality than if they were not certain about the cause or meaning of these symptoms.

Situational variables may also be related to the elicitation of certain motives. There is some evidence that when people are involved in goal-setting, when they are in a “deliberative mindset” and deciding on a course of action for themselves, they are more likely to self-assess (Taylor & Gollwitzer, 1995). This is consistent with people in the current study being more willing to take in challenging information when they had available a supportive relationship, such as being in psychotherapy, to help them structure and deal with it.

It has also been suggested that certain aspects of personality may influence the activation of particular motives. Sorrentino and colleagues (Roney & Sorrentino, 1995;

Sorrentino & Hewitt, 1984; Sorrentino & Short, 1986) have looked at trait-like variables they call "certainty orientation" and "uncertainty orientation." Certainty orientation is characterized by comfort with the familiar and discomfort with uncertainty. Uncertainty orientation involves an inclination to explore and tolerance of uncertainty. They have found that people high in certainty orientation tend to self-verify (by selecting tasks that will provide self-confirmatory feedback), while people higher in uncertainty orientation tend to self-assess (choosing tasks that will provide diagnostic feedback of unpredictable valence).

These studies are consistent with the model developed in this study in looking for factors or circumstances that might influence the responses people choose to make to challenging information. They do not assume that people always respond to challenges in the same way, but rather look for what accounts for differing responses. Some of the factors proposed in my model are similar to those cited above; others are different and perhaps more specific to people experiencing bipolar disorder. Understanding what leads to different responses to information about the self is the least developed aspect of the previous research in this area. This parallels the development of the current model, in which the mechanisms of choice about response to challenge were the most complex and difficult parts of the model to discover and document. Studying a particular type of response, even across many situations, is easier than studying choices among a variety of potential responses. Integrative models of responding to challenges to identity remain quite incomplete, but the research about factors that may influence how people respond to information about self does move the field in an integrative direction.

Discussion

This section has compared the model developed in this study with both past qualitative research on related populations and past quantitative research on related concepts. This provides an example of the potential interplay between qualitative and quantitative approaches to research. Qualitative exploratory research, such as that done for this study, can provide an overview of a complex human experience, as lived by those going through it. It can provide a sense of the richness of experience and the interrelatedness of the processes involved. Quantitative hypothesis-testing research, such as the studies of self-enhancement, self-assessment, and self-verification cited above, can focus on demonstrating and further elucidating specific processes in a broader context. Returning to look at qualitative findings can help to suggest how these specific processes might be interlinked in everyday experience, and what might be fruitful areas for future quantitative research. An example of such an area, suggested by my model and related to the research reviewed above, would be the relationship between self-assessment and self-verification. Qualitative observation, in this study and in the earlier qualitative studies of illness experience, suggests that people do take in information that challenges identity, information that is not self-validating. In fact, the qualitative studies tend to focus on this aspect of responding to challenges to identity. The body of quantitative research, however, focuses more on times when people do not seek accurate information about themselves, but rather information that confirms or enhances their self-images. This is an interesting discrepancy, and suggests that both future qualitative and quantitative researchers pay fuller attention to the possible range of responses to challenges to identity and the factors that lead to a choice of one response over another.

Practice Implications for Psychotherapy

The model developed by this research project has direct implications for conducting psychotherapy with clients with bipolar disorder, both in understanding what is going on with a client, and in making decisions about intervention. This model is consistent with a wide range of theoretical approaches to therapy, and suggests what are likely to be important areas of focus in therapy within any of those approaches. These suggestions are also consistent with the use of psychotropic medications, which may control symptoms enough to make the psychotherapy possible.

Perhaps the most obvious implication of the overall model is the importance of considering the operation of the process responding to challenges to identity when working with clients with bipolar disorder. Whatever the current issue being discussed in therapy (job, relationship, alcohol use, medications, etc.), it is possible that part of what is determining the client's actual behaviors is a challenge to identity and the client's response to that. Looking at how this process is operating for a particular client may help in understanding the function of otherwise very confusing behavior.

I conclude the dissertation with this section, which looks at each of the major parts of the model, challenges to identity, responding to challenge by discounting information to protect identity, and responding to challenge by using information to restructure identity , in terms of the psychotherapy process. I discuss what the model suggests that may help in understanding what is happening with a client, and implications for possible roles of the therapist in helping to navigate the process.

Challenges to Identity

People with bipolar disorder are exposed to multiple challenges to identity from many directions, putting them frequently in the position of having to do something to maintain or establish a sense of a coherent identity. Chapter Five discussed in detail many of the possible sources of challenge for people diagnosed with bipolar disorder, focusing on symptoms, diagnosis, medication, and even psychotherapy, itself. The model suggests that it is important to know what specific potentially challenging information a particular client is dealing with, paying attention to both intrapersonal and interpersonal sources of information. A therapist would want to know what a client is observing about self, and what the client is noticing about how other people react. It would then be important to find out which pieces of this information actually are currently challenging to identity. Which strands of information are consistent with the client's self-views, and which are not? Information that is challenging to identity is likely to be related to "where the action is", both in therapy and in the client's life. The reason for this, as suggested by the model, is that challenging information requires some action of the client, either keeping the information away to protect identity, or considering the information and possibly restructuring a part of identity as a result.

Understanding the wide range of potential sources of challenging information, as discussed in Chapter Five, will help the therapist keep in mind issues that may turn out to be salient for a particular client with bipolar disorder. Understanding as much as possible about that client's self-views will, of course, help in identifying which information is most likely to actually be challenging for that individual. As the therapist identifies information that challenges a client's identity, the therapist will then need to consider how the client is responding to that challenging information. Responding to challenge is discussed in the next two sections. Even before fully understanding a client's response, however, the therapist is in a position to intervene simply by observing or clarifying that certain information appears to be challenging to identity, and that this, itself, may be a significant part of the distress a client is experiencing.

It is possible that an individual client would not seem to find a particular type of information challenging, even though this model suggests that it would be challenging for many. These areas should also be of interest to a therapist. It would be illuminating to know if a particular type of non-challenging information was ever challenging in the past, as this might indicate some restructuring work that a client has already done. Knowing how a client has previously succeeded in integrating challenging information may help in facilitating further restructuring. On the other hand, the client may be employing a protective strategy that obscures information which really is a challenge to identity. (That is, after all, one thing these strategies may be designed to do.) Such protective responses to challenge are discussed in the next section.

Responding to Challenge – Protecting Identity

Discounting information to protect identity, as discussed in Chapter Six, is often a first response to challenging information. What a therapist is actually likely to see, however, when a client is employing a protective response, is behavior – often puzzling, sometimes seemingly self-defeating, behavior. The therapist then has the task of trying to figure out what is really going on. A therapist may see a client discontinue medication that seemed to allow him, for the first time, to function well in his job. Another client may insist, despite all evidence to the contrary, that her bipolar diagnosis is a mistake. Another person may “fake it” with friends, family, and therapist when feeling depressed, rather than taking advantage of the support they could provide. This model would suggest that the therapist consider the possibility that such behaviors, and others that may not seem to “make sense”, might be reflections of strategies to protect identity from a challenge. The therapist is likely to have to work backwards from the observed behavior, looking for what strategy a person is using to deal with challenging information, and then at what circumstances and what challenging information make it seem necessary to protect identity at a particular time.

Seemingly self-defeating behaviors often invoke in therapists a desire to intervene in some way. Attempts to directly influence the behaviors, however, may not be very effective. When clients stop taking medications, for instance, power struggles over “medication compliance” are not uncommon. Unfortunately, they are likely to lead to ending therapy or, at best, a cul-de-sac in the process. Clients in these interactions are likely to complain, as did several of those I interviewed, that their therapists did not seem to understand the complexity of the medication dilemma for them. Understanding the process underlying the puzzling behavior for a client should help a therapist think about intervening in ways that are more likely to be effective. The model would suggest that a therapist look for what strategy a person is using to protect identity, what factors led to the decision to discount information, and just what information is so challenging. This should help to clarify the function of the puzzling behavior for the client. Once this is clearer, several possible points of intervention are suggested. A therapist might consider intervening by challenging a protective strategy directly, hoping to decrease its effectiveness so it will not “work” as well. Or, a therapist might intervene at the point of the client’s decision to discount information by attempting to affect one or more of the factors that led to that decision. This could be done either by decreasing the salience of factors that lead to discounting information (listed in Chapter Six), or by increasing the salience of factors that lead to using information (listed in Chapter Seven). Either would change the balance of factors contributing to the decision. Another therapist might intervene by working with a client on restructuring identity in a way that would make certain information less challenging and the protective strategy, therefore, less necessary. Any of these interventions would address the process underlying the behavior, likely leaving the client with more options for changing the behavior.

Returning to the diagram of the model responding to challenges to identity, some possible therapeutic intervention points are shown in Figure 6. It should be remembered that any interaction with the therapist becomes additional Information from Others, which affects the process for the client and may provide additional challenges to identity.

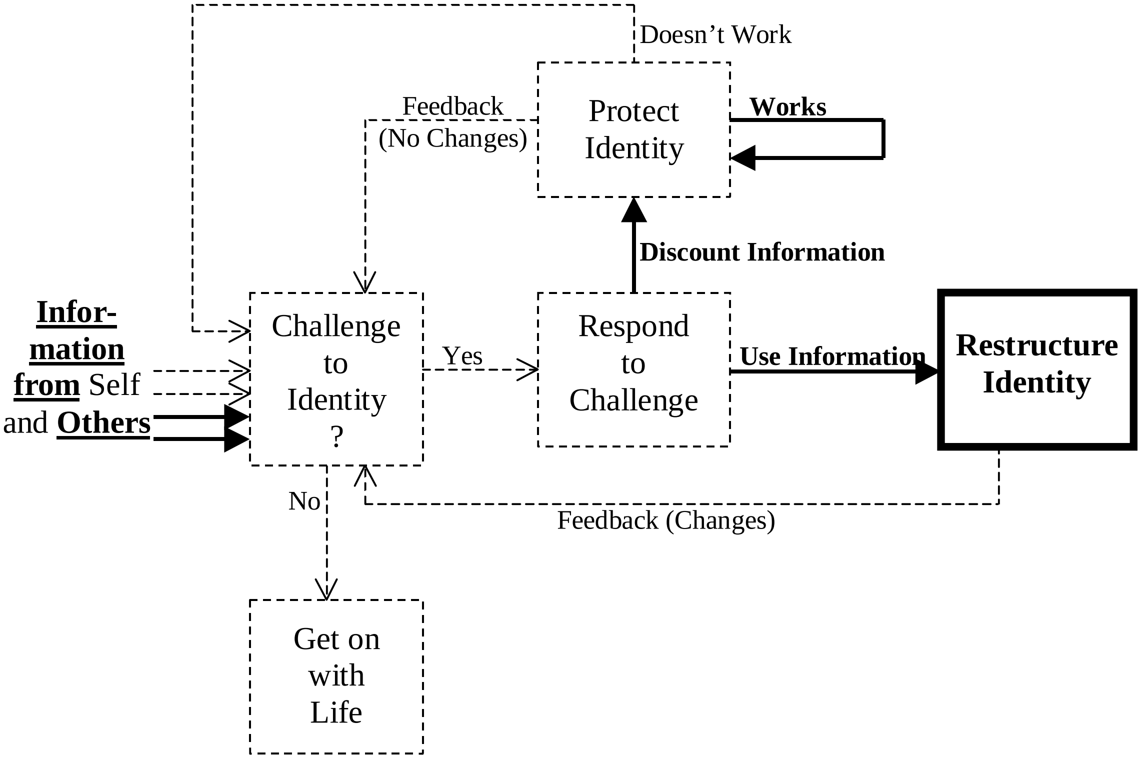

Figure 6: Possible Points of Therapeutic Intervention

Responding to Challenge – Restructuring Identity

A major goal in therapy for many clients is dealing with obstacles that interfere with getting on with life. This model suggests that, for clients with bipolar disorder, a barrage of information challenging to identity and the resulting efforts to protect identity can become major obstacles. Getting on with life requires a different way of responding to challenging information which involves letting in bits of information, tolerating a temporary threat to one's sense of coherence, and finding a way to integrate challenging information with self-views. This restructuring process results, over time, in a more stable and coherent identity that is not continually challenged by incoming information. As less energy is spent on protecting identity from challenging information, more time and energy are available for getting on with life. This implies a role for the therapist of helping a client to navigate this process.

To restructure identity around challenging information, a client must first be open to taking in and considering such information. As each strand of information comes in, a separate decision is made about how to deal with it. As discussed in the previous section, one possible point of intervention is at this point of decision by the client about how to respond. A therapist may be able to affect the balance of factors leading to the decision in a way that increases the likelihood of considering, rather than discounting, information. (See discussion of factors contributing to discounting and using information in Chapters Six and Seven.) Just being in therapy likely begins to tip this balance by increasing a client's resources for dealing with information. A beginning sense of accomplishment in therapy would shift the balance further as the client gains confidence in the restructuring process. A therapist might affect other decision factors by, for instance, observing that a protective strategy is beginning to break down, or mentioning a really bad experience the client wishes not to repeat.

The model would suggest, however, that the therapist's efforts should not always be aimed at encouraging the client to take in information. If the amount of challenging information, or the level of threat, is so high that a client cannot maintain some sense of coherence, predictability, and control, then the model predicts that the client will need to discount that information to protect identity. The therapist, therefore, might help the client to titrate challenging information, setting priorities for what can be dealt with now and what can wait until later. This could mean temporarily supporting some protective strategies while the client considers and works with a manageable amount of information.

Everything a therapist does or says in interaction with a client becomes "information from others" in the terms of the model, and is potentially challenging to the client's identity. The therapist, therefore, has no choice about whether to affect the process, but many choices about how to do so. The therapist is in a position to present potentially challenging information in a much more precise way than it is likely to arrive from the rest of a client's environment. A therapist might restate very threatening information that the client has been discounting in a milder, more tentative, or partial form that the client can begin to consider. The therapist might consider timing, introducing challenging information when a client is between episodes. And a therapist is able to take into account, from moment to moment, what resources a client is likely to be able to muster to deal with incoming information.

The model suggests that there are certain issues, specific to bipolar disorder, that need to be resolved in the restructuring process on the way to getting on with life. These are discussed in detail in Chapter Seven. By being aware of what these issues are, a therapist may be able to get a better sense of what territory still needs to be covered in the restructuring process with a client with bipolar disorder. This is a way that a therapist can, in a real sense, bring into therapy the experience of others with bipolar disorder who have felt and grappled with its challenges.

How a client gets on with life will be very much affected by how that person has experienced challenges and responded to them. This is discussed in Chapter Eight. As clients get on with life, they are likely to carry with them not only the results of the personal stances they have taken, but also the ability they have developed to navigate the process, itself. This is a capacity they can call on even after therapy has ended to deal with ongoing challenges to identity.

Finally, any therapy helping a client to navigate the iterative process <u>responding to challenges to identity</u> is, itself, likely to be an iterative process. Such therapy would move with the client, looping countless times and in many ways through the process, following the process and affecting it at the same time. The model would imply a measure of success for this therapy, observable as the client experiences less frequent challenges to identity and more time and energy to get on with life.

APPENDICES

- Appendix A: **Invitation to Participate**

- Appendix B: **Consent Form**

- Appendix C: **Interview Guide**
    - Interviewer's "Map"
    - Bipolar History Questions
    - Demographic Information

- Appendix D: **List of Published Personal Accounts**

Appendix A: Invitation to Participate

Greetings,

I am currently conducting a study to try to better understand the experiences of people who have been diagnosed with Bipolar Disorder.

I am asking for your help in doing this study. As you probably know, a lot has been written about Bipolar Disorder, but not much of this is in the voices of people who have experienced it. One of my goals, by hearing directly from you, is to begin to change this. I hope to learn from the perspectives of those who have “been there”, and develop understandings that will be helpful to people who in the future are diagnosed with Bipolar Disorder. I would also like to be able to help mental health practitioners understand what the central issues are in dealing with this diagnosis, and perhaps help the general public to better understand these issues as well.

Participating in this study will involve talking with me for an hour and a half or so about your experiences. In addition to helping others, you may find the interview to be an interesting and illuminating experience for yourself. It should allow you to review your own story from a new perspective, and reflect on some of the ideas you have about your experiences.

My name is Jennifer Chapman, and I am a doctoral student at the University of Texas at Austin in the department of Educational Psychology. I would be happy to talk with you about the study, answer any questions you might have, and set up a time for the interview. Please call me at (512) 440-1104.

The faculty sponsor for this project is Professor Deborah Tharinger. If you would like to ask her any questions about the study, you can reach her at (512) 471-4407.

I look forward to meeting you.

Jennifer Chapman
(512) 440-1104

Appendix B: Consent Form

CONSENT FORM

Experiencing Bipolar Disorder

You are invited to participate in a study of what it is like to receive and deal with a diagnosis of Bipolar Disorder. My name is Jennifer Chapman and I am a graduate student at the University of Texas at Austin, Department of Educational Psychology. This study will be the basis for my dissertation research. I hope to learn more about what people experience when they are told they have a diagnosis of Bipolar Disorder. You have been selected as a possible participant for this study because you have received a bipolar diagnosis. You will be one of about 10 to 15 individuals participating in this study.

If you decide to participate, you will be asked to participate in an interview about your views on issues involved in the experience of Bipolar Disorder. I may also contact you for a brief follow-up phone interview.

Some of the questions will be about experiences that may have been difficult for you, so it is possible that you would experience some uncomfortable feelings while discussing these things. It is often the case, however, that people find this kind of interview to be interesting or helpful. You may decline to respond to any questions you would prefer not to answer.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. The interview will be audiotaped, so I can transcribe and analyze the information. Your name will not be included on the tape. The audiotapes of interviews will be kept by me in a locked cabinet until the end of the study, and then destroyed. I may use excerpts from your interview in written materials resulting from this study, but they will never be presented in a way that would identify you. Any names or identifying information would be changed.

Your decision whether or not to participate will not affect your future relations with the University of Texas at Austin, any other agency or program with which you are affiliated, or with the person who referred you to this study. If you decide to participate, you are free to discontinue participation at any time.

You are making a decision whether or not to participate. Your signature indicates that you have read the information provided above and have decided to participate. You may withdraw at any time after signing this form, should you choose to discontinue participation in the study.

If you have any questions, please ask me. If you have any additional questions later, you may call me, Jennifer Chapman, MA, Investigator (512-440-1104) or Deborah Tharinger, PhD, Faculty Sponsor (512-471-4407).

You may keep a copy of this form. I will provide you with a copy if you request it.

Signature of Participant	Date
Signature of Investigator	Date

Appendix C: Interview Guide

Interviewer's "Map"

Beginning the Interview

time you first considered you might have bipolar diagnosis
story of you and bipolar until present

Possible Inquiry Topics

- view of illness
  - previous explanation
  - doctor's explanation
  - current explanation
  - why you?
  - illness?
  - feelings about having this
- view of self
  - changed?
  - how?
  - future, current, past
- others' views
  - tell anyone?
  - reactions
  - family's views
  - disclosure
  - experienced stigma?
- losses and gains
  - how handled losses
  - growth, development
- self – illness
  - I am, I have
  - you, not you
    - how do you differentiate?
  - responsibility
  - accepting diagnosis
  - get rid of it?

Ending the Interview

- thinking back to original diagnosis
  - what changed for you?
    - thoughts, feelings
    - how you did things?
    - how people treated you?
    - views of self?
  - could have been presented better?
- other milestones in journey?
  - things you've learned
- what like talking today?
- anything important in story we've missed?

Bipolar History Questions

(Asked only if not covered spontaneously by interviewee.)

- When did you first realize there was something going on?
- When did you first get officially diagnosed?
- Were you told that you have any particular type of bipolar disorder?
- Have you been given other psychiatric diagnoses, before or after bipolar disorder?
    - What?
    - Does the other diagnosis "still stand"?
    - Previous diagnosis changed to bipolar?
- Are you currently taking medications for bipolar disorder?
    - What?
    - Effective?
- Have you been in psychotherapy?
- Still have symptoms? Mood episodes? How frequent?
- What types of mood episodes have you experienced?
    - How frequent were they before medication?
- Have you experienced psychotic symptoms that you are aware of?
- Have you been hospitalized? # of times?
- Do you have a family history of bipolar disorder? Who?
    - Depression?
    - Other psychiatric illness?
    - Suicide?
- Have you ever felt bad enough that you attempted suicide?
- Anything else about "the facts" of your history that you think is important that I didn't ask about?

<u>Demographic Information</u>

Date of Interview: ______________________________________

Age: __________

Sex: Female Male

Ethnicity: ______________________________________

Years of Education: __________ Highest Degree: ___________

Current Employment: ______________________________________

Relationship Status: Single Married Divorced Living Together

Separated Widowed

Appendix D: List of Published Personal Accounts

Published Books:

Benjamin, B. & Dougherty, I. (1994). Out of my mind. Auckland: Tandem Press.

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Duke, P. & Hochman, G. (1992). A brilliant madness: Living with manic-depressive illness. New York: Bantam Books.

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Orum, M. (1996). Fairytales in reality. Sydney: Pan Macmillan Australia.

Pride, C. (1994). Pride: The Charley Pride story. New York: William Morrow and Company, Inc.

Accounts published at www.bipolarworld.net (Downloaded May 11, 2001):

Amy's Story
Andrea's Story
Brenda W.'s Story
My Story About Bi-Polar, by Budd Abbott
Buster's Bipolar Story

Carebear’s Story, Autobiography of a Madman
A Journey Through The Bipolar Mind, by Caroline Mondoux-Gardiner
Carolyn’s Story
Cheryl’s Story
My Bipolar Experience, by Colleen
Curt’s Story
Dave’s Bipolar Story
Elise’s Bipolar Story
Eric’s Story
Gina’s Story
Harry’s Story, My Manic Depression Story
My Story, by Janus
Jennifer’s Bipolar Story
Jim’s Story
John Haec’s Bipolar Story
Kaycee’s Story
Kevin’s Groove
Linda’s Story
Marion’s Bipolar Story
Michelle B.’s Story
A Bipolar Story, by Susan Dime-Meenan
Steph’s Story, by Steph Gagne
Susan B.’s Story

<u>Accounts published at www.a-silver-lining.org</u> (Downloaded May 11, 2001):

Justin
Mongan
Spark
Zanny
Daver
Eyeore
Stormy
Day
Fergie
Sabrina
Taylor
DDCG3
Jinxie
Mela
Vicki

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