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# Language and the making of meaning for individuals diagnosed with bipolar disorder

Kathleen Anne Freeman

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Kathleen Anne Freeman  
Language and the Making of  
Meaning for Individuals  
Diagnosed with Bipolar  
Disorder

### ABSTRACT

This qualitative phenomenological research study examines language, specifically the language of diagnosis, and the making of meaning for individuals who have been diagnosed with bipolar disorder. The study sample consists of six participants who had received a diagnosis of bipolar disorder three or more years ago. Data were collected through hour-long, semi-structured interviews with each participant at a single point in time. Findings revealed three broad themes: (a) The participants' experience of language, (b) The participants' making of meaning, or where strength was found, and (c) The function of language.

LANGUAGE AND THE MAKING OF MEANING  
FOR INDIVIDUALS DIAGNOSED  
WITH BIPOLAR DISORDER

A project based upon an independent investigation,  
submitted in partial fulfillment of the requirements  
for the degree of Master of Social Work.

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2007

## ACKNOWLEDGMENTS

I am most thankful to the participants of this study for their willingness to share their experience with me. The process of interviewing individuals about their experiences being diagnosed with bipolar disorder illuminated a much richer reality to me than theory, and even language, is capable of:

When I first thought about writing this book, I conceived of it as a book about moods, and an illness of moods, in the context of an individual life. As I have written it, however, it has somehow turned out to be very much a book about love as well: love as sustainer, as renewer, and as protector.” (Jamison, 1995, p.215)

We simply, thankfully, do not often what it is we set out seeking. Hopefully, we uncover what is, more truly, there to be found.

I wish to thank, as well, NAMI DuPage, the Depression and Bipolar Support Alliance of Greater Chicago, and Thresholds Psychiatric Rehabilitation for their facilitation of participant recruitment. I am also thankful to NAMI DuPage, the Palatine Public Library and the Mayfair Branch Library for their generous use of space.

I wish to thank my research advisor, Dr. Marian Harris, for her ongoing assistance, support, feedback and encouragement; my parents, sister, and Emily for their consistently gracious support, thoughtfulness, and patience with me.

This thesis is dedicated to the memory of Stephen Kelly.

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## CHAPTER I

### INTRODUCTION

The purpose of this qualitative phenomenological research study was to explore the impact of language, specifically the language of diagnosis, and the making of meaning for individuals who have been diagnosed with bipolar disorder. This study explored the various ways the language of diagnosis is taken in and understood by individuals, and the ways in which individuals make meaning of the experience of being diagnosed with bipolar disorder. The study explored the following research questions:

1. Are there differences in the meaning created by individuals from the experience of being diagnosed with bipolar disorder?
2. Are there differences in the words used to describe this experience and this diagnosis by individuals who have received it?
3. Has the language used by professionals informed the meaning created by the individual?
4. How has language used by professionals informed the meaning created by the individual?

The history of mental illness in the United States can be thought to parallel the history of the language surrounding mental illness in the United States. The role of mental illness in society is deeply politicized, and has been since its first naming of individuals; the “deranged minds,” “insane,” “madmen;” and when it replaced leprosy as

society's scapegoat in the 17<sup>th</sup> century (Foucault, 1965, p. 7). Throughout history, our conception of mental illness reflects our philosophical, scientific, and political beliefs and values: from the religiosity of mental illness to its medicalization, institutionalization and the psychiatric movement, and to the more recent community mental health movement (Porter, 2002, pp. 7-9). Roy Porter (2002), in *Madness: A brief history*, asserts that "the history of madness properly written would thus be an account not of disease and its treatment but of questions of freedom and control, knowledge and power." (p. 3). These questions of freedom and control, knowledge and power are reflected in language and its impact on individuals.

This study will be of importance to the practice of social work, and to mental health clinicians in particular, as it explores the power of language to create experience and meaning, specifically in terms of mental illness. Work within the social work context is highly politicized. One aim of this study is to draw attention to the importance of our developing a greater awareness of the implications of the language we use.

Creating an awareness of the politicization of language may allow us as individual practitioners to question and challenge our role in the implied power structure. Further, an awareness of the impact of the language we use may enable us to think creatively about language and experience it in a way that shifts the power back to the individuals with whom we work and their lived experience. Understanding the role and the impact of language on individuals is of vital importance for clinicians, especially as we are often working with individuals through the medium of language. Most importantly, this study will be of interest to social workers because it gives us this insight with the words and the language of the people we care about.

## CHAPTER II

### LITERATURE REVIEW

Literature was reviewed regarding how mental illness has been constructed and defined historically. Some of the major changes that have impacted how the mentally ill are viewed; from the introduction of “mental illness” to current Western consciousness in the 17<sup>th</sup> century, through institutionalization and deinstitutionalization are also noted. The current language that is used in the United States to describe and define mental illness is discussed. More importantly, the literature review provides a vital ‘theory of language’ and meaning-making that informed the researcher’s thoughts and interpretations about language throughout the study. This ‘theory of language’ primarily focuses on the work of Jaques Lacan and Michel Foucault. The role of language in creating meaning, its function in the power dynamics of relationships, and the possibilities it provides for reclaiming identity and the ‘meaning-making’ of experience are explored.

#### *Historical Articulations of Mental Illness*

Various writers have documented the history of mental illness in the Western world and have related the history of mental illness to its descriptions, definition, and the language used to describe it (Foucault, 1965; Ghaemi, 2003; Porter, 2002). Concepts of mental illness have evolved with and, it will be argued, because of the particular, often politically charged, language employed to describe it. The mentally ill were first defined as “deranged,” “insane,” “madmen” in the 17<sup>th</sup> century, and were soon afterwards filling



the Renaissance's 'Ships of Fools' whose voyages carried its crew from port to port and city to city (Foucault, 1965, p. 8). In the Western world madness had been allowed "free reign" and "formed part of the background and language of everyday life" until the middle of the seventeenth century when "the world of madness was to become the world of exclusion" (Foucault, 1987, p. 67). Institutions were created to intern the mad, the poor, the elderly poor, the disabled, beggars, the unemployed, those with venereal disease, among others; "all those who, in relation to the order of reason, morality and society, showed signs of 'derangement'" (Foucault, 1987, p. 67). In this 'setting apart,' a distinction is drawn between the 'ordered' and the 'disordered.' This distinction necessarily parallels the political and ideological climate which became one of emphasizing production and accumulation. Linking all of these interned individuals together, as well, was their inability to contribute to the production or accumulation of wealth. From this, we see an example of the changing political vocabulary resulting in the exclusion of groups of individuals. Interestingly, this physical exclusion is simultaneous with the creation of a particular language with which to refer to these individuals. Where the mentally ill had been included in the mundane "language of everyday life" (Foucault, 1987, p. 67), they are now set apart, and the language used to describe and define them is new, and 'other-than' the language of everyday life.

Clearly, this situation was not yet one of treating the ill, but of containing, and separating from society, "undesirable" individuals. Thus, "madness entered a phase of silence from which it was not to emerge for a long time; it was deprived of its language; and although one continued to speak of it, it became impossible for it to speak of itself." (Foucault, 1987, p. 69). The language created was not one by and for individuals, but

without and about, or of, them. In the mid-eighteenth century, internment was reserved for the mad alone, and “the mad came to be the natural inheritors of internment, the privileged titulars of the old measures of exclusion.” (Foucault, 1987, p. 70). As well at this point, a superficial “medicalization” of mental illness was initiated, and physical and material bonds were replaced by complete and continuous moral and ethical supervision:

In the new world of the asylum, in that world of a punishing morality, madness became a fact concerning essentially the human soul, its guilt and its freedom; it was now inscribed within the dimension of interiority; and by that fact, for the first time in the modern world, madness was to receive psychological status, structure and signification. But this psychologization was merely the superficial consequence of a more obscure, more deeply embedded operation – an operation by which madness was inserted in the system of moral values and repressions. (p. 72).

State of mind becomes synonymous with the state of the soul. The mad are set apart not only physically, linguistically, and mentally, but from the interior; the soul, that which makes us human. From this, we see the multiple and deep layers of ‘othering.’ Foucault (1987) goes on to make clear the point that descriptions and definitions of mental illness have historically been politically informed when he states that:

What one discovers under the name of the ‘psychology’ of madness is merely the result of the operations by which one has invested it. None of this psychology would exist without the *moralizing sadism* in which nineteenth-century ‘philanthropy’ enclosed it, under the hypocritical appearances of ‘liberation’. (p. 73).

Foucault is adamant about the distance between the original language of madness and the language with which it has been, and is, inscribed within society. He states that, “What is called ‘mental illness’ is simply *alienated madness*, alienated in the psychology that it has itself made possible.”(p. 76). Obviously this is a deep irony, and one that makes the clear the subjectivity of the mentally ill. Foucault states further that, “One day an attempt must

be made to study madness as an overall structure – madness freed and disalienated, restored in some sense to its original language.” (p. 76).

The mapping of the evolution of the concept of mental illness has continuously paralleled various philosophical and scientific developments; from the religiosity of mental illness to its medicalization, to institutionalization and the psychiatric movement, to the current ‘community mental health movement’ (Porter, 2002, pp. 7-9). While beyond the scope of this study, Foucault asks a poignant question that does beg to be considered in however limited a way: “How did our culture come to give mental illness the meaning of deviancy and to the patient a status that excludes him? And how, despite that fact, does our society express itself in those morbid forms in which it refuses to recognize itself?” (Foucault, 1987, p. 63). In response to the second question, this study aims to explore whether or not this expression is, at least in part, in the form of a pathologizing language.

#### *Current Articulations of Mental Illness*

For the most part, in current literature and practice, illness is defined as “the opposite of health” (Ghaemi, 2003, p. 135), in that, one is defined as healthy until they display, most often explicitly, manifestations of ill health or illness. In terms of mental health, Ghaemi cites Aubrey Lewis who first states that “the serviceable criterion commonly employed to define mental health is the absence of mental illness” (Ghaemi, 2003, p. 137). We can see from the reversibility of the definitions that health and illness are two ends of the spectrum, whereby one is defined by the absence of the other and cannot, in these terms, coexist. One is one or one is ‘other.’ In terms of the language, we see that mental illness is defined in negative relation to mental health. Ghaemi goes

further with Lewis, who concludes that “Two criteria have apparently been applied, then, to changes in function: a psychopathological one paying attention to the process, and a statistical one paying regard to the frequency of its occurrence” (Ghaemi, 2003, p. 137). In other words, we may see that mental illness is defined by how it deviates from a “norm,” and how often it does so.

Current research has examined representations of the mentally ill in the mediums that inform society on a daily basis: children’s stories, the media (Coverdale and Nairn, 2006) and newspaper stories (Corrigan, Watson, Gracia, Slopen, Rasinski, and Hall, 2005), and found that the depictions are most often negative; focusing on denigration, unpredictability (Coverdale and Nairn, 2006), and violence (Corrigan, Watson, Gracia, Slopen, Rasinski, and Hall, 2005), serving to “segregate, alienate, and denigrate” the “crazy, mad, nutty” character (Coverdale and Nairn, 2006, p. 86).

An exploration of mental illness with a focus on the language employed to describe it, and the implied meaning of the language (i.e. how the mentally ill are conceptualized by society), will also entail an exploration of the stigmatization of the mentally ill. Porter (2002) discusses stigmatization in this way:

Stigmatizing – the creation of spoiled identity – involves projecting onto an individual or group judgments as to what is inferior, repugnant, or disgraceful. It may thus translate disgust into the disgusting and fears into the fearful, first by singling out difference, next by calling it inferiority, and finally by blaming ‘victims’ for their otherness. This demonizing process may be regarded as psychologically and anthropologically driven, arising out of deep-seated and perhaps unconscious needs to order the world by demarking self from other... (pp. 62-63)

Stigma is often reinforced by language. Porter sees the power of definition in the hands of the broader society and not with individuals who experience mental illness. Definitions of

mental illness are “psychologically and anthropologically driven” by the majority. Foucault (1987) makes a similar point concerning the deep structures of society when he states that: “The recognition that enables one to say, ‘This man is mad,’ is neither a simple nor an immediate act. It is based in fact on a number of earlier operations and above all on the dividing up social space according to the lines of valuation and exclusion.” (p. 78). Thus, it is possible to see the connection between the power of construction in language (who gets to do the defining, and why) and the effects (one of which is stigmatization) of the (mis)use of this power.

This kind of exploration is important because the language of health and mental health are so entwined with political ideologies and are often framed in metaphorical terms: “Like all metaphors, political and economic metaphors can hide aspects of reality” (Lakoff and Johnson, 2003, p. 236), and thus constrain aspects of our lives. In using a particular language, or particular words, to describe and define mental illness, we leave others out. In so doing, it seems, we may contribute to the alienation of individuals from their own experience. This is not only historically the case, but continues to be, as is demonstrated by current definitions of mental illness as fundamentally the absence of health, and depictions of the mentally ill as uncontrollable, disordered, disturbed, and disgraceful.

#### *Current Mental Health Policy and Language*

Considering the language of recent national mental health policy necessitates the, albeit brief, consideration of the Americans with Disabilities Act (ADA), the *Olmstead v. L.C.* decision and the New Freedom Initiative.

The Americans with Disabilities Act was introduced by the Department of Justice as a federal policy initiative in 1990. The ADA “has made employment, public accommodation, information technology, telecommunication services, housing, school, transportation and polling places all dramatically more accessible” (U. S. Department of Justice, p. i) to individuals with disabilities, including mental illness.

In 1999, the Supreme Court’s *Olmstead v. L.C.* decision “held that unnecessary institutionalization of individuals with disabilities is a form of discrimination prohibited by Title II of the Americans with Disabilities Act (ADA). The decision affirmed that states have an obligation to move individuals with disabilities from institutional settings into more integrated settings in the community if moving them would not fundamentally alter the states’ service systems.” (Mathis, 2004). However, compliance with the *Olmstead* decision has been has not been consistent and is not without its challenges. Many states cite a ‘dismal fiscal situation’ as the major barrier to compliance, and movement into the community is still largely viewed as a depletion of resources (Mathis, 2004). While it “has been the most viable avenue for many people with disabilities to obtain desperately desired liberation from institutional environments and receive needed community services,” it is still true that “startlingly little movement has occurred” and “the number of individuals with disabilities who remain unnecessarily institutionalized is staggering.” (Mathis, 2004).

A call for stronger enforcement of the ADA, The New Freedom Initiative was announced in 2001 and “laid out a comprehensive set of goals and plan of action to eliminate the remaining barriers to full participation by people with disabilities in American life.” (U. S. Department of Justice, p.1)

The New Freedom Commission on Mental Health's interim report deemed that the current system is "not oriented to the single most important goal of the people it serves – the hope of recovery." (President's New Freedom Commission, 2002, p. 5). We may infer from this that there is something socially functional about the maintenance of illness. The New Freedom Commission on Mental Health therefore calls for a fundamental "transformation" in the delivery of mental health care across the country. Articulated in the Commission's Executive Report is the proposition that shifting the goal and outcome of treatment to one of recovery will fundamentally work towards reducing the stigma of mental illness (President's New Freedom Commission, 2002, p. 6). The goals of a transformed mental health care system are: (a) to achieve an understanding that mental health is essential to overall health; (b) for mental health care to be consumer and family-driven; (c) to eliminate the disparities in the mental health system; (d) to ensure that early mental health screening, assessment, and referral to services are common practice; (e) the delivery of excellent mental health care and acceleration of research; and (f) the technology be used to access mental health care and information (President's New Freedom Commission, 2002, p. 8).

The Mental Health Surgeon General's Report calls for policy development that would: (a) continue to build the science base and promote research; (b) reduce the stigma associated with mental illness; (c) increase public awareness of effective treatment for mental illness; (d) ensure a "supply of mental health services" that are consumer-oriented; (e) ensure the delivery of services and treatment to communities; (f) support "tailored-treatment" that considers age, gender, race and culture; and (g) reduce barriers

to the treatment of mental illness (U.S. Department of Health and Human Service, 1999, pp. 453-457).

Generally, these are national initiatives that are attempting to shift the language of policy from one of illness and treatment to one of treatment and recovery. As well, they are initiatives that reflect the philosophical turn that has slowly been struggling to take hold, perhaps since The Community Mental Health Act of 1963; where a language of institutionalization, rooted in procedural expectations and the medicalization of illness gives way to a language including ‘community-based care,’ ‘consumer-driven initiatives,’ and ‘empowerment.’

In contrast to recent national initiatives, current research has explored state legislation that affects those with mental illness by pinpointing legislation that impacts: liberties, protection from discrimination and privacy rights of the mentally ill (Corrigan, Watson, Heyrman, Warpinski, Gracia, Slopen, & Hall, 2005). Interestingly, this research also found that current legislation, for the most part, only takes into account the diagnosis of a mental illness. It does not often take into account individual issues of competence or incompetence; the implication being that an individual with a diagnosis of a mental illness is assumed to be incompetent. In other words, legislation itself seems to make a judgment based on a label, a diagnosis, without consideration of anything more specific. The individual is thus disregarded (perhaps for the sake of efficiency) in the act of labeling.

Some current policy as implemented, therefore, may be seen as standing in contrast to the expressed desires of people living with a mental illness:



Consumers and psychiatric survivors appear to want qualitative changes in the mental health system— changes that have to do with a fundamental alteration in the nature of both the macro-level power contract (how the entire mental health system operates) and the micro-level power contract (how professionals help their patients and clients). (Everett, 2000, p. 185).

Everett goes on to describe mental health policy's inefficacy, despite these desires for change:

However, as professionals, I and my colleagues were unable to provide these sorts of supports and, instead, translated patients' expression of suffering into a psychiatric diagnosis which, in turn, led to things like hospitalization, medication and ECT, marginalization, poverty, unsafe and inferior housing, violence and many of the other hard realities that typify patients' lives. In fact, respondents repeatedly charge that professionals miss the point, fail to help and actually make their problems worse through the trauma of involuntary treatment and the stigma of psychiatric diagnosis. (Everett, 2000, p. 197)

This makes clear the imposed distance between the mentally ill individual and the 'rest of the world.' It is as if they speak another language than the professionals. Also important here is acknowledging the intersections of oppression, where mental health issues are often compounded by issues of poverty, poor housing, abuse and unemployment. Policies in each of these areas may affect mentally ill individuals in a profound way. So we see the intersection of various and multiple policy areas, each with their own politically informed languages, with the lives of individuals. There is a 'setting apart' in current mental health policy, which is perhaps compounded by its intersections with other policy areas, and this echoes Foucault's recognition that "our society does not wish to recognize itself in the ill individual whom it rejects or locks up; as it diagnoses the illness, it excludes the patient" (Foucault, 1987, p. 63).

National initiatives like the ADA and the New Freedom Initiative, however, have sounded hopeful, and indeed have provided hope, that policy may effectively be informed by the experience of individuals, and in this way can initiate relevant and lasting change.

At the same time, it may be continually important to remember that policy initiatives seem initially to reflect the political climate and the intended changes are not necessarily operationalized as envisioned.

### *Language and the Making of Meaning*

Lacan asserts the importance of articulation, specifically of verbalizing. He states that in the articulating, one has “made it pass into the *verbe*, or, more precisely, into the *epos* by which he brings back into present time the origins of his own person” (Lacan, 1977, p. 47). ‘Verbe’ and ‘epos’ here mean ‘the Word’ and ‘the word,’ respectively. So we see the raw power of language, the potential for creativity; the creation of self, in the beginning, and quite possibly recovering oneself as well. Lacan states as well that, “If the domain defined by this gift of speech is to be sufficient for your action as also for your knowledge, it will also be sufficient for your devotion. For it offers it a privileged field” (Lacan, 1977, p. 106). In a manner too profound for the researcher’s attempt, eliciting and honoring the words of individuals who are so much more often affected than affecting, is an attempt to bring them back into the privilege of their own experience. However, it is also fundamental to Lacanian analysis that we recognize language, and the act of speaking, or articulating, as fundamentally alienating; taking us further from, and truly obscuring, what we desire.

Developmentally, for Lacan, it is the going through and into language that introduces us for the first time to the idea of loss and absence in the world. Language is castrating: “Speaking thus separates us from what we want. Entering the register of language, of the signifier, does this not by chance but by necessity: it is a structural feature of language that it will distort whatever message we have” (Leader & Groves,

2005, p. 99). This entrance is as necessary and it is alienating. Judith Butler articulates a similar point when she asks: “Is our vulnerability to language a consequence of our being constituted within its terms?” (Butler, 1997, p. 2). The individual’s entry into language is also their entry into subjectivity, which is to be “enmeshed in the endless web of signification” (Cobley, 1997, p. 83). This occurs on an individual level, but it parallels Foucault’s account of madness in the “new world of the asylum” receiving “psychological status, structure and signification” (Foucault, 1987, p. 72). On this broader level, we can see how a diagnosis enmeshes an individual into the world of signification that is mental health, mental illness, and mental health policy; and that this is not one’s doing, but rather, what is done.

Language does, at the same time, profoundly inform how we interact with and interpret the world, and how we know one another. Particularly in the fields of clinical social work, psychotherapy and psychoanalysis, we pay attention to the processes of language; as words are repeated, and where there is rupture and distortion in language as it is expressed. For Lacan and in psychoanalysis, this plays out again in transference: “The more the subject finds alienation in speech, the more he separates from it to find refuge in the phantasy relation to the object” (Leader & Groves, 2005, p. 139). We experience in the transference the oscillation between speech and silence as the oscillation between separation and relation. Obviously, this contributes a great deal of complexity in considering how language is used and its impact on the individual.

A Foucauldian notion of language necessarily involves an examination of power and domination. Jerry Floersch (2000) points to Foucault’s signature concept of

‘biopower,’ and relates it to the work that is done each day in the fields of social work and mental health care:

Biopower refers... to the myriad of ways that dominant discourses on gender, sexuality, ethnicity, and work, become taken for granted, normalized, and internalized; the individual becomes the subject dictated by the dominant discourse. And it is in this way that biopower includes practitioners’ “dividing practices” (e.g., assessment and diagnostic schemes) that work to place the clients either inside a normal circle of behavior or outside, among the abnormal. (p. 3)

Where Lacan emphasizes language’s role in our experiencing of subjectivity, Foucault begins to point to the systems that we are subjected to by language. Everett (2000) has also implicated social work in these detrimentally divisive practices:

The role of rehabilitation is to exert a powerful socialization process that first severs people from their personal histories and then redefines them in the language of disability and handicap— a role that is reminiscent of the Foucauldian view of medicine and psychiatry. The skills people learn during the rehabilitation process are those appropriate to being a “good” patient— someone who is easy to manage, dependent and ignorant of his or her rights— an agenda that appears to be the precise opposite of the consumer and survivor vision of a power contract based on self-empowerment and liberating power relations. (p. 201)

These divisions take place along the lines of language and the meaning language acquires.

Foucault (1994) asks:

How is it that words, which in their primary essence names and designations, and which are articulated just as representation itself is analyzed, can move irresistibly away from their original signification and acquire either a broader or more limited adjacent meaning?” (p. 110)

He has previously intimated a part answer to this question when he discusses one common, but not the only, process of classification: “By a horizontal articulation, grouping together individuals that have certain identities in common and separating those that are different; such articulation then forms a sequential generalization of groups

growing gradually larger and larger (and less and less numerous).” (Foucault, 1994, p. 97).

Hacking (2004) has cited the importance of a Foucauldian perspective in “understanding how classifications of people interact with the people classified” (p. 277). Hacking (1999) understands that, “All our acts are under descriptions, and the acts that are open to us depend, in a purely formal way, on the descriptions available to us.” (p. 31). Again, this interaction, or intersection, is vital to exploring how language is experienced by individuals and how that experience is understood. Hacking (1999) writes that:

‘Interactive’ is a new concept that applies not to people but to classifications, to kinds, to the kinds that can influence what is classified. And because kinds can interact with what is classified, the classification itself may be modified or replaced... the interaction occurs in the larger matrix of institutions and practices surrounding classification (p. 103)

He is particularly concerned with “classifications that, when known by people or those around them, and put to work in institutions, change the ways in which individuals experience themselves – and may even lead people to evolve their feelings and behavior in part because they are so classified” (Hacking, 1999, p. 104).

The importance of the meaning an individual makes is articulated by Foucault when he asserts that, “The way in which a subject accepts or rejects his illness, the way in which he interprets it and gives signification to its most absurd forms, constitutes one of the essential dimensions of the illness.” (Foucault, 1987, p. 47). In an important way, Foucault acknowledges the subject as also acting, and as being part of what is constituted.

*The Impact of Language on Individuals Diagnosed with Bipolar Disorder  
and the Making of Meaning*

Everett's (2000) study includes some important preliminary points about how individuals diagnosed with a mental illness articulate their experience and their (dis)comfort with the language that has been imposed on them. She points out that they define mental illness tentatively and this may imply that they understand the seriousness of the meanings (p. 189). One of her respondents said:

This thing that we've labeled mental illness is really just sadness and discouragement. These feelings have a natural function...[but] we end up with a whole bunch of people saying there's something wrong with the way that we're behaving and medicalizing it so that we have diseases (p. 189)

Another respondent states that: "I think people have to develop their own understanding of their experience" (Everett, 2000, p. 189).

George Lakoff and Mark Johnson (2003) point to both the complexity and the individuality of meaning-making:

Truth is always relative to understanding, which is based on a nonuniversal conceptual system... what is significant for me will not depend on my rational knowledge alone but on my past experiences, values, feelings, and intuitive insights. Meaning is not cut and dried; it is a matter of imagination and a matter of constructing coherence" (p. 227).

This is echoed by Hacking (1999) who cites Hilary Putnam statement that there is a "common philosophical error of supposing that 'reality' must refer to a single super thing, instead of looking at the ways in which we endlessly renegotiate – and are *forced* to renegotiate – our notion of reality as our language and life develops" (p. 101). Lakoff and Johnson put forth an idea of the 'experientialist myth,' as a way by which to work from the middle-ground between rational knowledge and subjective desire. In describing the 'experientialist myth,' they go on to say that:

Its emphasis on interaction and interactional properties shows how meaning always is meaning to a person. And its emphasis on the construction of coherence via experiential gestalts provides an account of what it means for something to be significant to an individual. Moreover, it gives an account of how understanding uses the primary resources of the imagination via metaphor and how it is possible to give experience new meaning and to create new realities (Lakoff & Johnson, 2003, p. 228)

The experientialist myth acknowledges an individual's interaction with their environment and envisions this interaction to be one of mutual exchange. The process is described as such:

The nature of our bodies and our physical and cultural environment imposes a structure on our experience... Recurrent experience leads to the formation of categories, which are experiential gestalts with those natural dimensions. Such gestalts define coherence in our experience. We understand our experience directly when we see it as being structured coherently in terms of gestalts that have emerged directly from interaction with and in our environment. We understand experience metaphorically when we use a gestalt from one domain of experience to structure experience in another domain (Lakoff & Johnson, 2003, p. 230).

This occurs within the self, where "self-understanding involves consciously recognizing previously unconscious metaphors and how we live by them" (Lakoff & Johnson, 2003, p. 233), but also in communication between individuals or groups of individuals.

Meaning is not to be taken for granted, rather, meaning is negotiated.

Importantly, the meaning we have made of our experiences emerges in our language and speech, but also in our actions: "Our implicit and typically unconscious conceptions of ourselves and the values that we live by are perhaps most strongly reflected in the little things we do over and over, that is, in the casual rituals that have emerged spontaneously in our daily lives" (Lakoff & Johnson, 2003, p. 235). Foucault reiterates this notion by acknowledging that "mental illness effaces, but it also emphasizes; on the one hand it suppresses, but on the other, it accentuates..." so that "the

essence of mental illness lies not only in the void that it hollows out, but also in the positive plentitude of activities of replacement that fill that void” (Foucault, 1987, p. 17). So an exploration of meaning-making involves not only what one says about their experience, but how they illustrate this meaning in the activity of their lives.

### *Summary*

This literature review addressed each aspect of the research question by exploring current mental health research and policy language, as well as establishing an informative theoretical stance. Prior literatures provided this study’s framework for the following: (a) the qualitative interviews with individuals who have been diagnosed with bipolar disorder and (b) the exploration of the meaning they have created as “diagnosed” individuals.

The study explored the following research questions:

1. Are there differences in the meaning created by individuals from the experience of being diagnosed with bipolar disorder?
2. Are there differences in the words used to describe this experience and this diagnosis by individuals who have received it?
3. Has the language used by professionals informed the meaning created by the individual?
4. How has language used by professionals informed the meaning created by the individual?



## CHAPTER III

### METHODOLOGY

This research study explored the way in which language, specifically the language of diagnosis, does or does not impact individuals who have been diagnosed with bipolar disorder. The main research questions explored are as follows:

1. Are there differences in the meaning created by individuals from the experience of being diagnosed with bipolar disorder?
2. Are there differences in the words used to describe this experience and this diagnosis by individuals who have received it?
3. Has the language used by professionals informed the meaning created by the individual?
4. How has language used by professionals informed the meaning created by the individual?

Flexible methodology was used in this qualitative study. It is understood that in flexible method research, “unstructured data are used in order to capture the phenomena of interest in the words or actions of those who embody or live them and to capture them in context in terms that are ‘experience-near’ as possible” (Anastas, 1999, p. 57). The design philosophically reflects the research questions being explored. The main purpose in employing a qualitative design and flexible method was to draw out the participants’ experience and voice, as this is what constitutes the meaning and is the purpose of the

study. The researcher was interested in the language and meaning-creation of the participants and, as such, prioritized the use of participants' voice, verbatim accounts, open-ended questions, and interviews as "naturalistic" as possible (Anastas, 1999, p. 62). As well, this research was dependent "on analytic generalization for [its] validity rather than on demographic representativeness", as is consistent with its flexible design (Anastas, 1999, p. 276). The researcher used nonrandom purposive snowball sampling to recruit participants for the study.

The Interview Guide (see Appendix D) was composed of semi-structured, open-ended questions that aimed to facilitate individual narrative. The audio taped discussions were thematically and "linguistically" interpreted by the researcher. This decision, as well, was made in order that the occurrence of the interview itself, its progression and the experience of it, would be largely informed by the narrative of the participant. This research study did not explicitly aim to measure the phenomena of the impact of language, but to explore the tenability of this thesis (i.e. the impact of language) in terms of lived experience, as narrated.

### *Sample*

Inclusion criteria for participants in this study are as follows: (a) over 18 years of age; (b) diagnosed with bipolar disorder for a period of at least three years; and (c) in current stable mental and emotional health.

6 participants were interviewed for one hour each. Participants ranged in age from 29-69 years with a mean age of 55.3 years. Four participants were female and two were male. Their racial and ethnic representation included five Caucasian participants and one of mixed race/ethnicity. Participants had been diagnosed with bipolar disorder between 4-

31 years, with a mean of 17.3 years since diagnosis. Nonrandom purposive snowball sampling was used because of the vulnerability of the population and the specificity of the topic. Participants were initially recruited through National Alliance on Mental Illness (NAMI) DuPage Chapter, and the Depression and Bipolar Support Alliance (DBSA) in Chicago, Illinois. These organizations signed a letter of permission allowing research to take place through their agency (see Appendix E: Agency Letter of Permission). A flyer describing the study was distributed through each of these organizations which allowed participants to be self-selecting, i.e. they contacted the researcher if they were interested or had questions. The researcher also went to a Speaker's Bureau meeting at NAMI-DuPage to informally discuss the study and seek participants.

This being said, many of the participants had experience in supportive programs and had been engaged in advocacy work. While in some ways this limited the diversity of the respondents and their experience, it also provided a responsible safeguard against recruiting participants who were particularly vulnerable or unstable. It also may be seen as strengthening the study because it ensured that the participants were articulate and thoughtful about their diagnosis and their experience of it. After each interview, the participants were asked to let anyone they thought might be interested in being interviewed know that they could contact the researcher for an interview. This was the operationalization of the snowball.

#### *Data Collection*

The application for approval to conduct this study was received in February 2007 from the Human Subjects Review Committee at Smith College. The HSRA outlines this study's adherence to Federal Guidelines protecting participant confidentiality. The

interviews were audio-taped and notes were taken by the researcher. The researcher transcribed the interviews. The research advisor had access to the data after all identifying information was removed. Audiotapes of the interviews have been kept in a locked filing cabinet in the researcher's office. All tapes and files were number coded. No identifying information was used to mark tapes or files, and all audiotapes will be destroyed after a period of three years (2010). The Informed Consent forms (see Appendix A: Informed Consent Form) have been kept separate from all interview data. However, consent forms and the corresponding data are connected by a code, so that the data is traceable in the event that any participant decided to withdraw from the study. While the participants' words appear verbatim throughout the study, their real names have not been used and all details have been disguised. The content of the interviews will not be discussed in any way that identifies the participants, unless there is disclosure of impending harm.

Interviews were conducted in-person, audio-taped and then transcribed. Each interview was an hour long. Interviews took place in a neutral, quiet place that respected the participants' confidentiality. The Interview Guide contained a script that was used for clarifying the goal of the study. The Interview Guide consists of open-ended questions, and while there was a general outline in terms of the order in which themes were covered, the interviewer was flexible and responsive to the narration of the participant.

Individuals contacted the researcher by email or telephone to express interest in participating in the study. Participants and the researcher agreed upon a time and place to conduct the interview (see Appendix B: Recruitment Flier). Participants were informed that the interview would last one hour and their commitment would be no more than one

hour and fifteen minutes. The informed consent procedures were discussed with all participants prior to the initial meeting. The Informed Consent document was sent to any participant who requested it prior to the interview. At the beginning of each interview session, the participant signed two Informed Consent forms (one for their own records and one for the researcher's records) and completed a short demographics survey (see Appendix C: Demographic Survey). After completion of these two documents, the interviews started with the researcher's script clarifying the study topic; interviews were recorded via audio-tape.

### *Data Analysis*

The data collected from participant interviews were inductively analyzed: (a) thematically and (b) linguistically. The researcher made extensive memos on each transcription, clarifying what themes and issues had emerged within the interview and how those themes related to previous emerging themes, and the language used to express them. The coding of material evolved as the interviews continued in this way and drafts were made of potential codes. One potential weakness in this method is that it implies that the order in which the information was encountered influences the analysis. To counter this likelihood, emerging themes are discussed by the researcher, as they are related to the study, from the interviews with the research advisor, colleagues, and peer commentators in order to "check out" the developing analysis. This "checking-out" enhanced the reliability, or credibility, and trustworthiness of this study. Reliability was also enhanced with the availability of an audit-trail. The consent forms, the transcribed interviews, the notes of the researcher after each interview, the memos on the transcribed

interviews containing early theme identification and the theme word files are all components of the audit trail.

Once emerging themes had been clarified, grouping the themes was possible and larger themes were identified. Computer programs such as N-Vivo or Nudist were not necessary for this study because of its small data set. Instead, the researcher identified segments of the narrated text that expressed each theme and copied these segments into a new word file for the particular theme. At this stage, the researcher began to discern the best label to describe the theme and all of its components. Then, the researcher selected quotations that particularly illustrated or exemplified the theme, from the thematic word file, and used these quotations as the basis of the Findings Chapter of this research study.

## CHAPTER IV

### FINDINGS

This qualitative phenomenological research study explored the language of diagnosis and its perceived impact on individuals diagnosed with bipolar disorder. The primary research questions being explored were:

1. Are there differences in the meaning created by individuals from the experience of being diagnosed with bipolar disorder?
2. Are there differences in the words used to describe this experience and this diagnosis by individuals who have received it?
3. Has the language used by professionals informed the meaning created by the individual?
4. How has language used by professionals informed the meaning created by the individual?

Data were collected through interviews with six participants. However, the interviews were flexible and relatively responsive to each participant and there was a stated openness to the experience of the individual participant. Therefore the interviews largely explored: (a) the experience of diagnosis and (b) the participants' thoughts and ideas about how and if language had impacted that experience. When unexpected and interesting themes emerged in the interviews, these themes were allowed and explored over and above an adherence to the Interview Guide.

Analysis of the data revealed the broad themes of: (a) the participants' experience of language; (b) their making of meaning, or where strength was found; and (c) the function of language.

The participants' experience of language was further analyzed to reveal the following themes: (a) language as naming, labeling or categorizing; (b) language as relating to personal experience; (c) language as relating to acceptance of the diagnosis; and (d) language as used by the participants. The function of language was further analyzed to reveal the following themes: (a) language sets apart or "others;" (b) language creates a dichotomy, specifically between mental and physical illness; and (c) language as cultural expression and as reflected in media representation. These themes point to the various ways that language may, in part, both impact and create our experiences. Admittedly, with this study's theme being language, a unique complexity emerged in terms of identifying themes and, in fact, giving these themes, themselves, a name or label. For this reason, and because interviews were unstructured and flexible, the themes are broadly identified, overlap a great deal, and verbatim accounts have been privileged wherever possible throughout this chapter. This chapter is divided into ten sections.

#### *Description of Sample*

The sample included six individuals who have been diagnosed with bipolar disorder and who met all other inclusion criteria. Three participants were recruited through the DuPage Chapter of the National Alliance on Mental Illness; one was recruited through the Depression and Bipolar Support Alliance of Greater Chicago; one was recruited through snowball sampling; and one was recruited through personal



'acquaintanceship'. Interviews were conducted in varied physical facilities to protect the confidentiality of all participants.

The age range of participants was 29-69 years, with a mean of 55.3 years. There were four female participants and two male participants. The demographic survey included questions of age, gender, race/ethnicity, religion, approximate annual gross income, highest level of completed education, and number of years diagnosed with bipolar disorder. Five participants described their race/ethnicity as white or Caucasian and one described mixed race/ethnicity. Four participants reported being Christian (one identified Anglican, one identified Roman Catholic), one participant responded "not applicable" and one declined to report an identified religion. The approximate annual gross income of participants ranged from \$500.00- \$55,000.00 with a mean income of \$36,100.00. One participant chose not to divulge their approximate annual gross income. All participants reported their highest level of education completed; responses included: M.B.A. (two participants), one B.S., one PhD, one M.S., and one "college" level. Although it was not requested, it was revealed through the interviews that five participants were married and one was divorced. The number of years since being diagnosed with bipolar ranged from 4-31 years, with a mean of 17.5 years since diagnosis. It is important to note that because of the average age and number of years since diagnosis, many participants had initially received a diagnosis of "manic depressive disorder" which was later named bipolar disorder.

## *The Experience of Language*

### *Language as Naming, Labeling or Categorizing*

All participants articulated their reaction to a diagnosis of bipolar disorder considering the felt seriousness of the diagnosis and the connotations the diagnosis implied:

To me, the concept of, or the words bipolar, means that you're really sick, and obviously a lot of derogatory thoughts are associated with that.

I thought it was crazy, I mean, it was very offensive. The word, the manic, mania, maniacal, ah, maniac kind of connotations. That was very, very negative to me. I found it very offensive.

You don't want to be called crazy, because crazy is too cartoonish, you know, it's almost not-real, because crazy has so many different connotations.

He said the diagnosis was manic-depression, and at the time I was so surprised by that. I was thinking, no, I'm not that bad. And again, it just shows the power of that label... I thought, my God, if someone reads that they'll think I'm crazy, you know... they'll have less respect for me. So it put it into a whole different category than just being depressive.

I kept pushing that term away because I knew it was more, ah, I didn't want to admit that, and the implications, 'cause I lose control going down, I lose control going up, you know?

It was revealed as well that there is something attractive about not naming or labeling the condition:

I like the idea of this doctor saying 'let's not worry about the labels', you know, let's just get into it and find out what's going on with you and your mind, and what we can do about it.

There are also positive aspects to the naming of experience. Two of the six participants articulated this clearly. Naming can provide relief, by way of an explanation of experiences, and in this way can ease the burden of a sense of guilt:

Now when I look back I wish I had known, because, well back then there probably wouldn't be as much treatment, but this thing's ongoing within me and then you feel guilty because you're not producing, and I wasn't studying as much, but the reason I wasn't studying is because I was overcome by depression. It was only about ten years ago that I figured it out." Calling it something, naming the experience, "helped me then to put, to give a sense, yeah, this is the process that I've been going through since I was 19-20 years old, it's a legitimate, it's a valid, process from which I have suffered greatly. And it was a relief to me at that point to say now I know why, what was going on back there...because it took some of the stigma off when I wasn't able to perform as well... it was freeing because it gave some reason...

I was relieved, and I realize that's not the case for other people, for me, I heard those words and it was accepted at that very moment... I felt like it was an answer, I appreciated in terms of the fact that it was medical terminology, I was comforted by that, rather than someone just making a vague description of what I had or what I was diagnosed with... so I didn't feel odd at that point, like it was OK... I then had an answer, an explanation, not an excuse, but an actual understanding of why I did these things that were just, you know... not me.

Differing views were expressed in regards to specific names, or labels, and what they imply to individuals:

I knew that I was subject to cycles, cycling, but it's one thing to say cycling and another thing to say manic depression.

The fact that I'm bipolar has less emotional impact than to say I'm manic-depressive. 'Cause manic's a pretty strong word.

Why is it OK for someone to have, um, even if you use manic-depression, which is bipolar disorder, I mean, even if you use that word it's different than using its alias?

The emotional weight of the diagnosis comes across clearly, especially as it relates to depression, which in the cases of most participants had not only been a previous diagnosis but also how they had come to think of themselves:

I've always felt that manic depression is a term which has more emotional weight to it than depression. When you think of people with manic depression, now it's bipolar, it's a more painful diagnosis because not only do you suffer terrible depressions, you have to be careful not to go too high...

See depression is something everyman can relate to. Everyone's been sad, everyone's had some sort of bout of depression, of sadness, or whatever, this is something relate-able. So if you can tell someone that you suffer from depression, it's much more easily accepted. If you tell someone you're bipolar, they get all bent out of shape. Because they're afraid, because they think they've never encountered bipolar people before, but more than likely they have and didn't know it. So that, the stigma, is one of the reasons that people are reluctant to accept a diagnosis of bipolar.

The vulnerability of language, or labels, to carry-over meaning came across, particularly when there was discussion about the renaming of manic-depressive disorder to bipolar disorder:

They changed it from manic-depression, they changed it to bipolar, now everybody's bipolar, and you hear it everywhere, you know? So it's like, why change it? It didn't serve it's purpose, if the purpose of changing away from manic-depression was 'cause manic-depression had such a bad rap, then bipolar already had that bad rap or worse...

Despite the complexities and the difficulty of hearing a diagnosis of bipolar disorder, it also came across throughout the interviews that there is value and importance in giving experience a name:

Language can hopefully help other people when they're going through it to provide some understanding and for their families or what's going on...

Most people are interested in having something given a name, somewhere you gotta put a hook on it, a label on it.

The most accurate way, and the most reasonable way, to deal with it is to define it as it is and let it be that.

Don't dress something up, why are we afraid to call something what it is?

### *Language as Relating to Personal Experience*

More personal complexities arose when language was thought about in relation to what are often profoundly difficult and challenging experiences of living with mental illness:

What happens is often there's a denial process going on, sometimes, it's hard to put a label on things sometimes.

It's very difficult... Ah, and we're dishonored. And we're talking about bipolar here, it's at the heart of who you are... and your emotions, your perceptions of yourself and how people react to you and the stigmas involved, it cuts to your heart you know? You have to fight to keep a sense of self-esteem or respect for yourself because everyone else is saying, at different times, and in culture, you know, 'the other'...

Call it manic depression or call it bipolar, all I know is when you have severe depression, you have it. You can't get out of bed, just in constant agony, you don't know why, you go through all kinds of feelings, ah, but the language becomes important... but I tend to have to agree that most people the doctors are dealing with, ah, especially at that time when they're suffering with the illness, to go into a lot of detail on semantics is not where one ought to dwell.

It became clear that there was more positive regard for the language of diagnosis when it was felt to reflect personal experience. Of course, conversely, there is a reluctance to take on the language of diagnosis when it is not felt to reflect personal experience:

The problem with the diagnosis and the label and the words is they don't take into account what may've caused it. That's the big... that I would prefer a diagnosis of 'reactive'... or something like that in there, that would've been a big asset and help to me.

All I heard was random cycling, short cycling, ups and downs, unexplained, no reason, and I'm like, I can't relate to this, you know, I don't think I have that, but now I hear more about triggers... 'triggers' is helpful, 'reactive' is helpful. I mean, if it's true, for somebody that it's not, it's not.

Bipolar is unlike schizophrenia or schizoaffective. Those words, how do they describe? Versus bipolar, it's inherent, it's two poles, I mean the opposite, you know, mania and/or elation and depression. I mean, it's a term that makes sense... that's an accurate description of what the illness is about.

The difficulty of trying to talk about specific language when it relates so intimately to the participants' lived experience was often apparent:

I think that *I am that*, so I don't think it's come to *mean* anything. It's like an answer... it's part of me, I mean, that is. So I don't really... and it's not for lack of not thinking about it, I don't see it as anything more than just an illness.

### *Language as Relating to Acceptance of the Diagnosis*

Connected with the degree to which the language of diagnosis was felt to reflect personal experience, identifying with the language of diagnosis may also be seen to reflect a struggle with the acceptance of diagnosis. Another way of saying this could be that a reluctance to accept the diagnosis is a reluctance to accept the implications of that diagnosis, and this is evident in a reluctance to take on a word, a label, of bipolar as part of oneself:

I wanted to be me, you know, I wanted to be OK. And I had a lot of denial...

Denying the diagnosis itself, but more denying the need for any kind of medication and hoping that I could stay well, which I sometimes did for five years at a time, out of the hospital, working, doing fine...

I'm in the center a lot too, I'm not wildly bouncing back and forth between two poles. So, I'm not really sure, it took me a long time to get comfortable with even believing that this is what I have, you know, because I never considered myself a 'moody' person.

I imagine there's more of a stigma in our society to manic depression than depression, so yeah, that label or diagnosis I was very reluctant to take on, even though the evidence was very clear.

Two of the six participants did not feel themselves to be entirely accepting of their "diagnosis," but did understand it as something that they were living with. One participant in particular did not think in terms of acceptance. She said:

You think, when you think of acceptance, you think... I feel *resigned* to it.

The power, and the implications, of articulating were clear. In terms of a diagnosis, to take it on and to attribute it out loud to oneself, may represent a more full acceptance:

To know it on one level, and then accept the diagnosis on another level, are two different things.

I think to truly accept, to truly accept, what you have, you need to accept only the ramifications, what it means, what it tangibly means, but you also have to accept it's label. I mean, but I don't think... I think that's a harder thing for people. I think people can accept who they are and what it means, how it's gonna affect them in the future, how it affects them now, what their needs are, what medications... but to accept that name, I think that's hard.

I really truly do not believe that people can accept their illness until they can accept what it's called and the ramifications, the words, all the words, associated with it. You know, paranoia and mania, and you know... I don't know how you can accept your illness and not be able to handle that.

### *Language as Used by the Participants*

Participants brought forth various views on how they choose to use language in a way that may more accurately reflect how they see and know themselves:

You aren't a disorder, you have a disorder, or you suffer from a disorder.

But it's not who I am. I mean, I am so many other things besides having bipolar disorder. I'm an artist, I'm a computer scientist, I'm a mental health professional now...

I had a big problem with perhaps the language of diagnosis because the idea of bipolar disorder was totally new to me when I was diagnosed... And there's some people who are very comfortable with being bipolar or labeling themselves bipolar, and I don't understand... to me, the key is *disorder*.

I still like to say, 'I have bipolar disorder', so if that means I'm not fully at a point of acceptance, if it means that I think the language should be more... you could say, with diabetes, 'I am diabetic' or 'I have diabetes', but with cancer or heart disease or some other illnesses there's no adjective. You don't say, 'I am cancer', you just have it, you know what I mean?

And the other thing with the language is to say I have bipolar disorder, versus I am bipolar. I wouldn't say 'I am cancer', or 'I am heart disease', or 'I am foot fungus' or anything else. I would say I *have* those things.

It's like, could you imagine, OK, somebody who says I'm bipolar, would you say... I'm cancer?... I can't relate to people using the word, saying I'm bipolar, I can't... then get some help, quit being bipolar, you know?... To me; fight it, solve

it. So then I would prefer to say I *had*, I was diagnosed with and I'm under treatment and I'm doing fine...

The felt limits of a language of diagnosis were also acknowledged:

I think that fact of saying, OK you're mentally ill, you have depression... more caused the depression in a lot of times, that labeling, instead of saying you're mourning, you know, this is hard for you... I always wanted to deal with the causes, I didn't want to just say OK you're labeled, this is it, take this medication, that was not... so I don't know if that's language, but the language didn't help.

There are also extensive and, again, various personal and political reasons for the way individuals choose to use language. Understandably, these decisions are most often made in relation to others, or to society:

Let me put it this way, we just did a symposium and one of the speakers spoke on stigma and he said the only way to vanquish stigma is for everyone to come out, because there are so many people out there that are suffering from depression and bipolar illness and schizophrenia, and that is to come out. Ahh, that all sounds real good on paper, but in the real world... people who come to the support group, people I know, I always advise them not to tell a prospective employer that they're bipolar or even that they're suffering from depression, because that will stick with them. First of all, they'll be lucky if they get hired, and secondly, if they do get hired or if they reveal let's say to a current boss, something can happen that in the grand scheme of things would be accepted as a natural reaction, but if you're bipolar they see it as a symptom... if you're bipolar, it's 'you went bipolar on us.'

I think probably if I didn't have to associate with people, if I was a hermit, I probably wouldn't need to say it. But because I am in contact with others, to not say it, not say those words, would be basically the same as denying I have it.

I think *they're* uncomfortable. I don't know, I think it is the words, I don't know, that diagnosis, maybe that name, bipolar, maybe that's the problem, I don't know. So it's sad because you know what it does is, it's their own insecurity, but what it does is that it subconsciously or, basically, they're extending their shame, like I should be ashamed.

The more I say it the more comfortable I am with it, and that's important because even if you want to talk about your illness and you don't want to use that word, well, you're still then sending, even in your own mind, you're saying there's a stigma attached to that.



I would say for some people it's like a connection point. I think so many people are afraid to talk about it, or admit it, you know, even though they know that's something to struggle with. So I think using those words actually helps make it more real... I think it's important for people to understand those words, you know: schizophrenia, major depression, bipolar disorder. I mean, these things are OK to talk about, and they're OK, you know, it's part of life, it's not something they've done wrong, it's just that's who they are or what they're dealing with. So I find it's, it's a sensitive thing, people react and you never know, and I think that's always an apprehension of mine, like you never know how they're going to react, but it doesn't change my willingness to say those words, to talk about it.

The political use of words used interpersonally was a theme that emerged:

It's sort of like now in an ethnic group, you know like African-Americans can say, 'here's a word you've used against me all these years, now we can use it about ourselves and you can't hurt us with it anymore'.

Not the words, it's just the meaning behind the words. It's like, you know, there's an automatic negative. And I don't know. Is that continual exposure to people, is it saying that word over and over and over again, will that help? Maybe. I don't know how else you would get people used to it.

All of the participants spoke, whether positively or negatively, about "coming out" about mental illness and likened the importance of that to the "coming out" of gay, lesbian, bisexual and transgendered individuals.

The relativity of language also emerged; the relevance of how words are used, the intended meaning of the words as being more important than the words themselves:

T's depressed, OK, T's off his wagon, T's nutso. Those are the kind of terms that don't have any meaning. So how they're used, it could make somebody very irritated or it could be used as humor... it depends on the intention, it also depends on the specificity of the definition.

A rose is a rose. And people... I think probably people that have disorders just don't like to be called crazy. See, they can call themselves crazy, but they do not want to be called crazy by someone who means it.

### *The Making of Meaning; Where Strength and Support are Found*

The making of meaning was revealed not in terms of specific language, but rather, where individuals found meaning, strength, and support, in living with mental illness. The importance of a sense of community around dealing with a diagnosis was apparent. Most often, this was found through support groups, advocacy work, or creative work within an accepting community:

Being involved in a good support group is paramount to lifting a huge burden off you, because initially you really do feel like you're this poor little island in a sea of mental illness... I did feel a sense of community with the people there. I saw that there were some people that were obviously not, ah, healthy yet, but they were striving and working very hard, and I heard a lot of stories that made my situation seem less ominous.

I want to do well for myself so that I can do well for the organization and the people that come to us.

Part of the felt acceptance was the group's openness about their diagnosis:

Because we're totally open about it, everybody who joins the project, when we have an exhibit all our names are used. It's not like a first name or anything, you know, first name, last name. Everybody is open... so we say it loud, 'I'm mentally ill and I'm proud,' so that's a different feeling than I had before.

I think I associated with people who were comfortable that they had it, and I found out that they were just normal people and they had their struggles and I realized some of their's were like some of mine and that yeah, maybe I do, you know... I started focusing on the disorder, rather than on the bipolar, and that make me more comfortable with it.

It's been liberating to feel like we can accomplish so much and educate the public... we've just continued to try and get the word out and educate everybody that, 'hey, people with mental illness are creative and capable, you know...

Most participants related the importance to them of reading the accounts or autobiographies of people who had lived, or live, with mental illness. Three of the six participants spoke in particular about Kay Redfield Jamison:

I've been more embracing of the diagnosis since, for the past ten years, I've been involved with the \*\*\*\*\* Project... and I read Touched with Fire by Kay Redfield Jamison and read her autobiography, and read other artists' autobiographies, and now I'm more embracing of it.

My sister, M, was always looking at all the artists and writers and stuff who had bipolar disorder. All these geniuses. And thinking that it had some... value and merit. And so she sort of glorified it almost.

As well, the importance of family, friends, spouses and role models was unanimously voiced:

Without a role model I might have assumed that I could never work or, you know, I could be disabled so badly, or be in an out of hospitals so much and end up homeless, and a lot of people do...

Personal characteristics or attributes, and personal faith, were also felt to be a valuable aspect of accepting and enduring:

I'm Irish, Irish-American I should say, I was born in the Bronx... something in me. In spite of the fact that I'm hypomanic or manic-depressive or bipolar or whatever else, there's something within me that says... you're worthwhile, you know? And I can be depressed and feeling badly about myself, but there's something on a deeper level almost, that remained with me to fight... also my faith.

I think some people are more willing to accept change or accept difficult things than others... there are people more comfortable with talking about things than others, that maybe I do feel a good portion of my acceptance and treatment has been talking about it. So if people are not comfortable speaking, and I don't mean like on the podium speaking, I'm talking about in general speaking, I think they would have a harder time coming to terms with the ramifications and the words...

Suffering is not the final word, suffering is not the final word. That has helped me tremendously. It doesn't mean my suffering is less, that it isn't painful, but that helps me to know that it's not the end, and that I'm not alone.

I've been to the bottom and I know there's no other choice, there's no option but to accept it...the deeper the bottom, the more readily someone is willing to accept what they have... so I think part of it is being at the bottom and knowing that you can only go up, you have to accept it to move up.

It was also clear how meaning can be found simply in the way that we, as people, and certainly as allies working in the field, interact with one another. One participant spoke about the importance of being treated with dignity. This participant described an incident that communicated a true sense of worth and dignity to him when he was in a vulnerable and frightening situation:

Dignity. It's in that. It's in that priest running up to me in the parking lot in his robes to hug me.

### *The Function of Language*

#### *Language Sets Apart or "Others"*

A more macro-level analysis reveals another vital aspect of language, which is the way it functions. That is, what it succeeds in doing. Most clearly, it succeeds in setting things apart from one another because it draws lines and makes distinctions:

OK, and as a rape survivor, when I would tell people about being raped, a lot of people would either kind of distance themselves in the sense, thinking, it's everybody knows this could happen to them but they want to feel like it couldn't happen to them; 'so what did you do wrong, what did you do, what did you do to cause this?' ... everybody wants to kind of think it couldn't happen to them, and the same thing with this label of mental illness.

It's interesting because I think if I were to not use the word bipolar disorder, but if I were to be talking about it with someone and I just described it, like even with medical terms; like rapid cycling and mania and if I were to use these words, I think people would be fine. But as soon as you throw that word in there, bipolar, I think it changes peoples' ... feelings or categorization.

I'm not even sure so much people are afraid of the people as they are of the name, you know?

The physical internment of the mentally ill is remembered as a means by which to separate the mentally ill from the rest of society:

Well, the way they used to control it, they'd put you in a mental institution, that was the control, they didn't know how to deal with it, so lock 'em up... it keeps the problems out of society's way so they don't have to deal with it.

One participant described the way the physical separation and 'othering' of the mentally ill still persists:

And a lot of people do [end up] in long-term care 'cause they've shut down all the long-term hospitals, and they get placed somewhere like nursing homes. All these young people, bright young people with mental illnesses, are in nursing homes, it's horrible...

Encountering a double standard can be thought of as an illustration of dividing practices or 'othering':

I thought I was gonna grow up and be somebody, you know? And so I was teased by that, even without me saying it, you know, it was I had that kind of stuff which could get to mania in the sense that it's grandiosity, you know, I had that. Um, but you know, Bill Clinton, when he was in highschool he wanted to be president and nobody's saying he's grandiose because he did it! But, you know, somebody else who does that, it's very tricky, because practically everything in there [the DSM], other than maybe psychotic, you know, a normal person can also do and be perfectly normal... these are all fairly normal things in isolation, but if you have them all together and they become a problem, you know, you have a disorder.

If we're not held to the same standards and held accountable for our actions... then, you know, we are setting ourselves apart.

One participant spoke about losing friends, specifically after being diagnosed:

I think that they associated with the stigma. I think they felt, I don't know if they felt that I would rub off on them or if they felt like they were just done, they don't want to deal with that, or learn how to deal with someone. Maybe they didn't want to learn to understand.

Other participants echoed thoughts on the stigma attached to a diagnosis of bipolar disorder:

[Stigma is] ignorance, it's caused by ignorance. It's caused by fear. People who are afraid they could get it, or you know, it's almost like they act like it could be contagious. There's just a lot of ignorance still in the world.

In a way it puts you in another category in most peoples' minds, that's where we are... there's an automatic categorization that goes on in peoples' minds... even I think people who are familiar, maybe people who are nurses, maybe people who are doctors, I think there's an automatic categorization that this person is a liability.

I think a lot of it in the beginning I did was making assumptions that other people are me knew that I had this illness, and I self-stigmatized, I was afraid. All psychology has ever tried to do is categorize people in identifiable groups so you can break them down in certain sections but the reality is even within the group no two are alike.

The medication is a very stigmatic thing too, because when you go to the pharmacist and if you go to a pharmacist and you're pickin' up depacote, you don't feel embarrassed because that could be for you epilepsy, ok. You go to the pharmacist and you're pickin' up lithium, ain't nothin' else for that lithium but bipolar illness.

A negative feeling towards the felt permanence of the diagnosis was discussed more than once:

Once you've had that diagnosis, you always have that diagnosis. Why can't it be in remission?

There were clear views that this setting apart is an extreme disservice to individuals living with mental illness. However, participants did express hope and thoughts about how the service delivery system, and the individuals within it, could work towards bridging that imposed distance:

It needs to be much more human. It needs to be humanized. They need to treat people with dignity. 'Cause, you know, just 'cause I'm not well doesn't mean I'm not intelligent or, you know, sensitive, or capable of having a conversation...

What I would hope, eventually, it would become a word that, or a condition, that's treated no differently than any other medical condition.

## *Language Creates a Dichotomy Between Mental and Physical Illness*

The theme of a created dichotomy between mental and physical illness emerged consistently, and is presumably particularly important because of the stigma attached to mental illness:

And it was the split between mental and physical illness and why it's so stigmatized, like why having cancer or something else... that's what really hurts, that's something that really needs to be addressed. 'Cause we are *one*. A brain disease, to my mind would just be a label that's breaking it down even more, like a physical separating of what really should unite them. I mean, if we didn't have the word, or the distinction, mental or physical illness, then [mental illness] wouldn't be considered any different than any [physical illness].

Yeah, it's kind of overwhelming or something in a way that it shouldn't really be... it's interesting, there's other things, other symptoms, other illnesses, physical illnesses that may have psychiatric symptoms and once it's found to be caused by a germ or whatever, then it became no longer a psychiatric illness, it became considered a physical illness. I don't believe in that divide. I just think you have to get back to the larger question of mental illness, differentiating that from physical illness, I think that's where it's bullshit, that distinction, is wrong... let's look at the bigger picture, the whole idea of mental versus physical illness is the wrong distinction to begin with.

Much more than a philosophical distinction, the distinction between mental and physical illness has a profound impact on what treatment looks and feels like:

If I had broken my leg, they can call, I can call. So it's like, you know, why is this secrecy necessary, except with the stigma? What else is there? 'Cause you call or 'yeah they're in room such-and-such' and you get the name and number, and 'hey, I heard you're in the hospital, I'm your friend, I want to be there for you, can I come and visit you,' but they couldn't even get through, couldn't even get any information, and you think well, that a good thing. But it isn't. It's just stigmatizing. Re-stigmatizing.

Why should somebody be afraid to mention bipolar any more than somebody, say, well I've got cancer... why should it be any more difficult for you and I to talk about, ah, cancer or personal experiences mentally or physically in terms of illness and good health?

*Language as Cultural Expression and as Reflections in the Media*

Language can be seen as a reflection of cultural values:

It's so chicken and egg, what's the cause and the effect, you know? The great artists like Van Gogh, and some of the writers who committed suicide, Sylvia Plath and whoever, and you think, well, was it the illness that made them great or the greatness or the sensitivity or what that made them ill? Or did they just have a genetic predisposition and it's just a brain disorder? No, I don't know, I don't really buy that 'cause it's so societal, and there's so much cultural norms of how people behave and what's acceptable and what's not, and in other cultures people with what's labeled mental illness in this culture might be a shaman or, you know, really powerful leaders, and not looked upon as pariah.

Predictably, the media is a powerful purveyor of cultural values. If the media does not necessarily create the stigma, it all too often succeeds in maintaining it:

I mean, they don't do shows on, you know, bipolar disorder and how great it, you know, can be and how people can resolve. You don't see that in the shows, like I'm thinking about a law and order episode that was about a person with schizophrenia. I mean, it never got resolved, I mean, the person was a total nutcase, and you never saw that the person could be OK once they're taking their medicine, you know, you just see them sent to jail and that's the end and they're crazy and thank goodness they're off the street, that's all, you know?

I mean, there are a lot of people out there who have bipolar disorder, many of whom are treated but don't want to talk about it. And I'm talking about, like, celebrities. I mean, I wish people would talk about it, you know, 'cause you only see, it's only brought to attention, like in magazines, in TV and movies, the bad side of it. They use it an explanation, or excuse, or answer to bad behaviors. But if they're being treated, why aren't they talking about it?

The media, if they would quit sensationalizing every time...or how 'bout this bipolar teacher who had sex with her twelve year old student, and why is she all over the news anyway, because she's gorgeous? ...People want to generalize about these cases that show up in the news, or violent ones... it's so sensationalized, it's so negative in the news, in the media, that people just assume that we have... *everybody* has the potential to be violent...

Clearly, these representations have an impact on what it means for an individual to hear a diagnosis, and how they take it in:



And the first time I was hospitalized in that period the first thing they said was bipolar, of course then they said manic depressive because bipolar was not cool then, and I was just so irate and I was so in denial and I was so 'you gotta be kidding me'. I think partially because even though I'd read about manic depression, I had never really put it with me, you know. It was something that you usually hear about in a negative context. Some manic depressive person threw themselves off a bridge, some manic depressive person abused their child, some manic depressive person 'yada yada', so that didn't connect with me...

### *Summary*

This qualitative phenomenological research study explored the language of diagnosis, and its perceived impact on individuals diagnosed with bipolar disorder.

Analysis of the data revealed the broad themes of:

1. The participants' experience of language.
2. Making of meaning, or where strength was found.
3. The function of language.

The participants' experience of language was further analyzed and revealed the following themes: (a) language as naming, labeling or categorizing; (b) language as relating to personal experience; (c) language as relating to acceptance of a diagnosis; and (d) language as *used* by the participants.' The function of language was further analyzed and revealed the following themes: (a) language sets apart or "others;" (b) language creates a dichotomy, specifically between mental and physical illness; and (c) language as cultural expression and as reflected in media representation. These themes point to the various ways that language may, in part, both impact and create our experiences.

## CHAPTER V

### DISCUSSION

This qualitative phenomenological research study examined the ways in which the language of diagnosis impacts the experience of individuals diagnosed with bipolar disorder. In this chapter the results of the study will be discussed in relationship to each other in to prior work.

Analysis of the data revealed the following broad themes:

1. The participants' experience of language.
2. The making of meaning, or where strength and support were found.
3. The function of language.

The participants' experience of language was further analyzed to reveal the following themes: (a) language as naming, labeling or categorizing; (b) language as relating to personal experience; (c) language as it relates to acceptance of a diagnosis; and (d) language as it is used by the participants. The function of language was further analyzed to reveal the following themes: (a) language sets apart, or 'others;' (b) language creates a dichotomy, specifically between mental and physical illness; and (c) language as cultural expression and as reflected in the media.

An interesting and highly relevant complexity in trying to relate the theoretical underpinnings of this research study with its data collection and analysis was the use of language to discuss the impact of language. This complexity is articulated by Butler

(1997), who recognizes that "... we exercise the force of language even as we seek to counter its force, caught up in a bind that no act of censorship can undo" (p.1). There are numerous issues for further discussion that were illuminated by this research study.

### *The Participants' Experience of Language*

#### *Language as Naming, Labeling or Categorizing*

Participants in this study had distinct reactions to a diagnosis of bipolar disorder. In part, they reacted strongly because of the felt seriousness of the diagnosis. However, there was also a felt sense of relief because the diagnosis offered an explanation for, or an answer to, their experience. Naming, in this sense, succeeded in providing some context for their experience and in this sense was felt to be normalizing. Naming the experience eased a sense of guilt and confusion about what they had been experiencing in their lives. This view offers a potentially positive aspect of classifying individuals; where, by doing so, one becomes part of a group, a specific population, instead of an individual suffering on their own and without explanation. On the level of the individual, this would seem to contrast Foucault's (1987) notion that as society "diagnoses the illness, it exclude the patient." (p. 63). The personal experience of suffering on one's own, and without explanation, begs for a context wherein it can be felt that one is not actually alone.

This finding is also a flip side to Everett's (2000) coin, who states that: "I and my colleagues were unable to provide ... supports and, instead, translated the patients' expression of suffering into a psychiatric diagnosis..." (p.197); this description describes the recognition of suffering and the psychiatric diagnosis as being mutually exclusive, in that a clinician would do one or the other. However, the responses of a few participants may motivate us to question the necessity of this mutual exclusivity. Indeed, we may

consider that there are positive aspects to the naming of experience which language allows, while also being aware that there are negative consequences to this process and the system that it entails.

‘Bipolar disorder’ is a specific name, label or category that, for the participants of this study, held predominantly negative and serious connotations. While there were differing views about the seriousness of the labels manic depression (the majority of participants having been previously diagnosed with manic depression) versus bipolar disorder, bipolar disorder was felt to have a much greater emotional weight than does depression (again, the majority of participants were also previously diagnosed with depression).

There was also the expressed notion that with certain kinds of labels, the specific word used does not always matter. In the case of bipolar disorder versus manic depression, it was felt that the meaning carried over, despite the intention of disarming the diagnosis of its stigmatic connotations. In this way, language itself seems vulnerable to the previously created meaning. From this, we may hypothesize that language does not have the agency one may think. Rather, it is the meaning, the circumstances that a word implies, that may in fact have the agency.

This subtly echoes the findings by Corrigan, Watson, Heyrman, Warpinski, Gracia, Slopen, and Hall (2005) that current legislation regarding the liberty, protection from discrimination and privacy rights of the mentally ill only takes into account a diagnosis, and nothing more individual or particular. So, if language itself is vulnerable to the cultural values that create it, we may infer that the individuals who are subject to it, labeled by it, are all the more vulnerable.

Despite the complexities that ‘naming the illness’ entails, participants in this study also acknowledged that there is a general inclination towards, and a usefulness in, naming what is apparent and not being afraid to do so. Further, there is even something liberating about doing so.

### *Language as Relating to Personal Experience*

The participants in this study related that an exploration of how language impacts individuals does in some way depend on the personal experience of that individual. The language of diagnosis can be denied as easily as anything one wishes to, or needs, to deny. In this way, what you are able to hear depends on your personal experience, i.e. whether or not language resonates with one’s own personal experience. Acceptance of the language of diagnosis also depends on the degree to which one has felt understood by the clinician and how much the language conveys that understanding of personal experience.

Analysis in this vein illuminates a consistently felt complexity in this study, which is that of examining something as intellectualized as language when speaking with individuals about their lives. This being said, it was clear that there is a positive regard for the language of diagnosis when it was felt to reflect personal experience, and therefore that language has more power when it accounts for personal experience. This seems to reflect Hilary Putnam’s view, as cited by Hacking (1999), that we negotiate and renegotiate our notion of reality as it relates to our personal experience, “as our language and life develops” (p. 101). This finding is congruent with Lakoff and Johnson’s (2003) statement that “meaning is always meaning to a person” (p. 228), and that coherence is

constructed in relation to personal understanding and experience. As presented in the Findings, this is illustrated by one participant's stating:

All I heard was random cycling, short cycling, ups and downs, unexplained, no reason, and I'm like, I can't relate to this, you know, I don't think I have that, but now I hear more about triggers... 'triggers' is helpful, 'reactive' is helpful. I mean, if it's true. For somebody that it's not, it's not.

When aspects of the diagnostic language reflect personal experience it is felt to be helpful, it speaks to the individual and moves toward affirming their experience.

We can infer from the Findings as well that while language does not initially create experience, it is undoubtedly an expression of experience. Perhaps the relating of experience, through language, changes the experience into something else by being one of the means by which the experience can be translated into something shared. Language does not initially create the experience (for example, Lacan may agree that the breast is experienced more simply, more intuitively.), but that language is attributed to experience (as in the mother-child, as in the therapeutic encounter, and as with diagnosis), and it is then that it becomes part of conveying experience, articulating experience. Further, its meaning is in the relating of experience, through language, which is at once a relief and a recognition, and is simultaneously alienating; it sets us apart from the experience.

This study did at least reflect that language offers recognition to us, and one that is felt, truly, to be important. It is particularly effectively in demonstrating that language resonates when it is felt to reflect personal experience. As clinicians, we may see this as an invitation to broaden the language that we use so that it can resonate whenever possible with individual experience.

### *Language as Relating to Acceptance of a Diagnosis*

We see reflections of Lakoff and Johnson (2003) again when we look at the ways in which language relates to an acceptance of a diagnosis or, conversely, relates to the non-acceptance of a diagnosis; “We understand our experience directly when we see it as being structured coherently in terms of gestalts that have emerged directly from interaction with and in our environment.” (p. 230). This follows from a discussion of the importance of language reflecting personal experience, and was taken further by participants who related an acceptance of the language of diagnosis to acceptance of the diagnosis itself.

If language resonates, it is because it reflects our experience. As such, we can understand it in a personal way and are all the more willing to take it on as our own, or as a reflection of our very selves. Some of the participants in this study found that the language of diagnoses may well attempt to describe what they were experiencing, but that they were nonetheless hesitant to take on the label because it seemed such a narrow description. Denying the language, and denying its attribution to the self, parallels the denial of the diagnosis and all that the diagnosis implies for an individual, particularly its implications within the context of Western society:

Denying the diagnosis itself, but more denying the need for any kind of medication...

One participant, on the other hand, considered taking on the language of diagnosis as deeply important to her by accepting and living with her diagnosis.

I really truly do not believe that people can accept their illness until they can accept what it's called and the ramifications, the words, all the words, associated with it.

For clinicians, this may highlight the importance of making use of the language that resonates with individuals, lest we be complicit in their denial of aspects of their experience. The participants of this study reflected the idea that to state out loud and articulate, a diagnosis of bipolar disorder in relation to self is recognition, on a different level, than mere experience, or ‘what one knows.’ One participant in particular held that taking on a language of diagnosis, or more specifically a label of bipolar, was indicative of accepting the condition as part of one’s life. The implication is that if one is not accepting of the language of diagnosis, one is in denial, perhaps not of their experience, but of its formalization within the mental health system. We must be clear that the denial or acceptance of the language of diagnosis is the denial or acceptance of a particular language, and not, as Foucault (1987) reminds us, the “language of everyday life” (p. 67) within which the mentally ill were once contained.

#### *Language as Used by Participants*

The power of using language is stated by Christopher Bollas (1987) when he writes that “speaking becomes associated with the transformation of the self” (p. 194). This association implies (a) that one speaks and, (b) the way one speaks, has the potential to transform the way one sees her/himself and, in fact, who they are. Part of what was illuminated, in a preliminary way, by this study were the various ways participants use language in an intentional way to demark or illustrate the role a received diagnosis plays in their life.

Participants in this study, for the most part, drew a strong distinction between saying ‘I am bipolar’ and ‘I have bipolar disorder.’ The former was felt by some participants to be somewhat diminishing; a label not capable of portraying an individual’s



identity. The latter was felt by most participants to more appropriately convey that bipolar disorder was an aspect of their lives but does not constitute their identity. However, it was felt by one participant to illustrate ownership of the label and an important tool for self-advocacy.

Language was also found to be particularly important in relation to others, and within a given society. This theme emerged in this study, with participants articulating their awareness of their different use of language depending on who they were talking to. For example, participants largely viewed “coming out” about their mental illness as important in personal relationships, but were more divided when it came to “coming out” to employers. The function of language on a societal level may be seen as more complex, with more uncertain implications. It was acknowledged that the way one presents oneself to larger society is not necessarily the same as the way one would think of oneself in isolation, in their own mind:

I think probably if I didn't have to associate with people, if I was a hermit, I probably wouldn't need to say it. But because I'm in contact with others, to not say it, not say those words, would be basically the same as denying that I have it.

So the societal use of language is illustrated. This relates to both Lacanian and Foucauldian notions, where language necessarily alienates us from ourselves while providing a framework for engaging with others, but also functions as a tool of society's deep power structures.

The idea that language necessarily alienates us from ourselves while providing a framework for engaging with others was articulated when participants described the importance of establishing community and connection with individuals who may share similar experiences. Similar to the sense of relief felt by being diagnosed, owning a

particular language of diagnosis can facilitate a sense of empowerment for individuals who have received a diagnosis of bipolar disorder.

Both the political use of words and the relativity of words were illustrated by the participants. Words can be used by an individual to further important political gains, or to create new understanding. This was described by one participant using the example of the use of the ‘n-word’ within the African-American community to alter the impact of the word through conscious re-appropriation. However, language can also be used against an individual to further opposing political gains, as illustrated by the participants’ recognizing that how specific words are used, and the intention behind their use, is often more important than the word itself.

For clinicians, these findings may inspire us to explore the specific meanings individuals attribute to the words they use, and to more deeply examine the relation of these individual meanings to the meanings attributed to words in dominant discourse.

#### *The Making of Meaning and Location of Strength/Support*

Lakoff and Johnson (2003) state, “Our implicit and typically unconscious conceptions of ourselves and the values that we live by are perhaps most strongly reflected in the little things we do over and over, that is, in the casual rituals that have emerged spontaneously in our daily lives.” (p. 235). With this in mind, one way of examining ‘the making of meaning’ with participants in this study was to explore where they have found strength and support, and the activities that have become part of their daily lives as they live with a diagnosis of a mental illness.

The participants of this study found strength in the support of family (their spouse and/or children in particular) and friends. It is at least understood that personal meaning-

making is more possible when one feels supported and empowered to create that meaning for oneself. Participants also described the importance of being part of a community of individuals who share similar experiences, in this case a diagnosis of bipolar disorder. For one participant, this community revolved around the creative pursuit of creating and displaying art together. A common thread between these communities created around shared experience was the willingness for the community to state that part of their identity was being diagnosed with bipolar disorder. This was felt to be freeing and empowering.

In one way, this may lead us to see that meaning is often made collectively. At least, that a collective (whether its family and friends, or individuals who share certain experiences) may make a personal interpretation of meaning more ready, partly because it is shared.

A previously internalized language of the self also had an impact on how participants felt they coped with, or made meaning of, a diagnosis of bipolar disorder. This may include temperament and personality traits as well as individual intrapsychic structure. In addition, the reaction of others is an important aspect of making meaning of one's diagnosis. *We are* in relation to others. Being treated with dignity and reiterating the human aspects of the individual, conveys a powerful sense of individual worth and intrinsic value. As clinicians, it is important to hold in mind that daily interactions do inform the meaning individuals make of their experience, but we also need to be insightful about the strengths and capacities that individuals bring into the room.

## *The Function of Language*

### *Language Sets Apart or 'Others'*

Participants in this study did convey a sense that language does effectively make a distinction; that it does draw a line between those diagnosed with mental illness, bipolar disorder, and those who have not been diagnosed with a mental illness. Participants communicated the idea that a reason for this distinction is a fear of mental illness which results from the stigma surrounding it. This illustrates a tendency, or a need, to identify oneself not by what one is but by what one is not. This exposes an interesting aspect of our cultural or societal psyche and the anxiety therein. Despite all of the inclinations we have acknowledged towards naming, and the positive aspects of this naming, it is also understood that naming, or labeling, does by its nature separate things, and is, by its nature, divisionary. One participant makes clear that there is a felt distinction in peoples' reaction to her illness when she speaks of it descriptively versus when she labels it, or gives it a name:

It's interesting because I think if I were to not use the word bipolar disorder, but if I were to be talking about it with someone and I just described it, like even with medical terms; like rapid cycling and mania and if I were to use these words, I think people would be fine. But as soon as you throw that word in there, bipolar, I think it changes peoples'... feelings or categorization.

The same participant made the poignant comment, "I'm not even sure so much people are afraid of the people as they are of the name, you know?" The ways in which "classifications of people interact with people classified" (Hacking, 2004, p. 277) were explored, these comments may lead us to wonder whether part of this interaction is that classifications can inspire a reaction of fear towards those who are "classified." We can see this as a way in which individuals with a diagnosis of a mental illness are 'set apart.'

The physical separation of those with mental illness from the rest of society has historically been an acceptable way of drawing the same distinction that the mere classification of mental illness may imply. Importantly, mental health policy particularly since the Community Mental Health Act in 1963 has indicated a certain shift away from institutionalization towards greater inclusiveness. On a policy level, this is an important change in perspective. We may question how this change in perspective serves individuals who are living with mental illness day to day. Further, and in terms of considering the language of diagnosis, we may ask whether our need to categorize fulfills a parallel function to the historic physical separation of those diagnosed with a mental illness from those undiagnosed.

Foucault's (1987) question remains a pertinent and fascinating one; we wonder how "our society expresses itself in those morbid forms in which it refuses to recognize itself?" (p. 63). This question illustrates the reverse of Hacking's earlier cited question regarding the interaction between classification and the classified individual. Foucault wonders what the act of classifying illustrates about those who classify, and even more broadly, a society that classifies. Most immediately, we may wonder whether this inclination to classify, and further entrench concepts of mental illness in a medical model, is an illustration of mass denial and sublimation of our common fragility and vulnerability. Again, we see our tendency to identify what we are not, and act that out; perhaps in response to the anxiety of not being able to define precisely what we are.

We may wonder whether it is inherently the case that the process of 'othering' is a negative one. Exploring this entails recognition of the processes' cultural or societal construction, i.e. the fundamental function of this process may vary between cultures. It

can generally be said that in dominant Western culture when we “other” we usually set aside and, more often, set down the ‘other.’ This is an important clarification because it is not necessarily the case that classifying, or defining, or differentiating, is a negative process. Indeed, it is a necessary one.

An interesting question to ask is whether we can see the diagnosis of a mental illness as a site of Jean Laplanche’s ‘primary address’. For Laplanche, as discussed by Butler (2005), the “primary address which overwhelms” is both an impingement and a necessity (p. 71). Although the condition of passivity is vastly different between an infant and an adult, is there a way we could see these as parallel processes? If seen as parallel process, the individual who receives a diagnosis “enters the world,” even if just for a moment, like the infant who “enters the world given over from the start to a language and to a series of signs, broadly construed, that begin to structure an already operative mode of receptivity and demand.” (Butler, 2005, p. 77). And, “From this primary experience of having been given over from the start, an “I” subsequently emerges.” (Butler, 2005, p. 77). These ideas, far beyond the scope of this study, provide just a hint of a frame with which we can view the simultaneously experienced positive and negative aspects of diagnosis. Butler (2005) reminds us of the paradox that “the power imposed upon one is the power that animates one’s emergence.” (p. 198). It seems as though it would be a positive and empowering step if mental health clinicians recognized and nurtured this paradox in relation to a diagnosis of mental illness, where it may not imply a chronically stigmatizing label but would more often allow for the emergence of the individual.

### *Language Dichotomy between Mental and Physical Illness*

The dichotomizing language of mental versus physical illness is an interesting theme that consistently emerged throughout the interviews with the participants and seemed to reflect a broad, though culturally specific, philosophical stance separating the mind and body. Although not reviewed previously in the Literature Review of this study, this philosophical perspective is specifically a Western world one.

The subsequent stigmatizing of mental illness has perhaps been part of the reason for individuals diagnosed with mental illness to become interested in challenging this distinction. One participant clearly states that “that distinction is wrong... the whole idea of mental versus physical illness is the wrong distinction to begin with.”

The distinction between mental and physical health and illness has far-reaching consequences for the treatment of individuals as well. Participants found that within the health care system the created dichotomy between mental and physical illness serves to further stigmatize, or “re-stigmatize,” individuals receiving treatment.

The definition of mental health introduced in the Literature Review as “the absence of mental illness” was also reflected by participants who felt that this dichotomizing definition has permeated their experience. Mental health implies a lack of mental illness. Conversely, mental illness implies a lack of mental health. This is consistent both with the participants’ experience and with the theme of defining what one is by defining what one is not. Part of the dichotomy between physical and mental illness is a felt difference in what a particular diagnosis means. Physical illnesses were not as consistently felt to imply a chronic illness. A physical illness may be treated and disappear, no longer being part of how an individual is expected to define themselves.

Even a severe physical illness, like cancer, may go into remission. Mental illness, on the other hand, was felt to imply permanence far more often than physical illness. In this context, being diagnosed with a mental illness has come to imply permanent and chronic illness and, by extension, chronic stigmatization.

The fact that mental health policy perspectives are not often oriented towards the hope of recovery can be seen as echoed in the participants' questioning why it is that a diagnosis implies permanence and asking, "Why can't it be in remission?" In other words, why is it felt to be such a chronic and encompassing label? This is a particularly pertinent and important question to consider when we examine our conception of our work with individuals in the mental health care system.

#### *Language as Cultural Expression and Reflections in the Media*

The participants of this study unanimously echoed that media representations of mentally ill individuals are negative and stigmatizing. This demonizing process was felt by the participants to be profoundly demoralizing and demeaning. Coverdale and Nairn's (2006) findings that negative representations of mental illness in the media served to "segregate, alienate and denigrate" (p. 86) the mentally ill character, provides an example, consistently reiterated, of how mentally ill individuals are treated and stigmatized in our society. One participant revealed an important point in remembering a particular representation of a schizophrenic individual on a television program where the crisis "never got resolved... and you never saw that the person could be OK." This is a poignant illustration of the notion of the mentally ill individual being in perpetual crisis, uncontrollable and untreatable, and again, the chronic or permanent nature of a diagnosis and the resulting stigma.



Porter (2002) acknowledges that the process of stigmatizing “involves projecting onto an individual or group judgments as to what is inferior, repugnant, or disgraceful” (p. 62). We see these representations in various forms of media, and the media is undoubtedly informed by dominant cultural values. One participant in particular acknowledged the cultural relativity of these representations, where “what’s labeled mental illness in this culture might be a shaman... and not looked upon as pariah” in another culture. We may also see in media representations of individuals with a mental illness an answer to Foucault’s (1987) question concerning the ways “our society expresses itself in those morbid forms in which it refuses to recognize itself.” (p. 63). It would be a valuable transformation for us to recognize that more than seeing representations of others in denigrating media representations, we more accurately see ourselves and the qualities of ourselves we collectively wish to disavow.

### *Summary*

It may in some ways appear that this study hints at a question of the social construction of mental illness. However, it is more so an examination of the relationship between language and meaning; between language and understanding; and between language and experience. The initial purpose of this study was to consider a few theories about the role and power of language and the experience of individuals diagnosed with bipolar disorder. Attempting to elicit experience that relates to a somewhat abstract notion of ‘language,’ and language as viewed by Jacques Lacan and Michel Foucault, proved to be difficult and, indeed, beyond the capabilities of this researcher. However, the process of interviewing individuals about their experience with mental illness has illuminated a much richer reality, where language is challenged by personal experience.

That being said, there are potentially very interesting connections to be made between language as it is experienced and the impact of a language of diagnosis on diagnosed individuals.

### *Limitation of Study*

Although this research study contributes to the knowledge base regarding language and individuals with a diagnosis of bipolar disorder, due to the small sample size generalizability of the findings to the larger population is limited. There were limitations in terms of participant recruitment because of the population's relative vulnerability and the researcher's lack of connections or 'rootedness' in the city where the research was conducted.

As well, it is acknowledged that because participants were recruited predominantly through agencies that are involved in a significant amount of advocacy work, they may represent a particular perspective in terms of their acceptance of their diagnosis. Participants' involvement in these organizations may also imply a certain level of social support. The participants were also each interested and able to talk about their experience of being diagnosed, and self-reportedly fit the criteria of being in current "stable mental and emotional health." This was an important ethical consideration, but does nonetheless raise questions concerning this study's sample's maximum variation.

It is also important to note that participants were relatively well-educated, and predominantly middle-class, middle-aged and Caucasian. A more racially, ethnically and socio-economically diverse sample would potentially have produced more varied data, in terms of expressed themes and opinions, which could be generalized to the diverse larger population that is prevalent in society today.

An interesting complexity of this study which may also be a limitation was the necessary use of language to discuss the impact of language.

### *Implications for Practice*

This study illuminates some important themes for social work practitioners. Considering the vast system that we are often working within and the ever-present power structures and dynamics therein, being serious about the language we use is as consistently difficult as it is important. Increasing awareness about the various ways that the language we use impacts individuals and is taken in by them is a worthy consideration.

A vital finding was of the importance of participants feeling understood as a means by which they could work on the acceptance of their diagnosis of a major mental illness. For participants, this meant feeling heard, but also hearing language that resonated with their experience. This finding may highlight to practitioners the importance of using a more broad and personalized language when discussing a diagnosis with their clients. As we aim to root interpretations in the language of the individual's story, we could also aim to discuss, and name, an individual's experience with mental illness in a way that reflects their own language. Further we could make use of this broader language to explore individual experience and individuals' understanding and acceptance of their own experience. It should come as no surprise that it is important to explore the meaning individuals attribute to their words and their descriptions and it is important to attempt to understand as well how individual meanings relate to dominant discourse.

A further implication of this study is for clinicians to keep in mind, and work with, the paradox of naming experience as it is simultaneously necessary, fundamentally alienating, and full of potential for individual emergence. It is also important for clinicians to be aware of language that dichotomizes and the impact this has on the individuals with whom we work.

Clinicians should take seriously the notion of being oriented towards a hope of recovery for the individuals diagnosed with mental illness, so that a diagnosis of mental illness is not felt to be a sentence of certain chronic stigmatization.

A final implication of this study is for clinicians to be aware of their own vulnerability to dominant discourse and its perpetual representation in various media. We need to check our own assumptions about illness and health, and be aware that in our work with individuals our assumptions are inevitably communicated to the individuals with whom we work. Being treated with dignity was a poignant theme brought up by one participant. Individuals with mental illness must always be treated with dignity and respect; acting out of a sense of fundamental human dignity is a call to every person and most especially to clinicians in the mental health field.

#### *Implications for Research*

The aim of future research may be to conduct a longitudinal study that includes more in-depth interviewing with a variety of participants in order to draw out in a more intimate way what the felt impact of diagnostic language. These methods may allow for the themes that emerge to be more thoroughly explored and reflected on by participants. Further research may also seek more diverse participation, which would introduce unexplored themes.

Further research may also include interviewing practitioners to explore their view of the language that they use and the ways in which they consider it and its impact.

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## Appendix A

### Informed Consent Form

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Dear Potential Participant,

My name is Kate Freeman and I am conducting this research study through Smith College in Northampton Massachusetts, where I am a student in the Master of Social Work (MSW) Program.

I am interested in exploring the impact of the language of diagnosis on individuals living with bipolar disorder. Specifically, this study is asking: 1) How did you hear this diagnosis, and what did it mean to you at the time? 2) Have you thought about how the language of this diagnosis impacted you? 3) Are there ways that you have used to language to counteract that impact? 4) What does this diagnosis mean to your life now?

The data from these interviews will be used for my MSW thesis and for possible presentation and publication. My study is called: "The impact and meaning of language for individuals living with bipolar I-II disorder."

The criteria for participation in this study are: 1) diagnosis with bipolar I or II disorder, three or more years ago, 2) 18 yrs of age or over, and 3) English-speaking, 4) you are currently in a stable mental and emotional situation in terms of your mental illness. If you voluntarily agree to be interviewed about your experience, you will be asked to fill a short demographic questionnaire before we will talk together. The interview will be an hour long and will take place at an agreed upon time between February-April 2007. The interviews will be audio-taped and transcribed.

There may be some risk to individuals who participate in this research study. Some participants may experience emotional difficulty when they discuss their experience with mental illness. For this reason, there is a List of Resources attached to this form, with the names and numbers of professionals who can aid you if you experience any emotional difficulty throughout this process. However, it is also anticipated that this project will help people become aware of how language, especially the language of diagnoses, affects peoples' lives. It may also give you a chance to think about language and how you've used it to get where you are, or what you would change about it.

Your confidentiality will be protected by the following measures (all in compliance with Federal Guidelines):

- 1) No names will be attached to the data or transcripts.
- 2) The tapes of the interviews will be kept in a locked strong-box, and will be taken out when they're being transcribed by me. They will be kept locked up for a period of 3 years and then destroyed.
- 3) My research advisor will not have access to any identifying information on the interview data.

- 4) All Consent Forms will be kept separate from the interview data and linked through a randomly chosen code number.
- 5) As a participant, you have the right to i) decline to answer any question, ii) to end the interview at any time and iii) can withdraw from the study at any point up until May 15, 2007. If you choose to withdraw from the study prior to this date, all materials pertaining to you will be destroyed immediately.
- 6) When the information is summarized in the research study, the stories will be disguised and your real name will never be used.

Always remember, participation in this project is voluntary.

Please feel free to ask me any questions, and thank you for participating in this study:

Kate Freeman 773-489-7916  
[kfreeman@smith.edu](mailto:kfreeman@smith.edu)

**YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.**

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**PLEASE KEEP A COPY OF THIS FORM FOR YOUR RECORDS.**

Appendix B

Recruitment Flier

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‘Language and the making of meaning  
For individuals diagnosed with bipolar’

A Qualitative Research Study

I am seeking to interview individuals who have been diagnosed with bipolar to explore:

- (1) the way you experienced the language of that diagnosis
- (2) how you have used language to make meaning from that diagnosis, and in your life.

You meet the inclusion criteria for this study if you:

- Are 18 years of age or older
- Have been diagnosed with bipolar 3 or more years ago
- Are currently in stable mental and emotional health
- And are interested in talking about your experience

**Please contact Kate Freeman (Master of Social Work  
Intern) at 773-489-7916**

**or [kfreeman@email.smith.edu](mailto:kfreeman@email.smith.edu)**

Interviews will take place in March and April, 2007 and will be **one hour** in length.

Participation in this study is completely voluntary and your confidentiality will be protected.

And thank you for your interest!

Appendix C

Demographic Survey

Participant: [number code]

Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

Age: \_\_\_\_

Gender: \_\_\_\_

Race/ethnicity: \_\_\_\_\_

Religion: \_\_\_\_

Approx. Annual Gross Income: \_\_\_\_

Education (highest level completed): \_\_\_\_\_

Number of years since being diagnosed with bipolar disorder: \_\_\_\_

## Appendix D

### Interview Guide

*Script for clarifying the theme of language at the beginning of the interview:*

As I've mentioned, I'm doing this study about language and the making of meaning for individuals who've been diagnosed with bipolar disorder. I want to clarify what that means before we begin. What I'm looking at is the language used to convey the diagnosis and how those terms, or words, were taken in by you; how you experienced them. I'm wondering about the ways in which language, or words, create certain meanings for us. Do you have any questions about this before we begin?

What was that process like when you were diagnosed; where were you, who was talking to you about it?

Do you remember what words were used?

What do you remember about your reaction?

What did you think and feel?

How did you hear the words?

Where did you go/who did you tell?

Can you say some more about what it meant to you to be diagnosed?

What words would you use to describe that?

[Going back to before you were diagnosed, do you remember your preconceptions about what bipolar is?

Do you remember, or have ideas about, where you had gotten those ideas, or formed those preconceptions?]

Do you have ideas about the way any preconceptions of what bipolar is affected how you reacted to this term, and being diagnosed with it?

Or made it harder or easier to understand what it means to your personal experience?

Tell me a bit about the process after that? After being diagnosed?

-what words come to mind to describe how you felt about yourself and your future?

-were there things that happened in your life as a result; in terms of relationships, employment, etc.?

-do you feel there were things you had to work at to regain (again, perhaps in terms of relationships, employment, etc.)?

**30-35 min.**

Is there a way that you feel you've created meaning from your experience of being diagnosed with bipolar?

Do you think there's a way that you've used language to redefine, or reinterpret, this experience; a way that you've described it to yourself, and what it means to you, that has been helpful?

**5-10 min**

And this is maybe like those dream questions: If you could write the DSM, (would you do it?), how would you describe/define bipolar disorder, and what would you call it?

Appendix E

Agency Letter of Permission

March 01, 2007.

Smith College  
School for Social Work  
Lilly Hall  
Northampton, MA 01063

To Whom It May Concern:

[Agency name] gives permission for Kate Freeman to locate her research in this agency. We do not have a Human Subjects Review Board and, therefore, request that Smith College School for Social Work's (SSW) Human Subject Review Committee (HSR) perform a review of the research proposed by Kate Freeman. Thesholds Psychiatric Rehabilitation Center will abide by the standards related to the protection of all participants in the research approved by SSW HSR Committee and will retain all responsibility for the individuals involved in the study.

Sincerely,

[Agency Director]

## Appendix F

### Human Subjects Review Committee: Approval Letter

February 14, 2007

Kate Freeman  
2215 West Belden Avenue  
Chicago, IL 60647

Dear Kate,

Your revised materials have been reviewed and all is now in order. We are able to give final approval to your study, with the understanding that you will obtain permission letters from any Organization where you recruit before you contact your participants and that you will send us copies of these permission letters.

*Please note the following requirements:*

**Consent Forms:** All subjects should be given a copy of the consent form.

**Maintaining Data:** You must retain signed consent documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project. Another good quote, but I can't remember who said it, is "words create worlds".

Sincerely,

Ann Hartman, D.S.W.  
Chair, Human Subjects Review Committee

Cc: Marian Harris, Research Advisor