THESIS

PEER SUPPORT TRUMPS DRUG COCKTAILS:

CULTURAL VIEWS OF TREATMENT OPTIONS FOR PERSONS

WITH BIPOLAR AND DEPRESSIVE DISORDERS

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ABSTRACT

PEER SUPPORT TRUMPS DRUG COCKTAILS:

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In this thesis I propose that participants of a peer-support group for depression and bipolar disorder cognitively "model" their conditions in culture-particular ways. Specifically, I suggest that these patients embrace a particular clinical storytelling process that helps them to regulate their daily personal habits and bodily states, while seeing as ineffective and even potentially detrimental the drug regimens more commonly favored in U.S. psychiatry. I argue that patients' fixing of control and responsibility for cure are on the clinical encounter and on their own practice is *cultural*: involving shared in socially transmitted understandings of how mental health and healing work, a particular reaction to a biomedicine more dominant in U.S. society. Further, I show that being "consonant" or in sync with the shared cultural model I call "managing the disorder" correlates with improved symptomology. I suggest that this improvement may be the result of social support and reduced stress due to the feelings of belonging to the group- a process referred to in the literature as "cultural consonance"- as well as the actual strategies which participants employed in addition to, or in some cases, instead of, their medications. Marijuana use and religion/spirituality were also sometimes mentioned as factors which contributed to helping patients manage their disorders. For this project, these themes were explored in the academic literature, through participation in the peer-support group, in semi structured interviews, and quantitatively through survey data. I suggest that studies of this type may contribute to understanding and evaluating treatment models among various cultural groups.

ACKNOWLEDGEMENTS

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Chapter I-Introduction:

"Clonazepam, Lamictal, Seroquel, Abilify, Pristiq, Synthroid"; "Lamictal and Seroquel"; "lithium, Luvox, Abilify, vitamin B12"; "Clonazepam, Topamax"; "Seroquel, Abilify, Viibryd, Ativan"; "Cymbalta, Lamictal, Abilify, Ambien, Lorazepam." These are just a few of the prescribed drug cocktails mentioned by the people I met through the course of my research on bipolar and depressive disorders. Through my participation in a depression and bipolar peer support group, interviews I conducted with its participants, as well as survey data, I learned that although they considered medications necessary and continued taking them, most (if not all) of the people I met at the meetings were dissatisfied with the efficacy and side effects of their medications. I became interested in what else people were doing to treat their illness. It was through this line of inquiry that I decided to determine whether or not there was a shared "cultural model" of what a bipolar person could do in addition to taking prescribed medications to treat their illness. Cultural models are shared frameworks among groups which influence patterns of thought and behavior (D'Andrade 1995; Holland and Quinn 1987; Strauss and Quinn 1997). In the context of this research project cultural models describe the shared experience and treatment choices of persons with bipolar disorder in the cultural setting of a peer support group. As an anthropologist I was interested in determining how these models contributed to the manner in which persons in this peer support group conceptualized the treatment of their disorder and what effects, if any, adherence to the models had on symptomology.

In both my participation in the group and interviews with people who attended the group, I was impressed by my interviewees' painstaking attempts to manage their disorder. I found that group participants agreed on several methods to help manage their disorder, and I decided to name this model *managing the disorder*. The cultural model of *managing the disorder* included

aspects connected to group participation such as hearing the stories of others, getting advice from participants, sharing stories, and feeling accepted. Participants also suggested that keeping a schedule of sleep, medication, and exercise, as well as limiting alcohol and keeping a healthy diet were instrumental in managing their disorder. I also noticed the prevalent themes of religious states and spirituality being credited with both helping to manage, as well as possibly being the result of, mania. Marijuana use was also mentioned by several people as beneficial to mood management. However, because marijuana use and religion/spirituality were not discussed openly in group, I did not include these two factors as part of the *managing the disorder* model, but rather examined their correlations to symptomology separately. These themes were repeated throughout the research project and will form the basis of my argument that these management strategies are implemented, in varying degrees of success, by many of the people I met in the support group. I propose that these methods may be beneficial to improving symptomology in people with bipolar disorder.

It is also my hope that this project will help to illustrate the usefulness of using ethnographic methods to examine the relation of culture to mental health. It was only through the method of participant observation that I was able to build rapport and trust with the individuals who attended group. As a result of interacting with the people in group over an extended period of time, I was able to discern patterns of behaviors and how these behaviors were associated with various degrees of symptomology. Indeed, I was to discover that people will often tell their anthropologist things they will never tell their doctor. These observations, combined with candid interviews and casual conversations, formed the basis of my contention that these people were creating their own models of what bipolar disorder and depression meant to them and how best to treat the resulting symptoms. These models of treatment and conceptualization of their

disorders exist either alongside or in place of the current western medical model of treatment with medication and occasional therapy. More about the contribution of anthropological methodology to the study of mental health will be discussed in chapter two.

I began attending a support group for persons with depression and bipolar disorder (BD) in the spring of 2011with the plan of conducting an ethnographic study of persons with BD. In this manuscript I will refer to the variety of diagnoses the participants had in conjunction with bipolar disorder simply as BD. This is due to the difficulties of finding a specific diagnosis for most of the people I met in group. Initially, I was interested in whether or not attending the support group had an impact on the participants' quality of life, but as time went on the responses from the group members led me to investigate what they viewed as important factors in managing their disorder and whether or not this moderated their bipolar symptomology. I also was interested in the recurring themes of religion/spirituality and the use of marijuana as both a mood stabilizer and means to reach dissociative states (a disruption of normal consciousness or sense of self). Finally I wanted to determine if there existed feelings within the group of *cultural consonance* (a sense of fit to a cultural model within a group) with a model of treatment (Dressler and Bindon 2000). Feelings of cultural consonance have been found to minimize stress and depression (Dressler 1998).

In this manuscript I propose that there exists a model of *managing the disorder* among at least a portion of the participants of the peer support group and feeling consonant with that model correlates with improved symptomology. This improvement may be the result of social support and reduced stress due to the feelings of consonance as well as the actual strategies, discussed later, which many of the participants employed in addition to, or instead of, their medications. For this project, these themes were explored in the academic literature, through

participation in the peer-support group, in semi-structured interviews, and quantitatively through survey data.

For this research project I used a combination of qualitative and quantitative ethnographic methods. My initial preparation for the project involved completing an extensive literature review about bipolar disorder, depression, related mental disorders, and the impacts of support groups in particular and group therapy in general. To complete the participant observation portion of my project I attended the peer support group an average of three or four times a month between February of 2011 and the completion of this project in May of 2012 for an approximate 80 hours of participant observation. I was also able to conduct nine semi structured interviews with members of the support group. Midway through the project, after discovering the themes of group cohesion, alternative means of managing their disorder, religious and spiritual experiences, and marijuana use, I did further research into those subjects. This illustrates the re-iterative process of ethnographic fieldwork and data analysis. After completing a significant portion of participant observation and interviews, I constructed a survey questionnaire which was distributed to as many persons (21) who attended the support group as possible. A more detailed account of my methods will follow in chapter five.

The value of this research project lies in its examination of cultural models of treatment modalities which may be incorporated in conjunction with medication to improve the symptoms of people with mental illness, in particular bipolar disorder and depression and their related disorders. The additional examination of participants feeling consonant with a model of being active in managing their disorder being correlated with improved symptomology has important implications for treatment as well. It is also my desire that this project will add to the testing of ethnographic methods and data analysis in the research of mental health.

Throughout the manuscript I will quote heavily from the conversations I had with members of the support group who had agreed to be interviewed for this project, and to whom I am very grateful. Their words are very valuable in the process of understanding the experience of people with BD. The remaining original data was gleaned from my own experiences while attending the support group and survey data completed by members of the support group.

This manuscript is organized in the following manner. In Chapter II I will outline my theoretical orientation for this study. In it I will describe the contribution of anthropology to the study of mental health, the idea of cultural models, and the concept of cultural consonance. I will also introduce the *managing the disorder* model and note a related model found by researchers in Ireland. The use of marijuana by persons with BD and the practice of religion/spirituality will also be examined. In Chapter III I attempt to define and describe what carrying a diagnosis of bipolar disorder may mean to the individual. I begin this chapter by focusing on the Western, biomedical model. I then describe some of the recent research being conducted on bipolar disorder, and finally use the words of people in the support group to define what carrying a diagnosis of BD means to the individual in this cultural context. In Chapter IV I illustrate the setting of this particular group of individuals, both at the macro state level and the micro level of the group itself. Chapter V will highlight my mixed methods approach. In it I will describe my participant observation, interview, and survey methods. In chapter VI I will discuss the results obtained through these research methods by focusing on effects of adhering to the managing the disorder model as well as the effects of marijuana use and religion/spirituality on symptomology. Finally in chapter VII I will note the limitations and conclusions of this study.

Chapter II- Theoretical Orientation:

Anthropology and Mental Health

In this chapter I will first discuss some of the most influential work in the area of ethnographic research of mental health including consonance with cultural models and effects on stress and symptomology. Next I will examine research into marijuana use and its possible efficacy as a mood stabilizer. I will conclude by listing research concerning the relationship between religion and spirituality and BD. One of the main contributions of psychological anthropology is its focus on studying the impact of social knowledge, institutions, and practices on physical and mental health as well as modalities of healing. In the United States there's been a shift away from psychoanalysis to a biological understanding and treatment of mental disorders (Luhrmann 2000; Watters 2010). The pharmaceutical industry plays a role in controlling the production of clinical evidence and influencing worldwide conceptions of mental illness and treatment. Laurence J. Kirmayer (2007:13) suggests that among the central questions for today's researchers entail examining the "nature of the interaction of psychopathological processes and cultural idioms of distress in the genesis and course" of disorders and the specific mechanisms of sociocultural factors on the course of mental disorders and finally the impact of emerging models of care.

Rather than assume the universality of psychiatric categories and psychological modes of expressing distress we should pay attention to the social and cultural context of suffering and healing. Like Kirmayer, Arthur Kleinman (1988:2) suggests that the emphasis on the biomedical model has provided many benefits, but there is "more involved in the causal web of psychiatric disorders than changes in neurotransmitters and endrocrinological activity." Kleinman suggests that the fundamental questions in psychiatry are caught up in a relationship between the social

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world of the person and his or her body/self. He suggests that mental illnesses are real but they are dependent on the physical reality of the person interacting with symbolic meanings within the culture. Even psychiatric diagnostic categories are embedded in history and affected by culture as much as by biology.

Cultural influences affect how persons view mental illness and the consequences of those lenses or models. Tanya Luhrmann (2000) suggests that the disease model has been an asset in the fight against stigma and for healthcare coverage but suggests that saying that mental illness is nothing but a disease to be eliminated from the person falls short of explaining the entirety of experience of people in the mental health professions and persons who suffer from various forms of mental illness. Major psychiatric illness has a complex cause and it is a combination of psychopharmacological and therapeutic treatments which provide the best outcome for most sufferers.

Ethan Watters (2010) echoes these researchers in summarizing that how people in the culture think about mental illness influences the diseases themselves. Forms of mental illness from one geographic place and varying periods of history can appear differently in a different time or place. He suggests that through the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and the global marketing of psycho therapeutics, indigenous understandings and treatments of mental illness are disappearing. This trend runs contrary to the idea of cultural anthropologists who suggest that the experience of mental illness cannot be separated from culture and that we rely on cultural beliefs to understand what is happening and choose how to treat symptoms.

According to cognitive anthropologists including Roy D'Andrade (1995) our brains automatically create organized frameworks of objects/ideas and their relations to each other and

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other schemas. Culture influences this process by defining what members of a particular culture must know or believe in order to function in a manner which is sanctioned and promoted by its larger membership (Goodenough in D'Andrade 1995). The resulting cultural knowledge is in turn shared through language, stories, and artifacts, thus further promoting acceptance and conformity among cultural members. This is important in studying culture because it is our schemas which orient us within our culture, indeed how we conceptualize aspects of life determines our action, or in sociological terms our agency within the social context. These schemas and propositions then lead to the formation of a model, in this research project I named the model *managing the disorder*. This is a model in which the person is not seen as solely a victim, but rather somebody with a degree of control and responsibility for their own health. The support group norms state that "This is an adult group for people with a diagnosis of depression or bipolar disorder who are *actively seeking to manage those disorders*." Kleinman, Eisenberg, and Good (1978) describe three domains of cultural models including professional, popular, and folk models. Depending on which domain is ascribed to by the individual, different beliefs and actions will follow. It appears to me from my time in the support group that the model of *managing the disorder* is currently a popular model. It is my hope that it is beginning to take hold with the medical profession, thus it may soon become a professional model, therefore further affecting illness conceptualization and treatment.

Cultural Consonance

Cultural models are abstract and simplified mental representations of the world that are socially learned and shared within a group (D'Andrade 1995; Holland and Quinn 1987; Strauss and Quinn 1997). Of interest to me is the cognitive anthropological literature that bases its analysis on the idea of "cultural models" (also referred to as "cultural frames"). As a foundation

to understanding health-related processes, William Dressler and his collaborators (Dressler and Bindon 2000) research how being in or out of sync with culturally normative models of success and idealized lifestyle, such as owning and consuming items valued by one's group, can affect levels of stress. Such stress can manifest in negative health outcomes such as high blood pressure or depression, as Dressler shows in a number of elegant studies. Dressler's form of research is premised upon disentangling the relationship between collective meanings and individual experience. He theorizes that the individual's belief about conformity (or lack of conformity) to cultural norms (cultural consonance), when properly situated in broader sociopolitical and economic contexts can determine health outcomes (1998, 2000, 2005). For example, in a 1998 study, Dressler assessed individual degrees of cultural consonance alongside blood pressure "biomarkers" and health. He found that cultural consonance correlated with respondents' blood pressure, in an inverse relationship (lower cultural consonance correlated with higher blood pressure). Cultural consonance also was correlated with less depressive symptoms and lower perceived stress.

Stress can be defined as the environment's pressure on the individual, or "a generalized physiological response to a wide array of ecological, physiological, and social challenges" (Wiley and Allen 2009:354, Sapolsky 2004). The *stress response* is the impact these forces have on the body. Ultimately, the stress response is affected by an individual's subjective appraisal concerning whether or not he/she can meet the challenge posed by the environment. The stress response evolved to enable our bodies to deal with an acute physical crisis. This occurs in all mammals, but what is different for humans is that we can imagine a stressor and thus experience psychological and social disruptions that are not merely objectively in our environments. In most animals, the stress response is accompanied by physical exertion, and the energy loss is

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replenished by cortisol. Stress responses which are not associated with physical activity (for example stress due to social problems) results in a flood of glucose, increased appetite, and fat storage (Wiley and Allen 2009:331, Sapolsky 2004). It is my assumption that for the group participants, a diminished stress response as a result of feeling as if they are managing their disorder, combined with direct effects from the management strategies employed, leads to better health outcomes including diminished depression, anxiety, and mania.

Kartalova-O'Doherty and Doherty (2010) interviewed mental health service users and participants in peer support groups in Ireland. They found two themes of "giving up" and "fighting to get better." Their model of *fighting to get better* was comparable to the model found in this research of *managing the disorder*. They noted that having a passive identity of a patient and a lack of intrinsic motivation to get better was associated with the code "giving up." Fighting to get better entailed strong, self-sustained motivation and included substantial and sometimes risky effort. The researchers state that the people they interviewed who were fighting to get better started with finding their own motivation for recovery. Fighting to get better was described as a day to day process which requires much energy and effort. They note that participants reported it was crucial to have something or someone to fight for. Turning points in the process of recovery included being listened to, feeling accepted, retelling and overcoming past trauma, making a conscious decision to get better, and changing or reducing their medication (2010:11).

From my conversations with the people I met in group I surmised that there existed among them a cultural model of *managing the disorder* which included aspects connected to group participation such as hearing the stories of others, getting advice from participants, sharing stories, and feeling accepted. Participants also suggested that keeping a schedule of sleep, medication, and exercise, as well as limiting alcohol and keeping a healthy diet were

instrumental in managing their disorder. Marijuana use was also mentioned mostly in private conversations, and although I perceived it was not a strategy shared by a majority of group members, it was mentioned often enough to warrant examination. Being religious or spiritual was discussed by some members also as a possible result of mania and as a beneficial management strategy. Like marijuana, religion was not discussed openly by the majority of group members, and was not included in the model used for cultural consonance analysis described below. For this research project, I was interested in whether or not being consonant with a model of managing the disorder, reported use of the above mentioned strategies, as well as using marijuana and reporting being religious or spiritual was associated with less severe symptomology. This led me to not only take note of what was said in group, but also to ask the group participants in casual conversations, interviews, and the survey instrument what they were doing to manage their disorders

Marijuana Use

Grinspoon and Bakalar (1998) have conducted many interviews with patients and present case histories of people with bipolar disorder who state that using marijuana is effective in the treatment of their fluctuating moods. They report that marijuana was used by these people to treat mania, depression, or both. Some stated that they used marijuana to help relieve the side effects of conventional drugs, and some reported that it was more effective than conventional drugs. One of my respondents, Rex, went so far as to discontinue other medications due to their side effects and use only marijuana to treat his BD, "I've noticed that when I smoke I feel normal, and it's not just when I smoke, it lasts for a few days after that" (December 29, 2011). In the year 2000, Colorado passed an amendment to the state constitution allowing patients to use medical marijuana (MMJ) under the supervision of a physician. Colorado is one of fourteen

states with laws that have legalized medical use of marijuana, despite the fact that marijuana is still illegal under federal law which classifies it as a Schedule 1 substance, a dangerous drug carrying a high potential for abuse and no accepted medical use. Health conditions that qualify a person to get their "red card," which allows them to purchase and be in the possession of medical marijuana include cancer, glaucoma, HIV/AIDS, severe pain, severe nausea, epilepsy, or persistent muscle spasms. There are no provisions for the use of medical marijuana to treat any mental health issues in the state of Colorado at this time.

After examining some of the many medical marijuana advocacy publications, it seemed to me that advocates have downplayed the psychoactive properties of the drug while arguing for its other medical utilities. But through the interviews and survey research for this project, in addition to one research article which interviewed patients in California (Chapkis 2007), I found that the mind-altering effects of marijuana may play a role in the therapeutic value for patients. Indeed, I would argue that the psychoactive properties of marijuana enable the user to enter dissociative states, easing the effects of stress which may be brought about as a result of the user's mental or physical complaints. As Tom confided in me, "sometimes and I go to the dispensary, I ask for something that will give me "couch lock." That means I smoke it to just sit on the couch and not do anything but watch cartoons. Sometimes this is really important" (June 5, 2011).

The people I met in group often mentioned, through either religious or spiritual states, or through the use of marijuana, seeking out experiences of *dissociation*, which the DSM-IV-TR defines as "a disruption in the usually integrated functions of consciousness, memory, identity, or perception" (2000:519). Dissociation has been shown to decrease the stress response in some instances (Sapolsky 2004; Wiley and Allen 2009; Seligman and Kirmayer 2008; Lynn 2005;

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Snodgrass 2010). I suggest that the dissociative state can be seen as being beneficial to patients who suffer from chronic pain. Seligman and Kirmayer (2008) describe normative dissociation as universal and common. They state that the context in which dissociation occurs is important in determining the functionality of the dissociation, whether it is beneficial or distressful (2008:40, 50).

Due to marijuana being classified as a Schedule 1 substance in the U.S., most research is being conducted in other countries. One interesting study conducted in the U.S. however, (Chapkis 2007), interviewed MMJ patients in California. Chapkis found many of her respondents reported that they valued the consciousness altering properties of marijuana significantly more so than its other various reported therapeutic benefits. These patients reported that the effects on mood and cognition were difficult to separate from its medical benefits. I theorize the consciousness altering properties allow patients to relax, dissociate, and ease the stress response from worrying over their pain or other conditions. This notion was echoed by several group members who stated that using marijuana either helped them relax or aided in the balancing of their moods.

> I actually smoke pot every night. I can't sleep without it. I have horrible, bizarre nightmares. When I smoke pot I sleep through the night and don't have any weird nightmares. I also think it really helps to balance out my moods. Especially when I'm manic, I can just smoke, smoke, and smoke, and it keeps me from going over the top, over the edge. [Tom June 5, 2011]

In research conducted by Ringen, Vaskinn, Sundet, Engh, Jonsdottir, Simonsen, Friis, Opjordsmoen, Melle, and Andreassen (2009) effects of marijuana use on neurocognitive functioning was assessed in patients with BD and patients with schizophrenia. The researchers found that in the patients with BD, marijuana use was associated with better cognitive functioning, while the opposite was the case for the patients with schizophrenia. This suggests

two things; first, that there may be different neurocognitive mechanisms in play in BD as opposed to schizophrenia, and second, that something about marijuana's effect on neurochemistry may have some benefits for people with BD.

In *Don't Think of an Elephant!* George Lakoff (2004) discusses the power of how we frame our viewpoints. The language we use affects not only how we represent our ideas, but also how others orient and respond to our ideas. This idea can be related to the language society uses when discussing marijuana use. Often marijuana is described as a "substance of abuse" and medicinal marijuana patients as "drug abusers." What effect does the use of this language have on the self-perceptions of patients? Would it not be healthier for these patients to be thought of as people who are undergoing treatment for their various ailments? Does feeling like a patient and not an abuser lead to better health outcomes? These questions deserve further research.

Religion/Spirituality and Bipolar Disorder

In the group norms which are read at the beginning of each group session, it states that "we will not discriminate against anyone due to their religious or spiritual beliefs," and I would not describe the group as spiritually or religiously grounded. The overall tone as far as the expression of spirituality or religion was somewhat reserved; people were very respectful of not only other people's beliefs, but did not push their beliefs on other members of the group. In spite of this, at the conclusion of the evening groups one group member would always read something from a book of quotes, and they were usually spiritual in nature. Group participants on occasion spoke of their church affiliation and how this membership was an important social resource for them.

Michalak, Yatham, Kolesar, and Lam (2006) while conducting qualitative interviews with people with BP found that many of the people they talked with mentioned that it was

difficult for them to separate "real" spiritual experience from hyper-religious experiences

brought on as a by-product of hypomania. As Lois told me,

> And I think depression, its chemical, but you have this enemy come in and try to
> push you down and try to use that weakness in you to bring you down. And I
> think there's a lot of discerning about whether I need to change my chemical
> imbalance when that happens or talk to my priest. [June 23, 2011]

They also found that the fluctuations of depression and mania made it difficult for people

with BD to participate consistently in the religious community (2006). Mitchell and Romans

(2002) surveyed persons with BD in New Zealand and found that 78% held strong religious or

spiritual beliefs. They report that most of their respondents saw a link between their beliefs and

the management of their illness and used religious coping methods which sometimes put them in

conflict with the illness models and advice given to them by their medical advisors.

After hearing about Sam's hospitalization after having a manic episode with religious

themology, Tom's spiritual experiences, Lois' statement that she often wasn't sure if she should

talk to her doctor or her priest when she was feeling manic or depressed, and the comments of

others, I became interested in these religious and spiritual experiences. Johnson and Friedman

(2008) reviewed specific methods for determining the occurrence of religious, spiritual, and

transpersonal experiences in relation to the DSM category of a Religious and Spiritual Problem.

They state that it is often difficult to determine if a person is experiencing a "transformative

spiritual experience" or a psychological disturbance and is delusional, and can be wrought with

difficulties (2008:506). This was spoken to by Rex, who talked about how his brother's (who

also had a form of bipolar disorder) religiosity disturbed him, because he felt it was "too much"

and possibly just the result of mania, "One of the things that keeps me from being religious, is

that my brother became very hyper religious when he went off of his bipolar medication"

(December 29, 2011). Johnson and Friedman also suggest that clients may feel misunderstood

when religious, spiritual, or transpersonal experiences are diagnosed as simply delusional and may lead to adverse outcomes or distrust of the clinician and inhibit future help seeking.

Often, the first symptom which leads to a diagnosis of BD is a manic episode which may present with features shared with Brief Psychotic Disorder (American Psychiatric Association, 2000). In some cases these episodes present with religious/spiritual aspects (Grof and Grof 1990; Grof 2000; Cortright 2000; Agrimson and Taft 2008; Holden, Miner, Vanpelt-Tess, and Warren 1999). Stanislav and Christina Grof have been instrumental in formalizing the idea of *spiritual emergencies*. In their book *The Stormy Search for the Self* (1990), they define spiritual emergencies as

> critical and experientially difficult stages of a profound psychological transformation that involves one's entire being. They take the form of nonordinary states of consciousness and involve intense emotions, visions and other sensory changes, and unusual thoughts, as well as various physical manifestations. [1990: 31]

Tom discussed one of these experiences with me, "I had what they call a kundalini experience. I was meditating and I felt this physical sensation was like being upside down in a waterfall, like I felt all this energy going up to my butt to my spine and up to the top of my head, it was really weird" (June 5, 2011). A spiritual emergency can be distinguished from *spiritual emergence* by the accompanying disturbances of psychological, social, and occupational functioning, whereas a spiritual emergence occurs without the accompanying disturbances (Grof and Grof 1990).

These spiritual manifestations can be viewed as processes of transformation. They can result in a greater sense of well-being and integration characterized by increased love, serenity, joy, wisdom, hope, and compassion (Holden et al. 1999). A spiritual emergency may start out displaying similar traits as a psychotic episode, but it should not be diagnosed as a mental

disorder because it may evolve into a spiritual awakening in which the person may grow personally and socially (Grof and Grof 1990). Cortright (2000) suggests that the first step in treating people experiencing a spiritual emergency should be educating them into a psycho-spiritual framework for understanding the process and depathologizing it to reduce fear and anxiety which inevitably accompany the diagnosis of psychosis.

In other interesting research, Dein and Littlewood (2011) examined the relationship between schizophrenia, religion, and everyday cognition. I cite this research here because of the similarities between schizophrenia and some forms of BD, in fact some forms of BD are treated with the same antipsychotic medications as schizophrenia. They suggest the three fall on a continuum, "Both religion and schizophrenia perhaps derive from an over attribution of agency and an overextension of Theory of Mind" (2011:329). They suggest that both religion and schizophrenia may have evolved together. In families with a member with schizophrenia, there is an increased likelihood of creativity, leadership qualities, musical skills, and religiosity (Horrobin 1998). Horrobin also suggests that schizophrenia was present in the earliest stages of Homo sapiens, around 150,000 to 100,000 years ago, accompanying the explosion of art and religion. Horrobin suggests that schizophrenia and genius in humans manifested as a result of evolutionary pressures that triggered genetic changes in our brains, allowing humans to make novel connections and solutions to events, leading to enhanced mental capacities (Horrobin 1998; Dein and Littlewood 2011). Thus, schizophrenia and its related bipolar disorder may have been a result of, and contributed to, these new cognitive abilities.

I found that many people with BD who I spoke to had had religious or spiritual experiences. The practice of meditation or prayer was also mentioned as a good tool to use to help relieve manic symptoms and quiet the mind. Although some people in group belonged to a

church and valued the social connection and support, some followed a spiritual path which was

not associated with any organized religion. As John said, "I don't really know if I fit into a

religion, I'm still looking" (June 28, 2011). More concerning the religious and spiritual

experiences of some of the group participants and relationships with stress and symptomology

will be discussed below.

Summary

The work done by these previous researchers greatly influence my current project. In a

broad sense, the theory behind this research project is grounded in what some would call "social

constructivism" (Vygotsky 1978). That is, this project examines how people in a specific group

are *constructing* ideas about their mental illness including models of treatment. These models of

treatment are embedded in the particular cultural milieu of this group. I suggest that this group is

influenced by the American virtues of self-responsibility and independence. But not only is this

self-responsibility and independence valued, aspects of social support are also included in the

treatment model. Many of the people I spoke to were dissatisfied with their treatment and were

developing their own model of what managing their disorder should entail. Through the culture

which was built by the members of the support group, participants to varying degrees formed

alternative models of describing their illness and how to treat it. Through participant observation

and qualitative interviews, I determined that there was a shared model of what can be done to

manage depression and bipolar disorder at least among a significant portion of the group. The

quantitative data suggested that although the model was not shared among all the participants

who were surveyed, those who did engage in the management strategies in the model reported

less severe BD symptomology (results will be discussed in detail below). This reflected my

impressions derived from participant observation and interviews that the people who were taking

steps to manage their disorder were, on average, experiencing less depression, mania, anxiety, and stress.

It was not the purpose of this research project to determine if there was a shared model of what exactly their illness was. My impressions are that this varied significantly from person to person. Through this research project I was able to briefly examine how participants were attempting to understand and treat their experience of depression or bipolar disorder. Like the researchers mentioned above, in my opinion it is important to document how groups of individuals not only in non-Western contexts, but also right here in the United States are framing or modeling their experience of mental illness and its treatment. More research should be done to examine the efficacy of different models of treatment in various cultural settings. Psychological anthropologists in my opinion are uniquely qualified to provide understanding concerning the interplay between culture and physical and mental health.

Chapter III- Explanatory Models of Bipolar Disorder:

> *I'd always been real crazy. I was a problem child in elementary school, class clown. Hard to keep control of myself. I'd get really sick, which was probably depression, sick and stayed in bed for days. And in my twenties things got really crazy, man I started being really manic, really depressed, my manic episodes were crazy. I would just throw things in a backpack and go hitchhiking cross-country, do things like that. I was homeless a lot. Living in tents on people's land and stuff, it was crazy, see. I definitely had symptomology before getting diagnosed.* [Tom June 6, 2011]

Introduction

Before discussing my time with the people in the support group, it is important to first try to describe what exactly BD is. I will rely first on the psychiatrist's diagnostic tool, the *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition Text Revision* (DSM-IV-TR), to give the clinical descriptions of BD. These descriptions form what can be thought of as a bio-medical approach to defining BD. The bio-medical approach looks at mental illness as having a biological origin and disorders can be diagnosed and treated with specific medications. In my opinion, the DSM is a beneficial tool for providing a basis for diagnosing mental disorders with a common language. It is also a necessary tool in the United States because insurance companies require a DSM diagnosis to provide benefits. However, it became obvious during my time participating in the group that these DSM definitions did not capture the complexity of peoples experience with BD. Therefore, I will explore the definitions of BD found in the DSM to illustrate what can be thought of as the current dominant Western medical model of the disorder. Following that I will cite some recent literature about BD in an illustration of how researchers are modeling BD. Finally I conclude with descriptions gleaned from the people I met in group to provide a model from the perspective of the people in this peer support group.

The DSM: Biomedical Explanatory Models

The *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition Text Revision* (American Psychiatric Association, 2000) describes bipolar disorder as two basic types; Bipolar I and Bipolar II. Bipolar I is characterized by one or more manic or mixed episodes accompanied by major depressive episodes. Bipolar II is described as exhibiting one or more major depressive episodes accompanied by at least one Hypomanic Episode. The lifetime prevalence of both types of BD in community samples has varied from 0.4%-1.6%, although the prevalence may actually be higher due to clinicians' tendency to over diagnose schizophrenia instead of BD, relating back to the issues within the group of being pinned down with a particular diagnosis. This may be the result of the positive psychotic features shared by both mania as occurring in BD and schizophrenia. Completed suicide occurs in 10%-15% of individuals with BD and the percentage of those attempting suicide can be considered much higher although exact numbers are obviously nearly impossible to obtain (American Psychiatric Association, 2000:384-385).

According to the DSM (2000), mental disorders occurring comorbidly with BD include Anorexia Nervosa, Bulimia Nervosa, Attention-Deficit/Hyperactivity Disorder, Panic Disorder, and Social Phobia. Studies in the United States indicate that BD is equally common in men and women though gender appears to influence the number and type of Manic and Major Depressive Episodes, in that the first episode in males is usually manic and for women it is usually a Major Depressive Episode. Average age of onset for both men and women is twenty with 10%-15% of adolescents diagnosed with recurrent Major Depressive Episodes going on to develop BD. More than 90% of individuals who have had a single Manic Episode will have future episodes, making BD a recurrent disorder. It is reported that 60%-70% of Manic Episodes will occur immediately before or after a Major Depressive Episode and although the majority of those diagnosed with

BD experience significant reduction of symptoms between episodes, as many as 60% continue to

have chronic interpersonal and occupational difficulties (American Psychiatric Association,

2000:386).

Research into Bipolar Disorder

Dr. Kay Redfield Jamison has written extensively about BD and her experience being a

person who carries a diagnosis of bipolar disorder. Her book, *Manic-Depressive Illness* (1990),

co-authored with Frederick K. Goodwin, provides an excellent look into the complexity of BD.

In this section I will highlight their descriptions and will also examine some other research about

BD which help to illustrate the experiences of the individuals who share this diagnoses. To

begin, consider the following from Jamison:

> The clinical reality of manic-depressive illness is infinitely varied, far more
> complex than the preferred term of the day, *bipolar affective disorder,* might
> suggest. The pathognomonic cycles of mood and activity serve as a background to
> ever-changing thought, behavior, and feeling. The illness encompasses the
> extremes of human experience: Cognition ranges from psychosis to a pattern of
> fast, clear, and occasionally creative associations to retardation so profound that
> consciousness is clouded. Behavior can be hyperactive, expansive, and seductive,
> or it can be seclusive, sluggish, and suicidal. Mood swings between euphoria and
> despair, irritability and vulnerability. The rapid undulations and combinations of
> such extremes result in an intricately textured clinical picture: Manic patients are
> depressed and irritable at least as often as they are elated, for example. The highs
> associated with mania are generally only pleasant and productive during the
> milder stages. [Goodwin and Jamison 1990:55]

BD is characterized by extreme fluctuations in mood which carry with them an array of

psychological and social issues. "Manic-depressive illness magnifies common human

experiences to larger-than-life proportions. Among its symptoms are exaggerations of normal

sadness and fatigue, joy and exuberance, sensuality and sexuality, irritability and rage, energy

and creativity" (Goodwin and Jamison 1990:3). For many people with the disorder, the effect it

has on family and friends can be one of the hardest issues to deal with. Many of the people I met

in group had lost jobs, homes, friends, and families. Goodwin and Jamison (1990) list some of the consequences of mania and depression which include the alienation of friends, lovers, and family members, the inability to move forward or naturally in a career, and major financial problems stemming from overspending, ill-considered investments, substantial and often uninsurable medical expenses, and loss of production. BD carries with it stigma similar to most mental illnesses and people who suffer from it must take care to avoid being discriminated against , either overtly or covertly, especially in the professional realms. Emily Martin (2007) states that being known as a person with a mood disorder puts your rationality into question. Everything from the ability to do your job, obey the law, or function within a family can be thrown into doubt.

Dealing with the aftermath of a depressive or manic episode can also be extremely difficult. I noted people from group who had returned after being absent for months and told of lost jobs, lost homes, being arrested, and being hospitalized. As John said one night after group "Today we had someone talking about anxiety messing up his life and trying to deal with the wreckage, and man I so relate to all of that. And maybe that's not where I am today, but I relate to that" (June 28, 2011). The act of repairing damaged relationships was often discussed as being extremely difficult. As Goodwin and Jamison (1990) describe it, people with BD experience shame and humiliation because of manic psychosis and for bizarre and inappropriate behavior, violence, financial irregularities, and sexual indiscretions.

BD is much more than a mood disorder; it affects every aspect of a person's life, self-image, relationships, behavior, cognition, career and finances, and ultimately the dreams and goals of the afflicted. "Changes in the rate, quality, and fluency of thought and speech, alterations in associational patterns and logical processes, and impairments in learning and

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memory are as fundamental to depression and mania as are the changes in mood and behavior" (Goodwin and Jamison 1990:247). It is often difficult for persons to discuss their illness with others; it is not as easy to reckon with as a biological disease with biological ramifications, like cancer. "Despite its indisputable biological roots, manic-depressive illness—as experienced by patients and as expressed to the world—is exquisitely psychological (Goodwin and Jamison 1990:245).The difference is that BD affects the mind, and it cannot be "beat" like a foreign cancer cell.

The states of mania and depression and the transitions between these states are the most pressing aspects of the illness.

> A manic-depressive person takes these desirable traits to extremes: when depressed the person is profoundly dejected and turned inward, unable to act or love; when manic the person is consumed by his desires and acts on all of them, whether for sex, or money, or power, at once. Freud described the "manic" just released from the inhibition of depression as someone who runs after his new desires like a starving man after bread. [Martin 2007:38]

In the context of biomedical interpretations of BD, depression is not viewed to be the result of circumstances, but rather a state which is assumed by many researchers and sufferers (particularly in this case of American culture) to be brought about due to imbalances in neurotransmitters.

> Others imply that they know what it is like to be depressed because they have gone through a divorce, lost a job, or broken up with someone. But these experiences carry with them feelings. Depression, instead, is flat, hollow, and unendurable. It is also tiresome. People cannot abide being around you when you are depressed [….] you're irritable and paranoid and humorless and lifeless and critical and demanding and no reassurance is ever enough. [Jamison 1995:218]

Depression is not the same as being sad. The depressive states are characterized by a "flatness" of mood and a slowing down of thought, feeling, and activity. People's mood can be dark and despairing. Frequently, the sufferer feels that the ability to experience any pleasure is

permanently gone. As one woman who was struggling with an extreme bout of depression cried, "I just hope the meds will start working, but I'm afraid they never will" (Lisa 2012).

People with BD often have a tenuous relationship with their manic states. A slightly elevated state (hypomania) can be exhilarating and addictive, but as the mood state elevates further it begins to bring on delusional thinking and sometimes hallucinations. "Mania is characterized by an exalted or irritable mood, more and faster speech, rapid thought, brisker physical and mental activity levels, quickened and more finely tuned senses, suspiciousness, a marked tendency to seek out other people, and impulsiveness" (Jamison 1993: 27). Many of the people with BD I spoke to enjoy these brief episodes of hypomania as periods of increased creativity. Hypomanic thought is characterized by fluency, rapidity, flexibility, and the ability to combine ideas or categories of thought which can form new and original connections. It is easy to see how such states can be addictive to those who experience them, especially when they occur after a depressive episode.

> The countless hypomanias, and mania itself, all have brought into my life a different level of sensing and feeling and thinking. Even when I have been most psychotic- delusional, hallucinating, frenzied- I have been aware of finding new corners in my mind and heart. Some of those corners were incredible and beautiful and took my breath away and made me feel as though I could die right then and the images would sustain me. Some of them were grotesque and ugly and I never wanted to know they were there or to see them again. But, always, there were those new corners and- when feeling my normal self, beholden to that self to medicine and love- I cannot imagine becoming jaded to life, because I know of those limitless corners, with their limitless views. [Jamison 1995:219]

In addition to the presence of extreme mood states in BD, the constant fluctuations and cycles, which can occur on a regular schedule, play a large role in the person's experience of the illness. "It is the interaction, tension, and transition between changing mood states, as well as the sustenance and discipline drawn from periods of health, that is critically important; and it is these same tensions and transitions that ultimately give such power to the art that is born in this way"

(Jamison 1993:6). Cycles of fluctuating moods and energy levels serve as a background to constantly changing thoughts, behaviors, and feelings. The cycles between mania and depression often show up as a type of rhythm. The mood states often follow a predictable pattern that can be dependent on the seasons. When we turned our clocks back in the fall, and the days got shorter, many people in group complained of the onset of depressive symptoms. Transitions between depressive or manic episodes can leave the person grasping for stability and understanding into just exactly just went wrong. "For a considerable period following a manic or depressive episode, many patients continue to question their judgment, their ability to assess situations, and their capacity to understand their relationships with other people" (Goodwin and Jamison 1990:18).

Associated problems occurring with BD include school truancy and failure, divorce, antisocial behavior, occupational failure, and substance use and abuse (American Psychiatric Association 2000; Michalak, Yatham, Kolesar, and Lam 2006; Grunebaum, Galfalvy, Nichols, Caldeira, Dervic, Burke, Mann, and Oquendo 2006; Joyce, Luty, McKenzie, Mulder, McIntosh, Carter, Bulik, and Sullivan 2004). Pope, Dudley, and Scott (2007) found an association between age of onset of BD and social functioning, with an early onset correlating with lower social functioning. The researchers also found that neuroticism (a measure of personality from the Eysenck Personality Inventory) was associated with more frequent relapses and higher levels of inter-episode symptoms.

As mentioned above, persons with BD have high rates of comorbid Substance Use Disorders (SUD), with self-reports reflecting as high as 60% comorbidity (Grunebaum et al. 2006; Joyce et al. 2004). "I was drinking a lot and doing drugs and having problems keeping things together with my work and I was seeing a counselor the time, off and on and he suggested

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that I start going on some meds for bipolar disorder" (Tom June 5, 2011). In a 2006 study, Grunebaum et al. found that SUD in persons with BD is associated with male sex and impulse-aggressive comorbidity, as well as an early age of onset of symptoms. They conclude that aggressive traits were less likely to be caused by SUD but rather are the predictors of SUD in their sample of people with BD. They explain that childhood and adolescent aggression may be a prodrome to a BD phenotype with earlier age of onset and a higher risk of SUD (2006). Many of the people I met in group were either currently struggling with substance abuse or had in the past, John was one example, "I've been clean and sober since March 17, 2009. And I haven't done anything rather than take prescription medication and for the last year I haven't done that either. So yeah, now I'm clean and sober" (June 28, 2011).

Research has shown links between BD and certain personality traits, suggesting once again that it is more than just a mood disorder. In a 2006 study Christensen and Keesing examined whether personality traits, especially neuroticism and introversion, are precursors of an affective disorder (BD) or whether these traits are the result of the disorder. They conclude that neuroticism can lead to depression but whether depression leads to neuroticism remains unclear, and that the time relation and causal association between personality traits and BD are unclear (2006). Also while researching the link of personality traits to BD, Joyce et al. (2004) found that Bipolar II patients often have comorbid borderline, histrionic, and schizotypal traits. They also suggest that hypomania occurring in adolescence or childhood specifically increases the probability for a borderline/histrionic personality disorder. Cluster B (dramatic, emotionally erratic) and cluster C (fearful, avoidant) personality disorders are common in those with BD, leading to increased severity of symptoms even during remission (George, Miklowitz, Richards, Simoneau, and Taylor 2003). It has even been suggested (MacKinnon and Pies 2006) that the

same mechanism may drive both rapid cycling between moods in BD and the affective instability of borderline personality disorder.

In one of the extremely rare qualitative studies of people with BD, Michalak, Yatham, Kolesar, and Lam (2006) interviewed people with BD about their perceptions of their quality of life (QOL) and found that the majority reported that BD had a profoundly negative effect on their life quality, especially in the areas of education, vocation, financial functioning, and social and intimate relationships. Clinicians' tendency to define "recovery" as simply the absence of clinical symptoms in BD fails to recognize the social impacts and functional consequences which continue throughout the course of the disorder. There are several studies which suggest the benefit of support groups and group therapy for persons with BD. In a 2005 study, Michalak, Yatham, and Lam found that an eight week group psychoeducation intervention was associated with improved perceived QOL in a group of euthymic patients with BD. They go on to state that the use of group psychoeducation along with pharmacotherapy in BD should be further studied with an emphasis on examining perceived QOL. Goldner-Vukov, Moore, and Cupina (2007) also found that through the group process, people with BD experienced an improvement in symptoms. "Our patients learned, through the group process, that even though they suffered from bipolar disorder, they each had ultimate responsibility for life no matter how much guidance they received from others" (Goldner-Vukov et al. 2007:33). This was echoed in the conversations I had with members of the support group, and formed the basis of the cultural model "managing the disorder" which will be discussed below. This model reflects the focus on individual responsibility which is present in American society.

While conducting qualitative interviews with people diagnosed with BD, Michalak et al. (2005) found that stigma associated with BD and disclosure of their diagnosis to others were

both areas of concern. Almost all of their respondents mentioned experiencing marginalization or stereotyping at some point in their lives. It follows to reason that sharing in a confidential support group would allow for disclosure and discussion in a safe environment. I found that the case in my experience in group. Often participants said that the people in group were the only people they talked to about their BD. I often heard people in group say "if you don't got it you don't get it."

The Support Group Model

The descriptions from people in group concerning what they were experiencing I found very valuable to increasing my understanding of BD. This supports my opinion that ethnographic methods are valuable for helping to explain people's experience with disease or disorder and what they value as far as treatment of their illness. The descriptions I heard from people in group were more varied than the definitions found in the DSM which focus mainly on mood fluctuation between mania and depression. The people I met in the peer-support group would complain that when you tell the average person that you have bipolar disorder, the response you get is usually along the lines of "So you have mood swings?" or "So you go on spending sprees?" On occasion, you will be looked at with a mix of amazement, or treated as if the disorder was somehow contagious. It's no wonder that most people with BD hide it from everyone except their most trusted friends, and rarely attempt to describe how it affects their lives. Indeed, the experience of BD is much more than mood swings. As Brad said, "There was a lot of other issues besides just mood swings. I mean psychologically I have a lot going on…" (August 22, 2011). The people I met experienced a mix of symptoms and a hodgepodge of diagnoses, illustrating the difficulty in pinning down exactly, with a single diagnosis, what these people are experiencing.

"So what's your diagnosis?" And I'll say "well that's not so clear-cut either anymore." So I have to go into this explanation of here's where we started and here's where we ended up, and I go to the list, and people will buy the bipolar disorder, but then there is the… we've been through generalized anxiety disorder, those are on the list. Also borderline personality disorder was added to that list and then taken off. I mean you can't take that off your record, but my present psychologist and psychiatrist are both like "no that isn't you." They see it as like a garbage bag diagnoses, well anyone will fit into that if we choose to limit the liability of our practice. So if you do something really crazy, and you're presenting yourself as unpredictable, they're covering their asses. So as they started looking further and started talking to my parents about what I was like as a kid and stuff- we kinda came to the conclusion that this wasn't just a simple mood disorder. And they were like, well what about the autism spectrum, what about like really, really high functioning autism, like Asperger's syndrome. So there was a lot of debate between me and Doc number one and Doc number two, and the hard part was you know, I'm an adult now and that's something that's more easily diagnosed in children, and adults having adapted more to their social milieu or environment but they settled on that diagnosis, they said yeah that's you. In addition to the mood disorder. [Brad August 22, 2011]

Kirk, who I only saw at group a couple of times talked about the crazy roller coaster his life is and how it is so hard to find "stability and peace" in his life. These transitions between mood states, and how these mood states affect functioning, contribute to a person's overall personality makeup. Kirk went on to say,

I argue with the idea that *I am a person with bipolar disorder*, no, I am bipolar disorder, I am bipolar. This biological disorder has affected me in so many ways that shape who and what I am. I cannot separate myself from it. Even though I take a medication that lessens my symptoms, taking that medication and having my symptoms lessen also shapes my personality- so the balance between illness, wellness, treatment, and how I subjectively perceive all of this makes me who I am, shapes my personality, determines how people see me. [September 15, 2011]

This seems to contradict the advice other group members got from their doctors, who suggested they practice saying that they were *individuals with bipolar disorder* rather than *I am bipolar*.

Often people expect the person with BD to simply try harder to act and function normally. The people in group expressed that they battled with acting and functioning normally with varying degrees of success. As Brad told me, "… it's like what I was discussing with some

folks the other night, we framed this whole discussion around what our families expected from us. Some families expected, and my family definitely expected, when you start medication that that means you're cured. And obviously that's not the case" (August 22, 2011). This feeling of not being cured led the people in group to attempt additional methods beyond their medications to improve their functioning and quality of life. It was my intention to examine how their model of treatment, or managing, was affecting their symptomology

Summary

As a result of my review of the literature and my time in the support group it became clear to me that the diagnosis of BD is complicated and not just a fluctuation of moods. People with this diagnosis suffer from damaged relationships, substance abuse issues, and stigma. The transitions between mood states and links to problematic personality traits are also evident. This illustrates the difficulty in both diagnosis and treatment, and creates the need for persons with BD to devote themselves to trying to manage their disorder through a variety of means. Participants in the support group discussed their experience in various ways, sometimes agreeing with the clinical descriptions, and sometimes not. This conceptualization has an influence on the management strategies people choose. For example, the model that the disorder is biological leads the sufferer to seek out treatments which affect biology, such as diet and supplements. I concluded that cultural model of *managing the disorder* included aspects connected to group participation such as hearing the stories of others, getting advice from participants, sharing stories, and feeling accepted. Keeping a schedule of sleep, medication, and exercise, as well as limiting alcohol and keeping a healthy diet were also noted as instrumental in managing their disorder. Marijuana use was also mentioned mostly in private conversations, and I perceived it was not a strategy shared by a majority of group members. Like marijuana, religion was not

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discussed openly by the majority of group members, although it was discussed by some participants in private conversation. Religion and marijuana use were not included in the model used for cultural consonance analysis because I perceived them as not being shared by a majority of the group. I still was interested in whether or not religion and marijuana effected symptomology and therefore examined correlations between them.

The element of culture- how individuals share knowledge and beliefs surrounding their conceptualization of their illness and how best to deal with it- is also an important aspect to consider. I hope to show through anthropological methods that culture matters in the diagnosis and treatment of mental disorders, whether that be in exotic cultures or in Colorado.

<u>Chapter IV- Setting:</u>

As an anthropologist I am of the opinion that culture matters in the conceptualization and treatment of mental disorders. As described above, people create shared models of diagnosis and treatment of illness. These models do not form in vacuum and in this chapter I will describe the cultural setting in which this population of persons with bipolar disorder and depression were situated. I will briefly examine the demographics of the county in which the support groups take place and then narrow the focus to the sponsoring agency of the groups and finally the setting of the groups themselves.

The State and County Level

This project took place in a county located on the Front Range of Colorado. As of the 2000 census there were 251,494 people residing in the county. The population density was 97 people per square mile. The County is mostly white as the 2000 census lists 91.44% as white, 8.27% Hispanic, .66% African-American, .66% Native American, and 1.56% Asian. The average household size was 2.52 and the average family size was 2.99. The median age was 33 years. The median income for a household in the county was $48,655 (www.census.gov 2012).

The makeup of the support groups mirror these demographics. The majority of the participants are white and during my time in the group I only met one African-American female and one Hispanic male. The gender of the groups are also reflective of the larger community with approximately half being male and half female. It is interesting to note that although there is a state university located in the County I did not meet any students who were attending the support group.

According to the National Alliance on Mental Illness (NAMI), there are close to 158,000 adults out of 4.9 million residents in Colorado who suffer from serious mental illness. NAMI

states that only 15.9% of adults who live with serious mental illnesses in the state receive

services from the public mental health system. They note that in 2006 Colorado spent just 2.2%

of the total state spending on mental health agency services (www.nami.org 2012). The

governing agency of the support groups was created to bolster services available to people

suffering from mental illness and at risk for suicide.

The Support Group

The sponsoring agency of the bipolar depression peer support groups was formed to

provide services to adults suffering from mood disorders and at risk for suicide. The agency is a

nonprofit [501(c)(3)] organization with an active board of directors. The agency has two full-

time employees and over 20 volunteers who provide services directly to the community. On their

website the agency lists their mission as educating and training youth and adults about

depression, other mental illnesses, and suicide, and providing resources for people who have

been impacted. Under "Our Vision" they state,

> Our vision is that the communities of this county will be caring and tolerant of
> those affected by depression, other mental illnesses, and suicide. People will be
> encouraged to recognize, intervene, and support those in need. Those suffering
> from mental illness and suicidal thoughts will seek treatment, resulting in a
> reduced suicide rate.

The vision of the governing agency reflects, and I suggest influences, the model of *managing*

the disorder which is shared by at least a majority of the participants in the peer support group.

The model of *managing the disorder* is also found in the descriptions of the peer support

group also found on the website. In their description of depression and bipolar disorder they state

that both are "highly treatable illnesses" and that the recovery process includes a mixture of

medication, therapy, peer support, and lifestyle changes. They also suggest that the group is a

"recovery focused group" in which participants can learn life skills to *manage depression*

(emphasis mine) and suicidal thoughts. They make it clear that it is a peer support group and not a therapy group. They do not charge for participation, although occasionally a hat would be passed around to take donations. The support group is for people eighteen years of age and older who are dealing with depression and BD. The group strives to offer a positive environment to share with others and learn life skills to manage depression and suicidal thoughts. It is a peer support and educational group, not a therapy group.

Groups take place four times a month, two being lunchtime groups and two being evening groups. The lunchtime groups last an hour and the evening groups last for an hour and a half. The evening groups take place in local churches, one of the lunchtime groups at a local community center, and the other lunchtime group at a local bank. All of these locations are chosen because the agency is not charged for using the space.

When I first started attending the groups, there were four different volunteer facilitators. When one of the facilitators, Lois, decided to quit attending she was seamlessly replaced by another participant who had been a steady group member. During this project I met approximately 30 people in the peer support group. Some people I only saw a few times and some people attended very frequently. Attendance at the groups range from usually around five people for the lunchtime groups to around fifteen at the evening groups. First-time participants are always welcomed and people are not judged according to how often or not they attend. People usually mingle and talk amongst themselves after groups are officially over. Often during these conversations people would exchange contact information and many people spent time together outside of group. I will discuss more on the specifics of the group process in the participant observation section below.

Conclusion

In conclusion, I'm suggesting that the cultural context in which these groups take place has an effect on how people conceptualize their illness and how they model their treatment. The idea that bipolar disorder and depression are highly treatable illnesses and that the sufferer can affect the course of the illness by seeking to manage the disorder are endorsed by the agency and by at least a large portion of the group participants. This again suggests that culture matters in the conceptualization and treatment of illness, in this context mental illness. It was my intention to determine if seeking to manage the disorder would actually lead to improved symptomology among the group participants.

Chapter V- Methods:

Participant Observation

       I came up with the idea for this study while I was enrolled in an ethnographic field methods class at Colorado State University. For our class project, we were supposed to pick a cultural group in which to conduct participant observation and interviews. I had written a paper on bipolar disorder in one of my undergraduate classes and because of a strong personal interest in mood disorders in general I decided to try to find a group of people with bipolar disorder in which to conduct my ethnographic research.

       My search began, as most searches these days, over the Internet. I consider myself lucky that on my first search I found an organization which facilitated peer support groups for people with bipolar disorder and depression. On February 8, 2011 I went to my first group which was held during the lunch hour at a local community center. I was incredibly nervous as I sat outside the community center in my car, doubting that these people would allow me to come into their space and eventually write about them. I gathered myself and entered the community center where I was greeted at the front desk. I told the receptionist that I was there for the bipolar depression support group and she directed me to a conference room across the hallway. I entered the room and was greeted by the facilitator, John. He asked if this was my first time in group and gave me an informational booklet and a copy of the group's norms. Several other people filed in and after everybody was settled John started the meeting. When it came time to introduce myself, I told them that I was a student at Colorado State University and was interested in participating in the group and interviewing some of them for a class project. John immediately asked the members of the group if they were comfortable with me being there. Unanimously they replied that they were comfortable with me being there and generally seemed supportive. After

the meeting was over, I talked to John and he said that he would talk to the other group facilitators to see if they were comfortable with me being in their groups. We exchanged phone numbers and he said he would call me as soon as he talked to the other facilitators.

A couple of days later I received a call from John. He told me the other facilitators were okay with me being in their groups and that it would be interesting for someone to conduct research concerning bipolar disorder and depression using their group. After attending a couple of groups, I decided that this would be a great project to turn into my Master's Thesis. I immediately began the process of getting this study approved by the Internal Review Board. This involved getting a letter of consent from the head facilitator, Lynn, and beginning the process of getting consent from all the group members. I accomplished this by introducing myself at the beginning of each group and telling the people that I was in the process of conducting research about their group for my Master's Thesis. If any of the participants were uncomfortable with me being there, the plan was that I would excuse myself and come back again to the next meeting. This never occurred and I was able to attend all the meetings. In fact, many people were excited about me conducting research and would talk to me after group about their ideas and experiences.

In this research project it was made clear to me that I was not supposed to take notes during group, and that I was expected to participate fully in group. I had to rely on my memory to take fieldnotes afterwards. For this project I was seen as a trusted insider within the group, indeed the members showed great trust in allowing me to attend, contribute, and write about the group. As a trusted insider, I was expected to share with the group details concerning my own personal life. As time went on I became more comfortable with discussing my own problems at school, difficulty with relationships, family issues, and my fears and dreams. In my opinion, it

was this honest sharing of myself with the group that led to the group members trusting me and rapport being built between us.

I have a strong desire to protect the identity of the people I met while attending the group. In that regard I am limiting the information about the support group. The number of participants per group varied; ranging from four people to as many as twenty. Some people I saw almost every single group, and some people I saw only once. I usually arrived around ten minutes early so I could mingle and talk to people as they showed up. We would always sit in a circle, and one of the facilitators would begin by welcoming everybody and passing out a copy of the group norms which we would take turns reading. Then the facilitator would suggest that we go around the group and have everyone introduce themselves, state their diagnosis, their medication, and how their week has been. Participants would be told to only participate if they were comfortable and they could pass if they wished. After everyone had the opportunity to check in, the facilitator would open the floor to anybody who needed to talk. There were usually at least a couple of people in group who had a lot to say, and solicited the advice of others about issues they were having with loved ones, medication, and the various other problems which result from depression or manic episodes.

The overall mood of the groups I attended varied greatly. At times it seemed as if everyone was depressed, and it was very quiet, or there was a lot of crying involved. Other times it was like being on a magic bus ride, with most everybody extremely talkative, with grandiose plans and high hopes. I became aware that for some people, fluctuations in mood would follow a pattern, seemingly dependent on weather patterns or the seasons. I was constantly struck by the fortitude and resiliency of the people I met in groups. They had gone through, or were going through incredible hardships; loss of spouses, suicide attempts, homelessness, job loss, and

financial difficulties to name just a few. Some people I'd met would disappear for months and then would show back up in group and tell their story, they had gone off the medication, had a manic episode, lost their job, ended up hospitalized, and now they were back rebuilding their lives and moving forward.

As time went on, I became convinced that this group provided a good example of how a cultural context can affect how people conceptualize illness and decide on treatment modalities. I began to take note of what people were doing to manage their disorder and began asking people about this both in group and in interviews. It was immediately obvious that in this cultural context people are expected to accept individual responsibility for attempting to manage and control their bipolar disorder and depression. I then set forth to determine which management strategies people were using and whether or not they seemed effective in improving symptomology.

Interviews

Additional methods of data collection for this project involved numerous casual conversations which I had with individuals after group was over and private semi structured interviews. The casual conversations after group meetings were instrumental in acquiring data due to the difficulty I had in getting semi structured interviews. After most meetings I would find myself engaged in conversation with one or more group members. Usually we would talk about what specific things they were doing to manage their disorder. It was after one of my first meetings when I was talking to Tom and Sam that I first heard them talk about using marijuana as a mood stabilizer. It was also during these after group discussions that I would ask particular individuals if they would be open to participating in a private interview. Although many people in group expressed an interest in being interviewed, most had difficulties finding a time when

they were functioning well enough to go through with one. I also limited myself to interviewing

individuals who were not experiencing distress at the time, this too contributed to completing

fewer interviews than I had hoped.

To find people who were willing to be interviewed, I would pay attention in group to

what was going on in the lives of the different participants and choose a person who seemed to

be managing well. I limited myself to asking participants who I had seen before at group, as I did

not want to overwhelm new participants who may have struggled getting to group in the first

place. Interviews were conducted in private; usually at the respondent's home. They were

recorded digitally and then transcribed later. I found my respondents very open about their

experiences and their quotes go far in illuminating their experiences with mental illness. I have

changed all my respondents' names and sometimes also changed the reported gender to help

insure confidentiality. I was able to complete ten semi structured interviews out of the

approximately thirty people I had met in group. Most of the interviews lasted between sixty and

ninety minutes.

I actually felt like I was more nervous than my respondents were during these interviews.

I would start the interview by engaging in small talk with the respondent. After a few minutes I

would ask them if they were comfortable with me turning on the digital recorder, everybody I

interviewed agreed to be recorded. I would start the interviews by asking which medications they

were on, what their particular diagnosis was, if they agreed with their diagnosis, how long ago

they were diagnosed, and if they were experiencing mental health issues before being diagnosed.

I would then ask them what strategies they used to manage their symptomology and how well

they thought each strategy worked. After exhausting their list of management strategies, I would

ask them if they took any other supplements or drugs in addition to their prescribed medications

and their reasons for taking them. In response to this question several people mentioned that they use marijuana as a mood stabilizer, reinforcing my perception gleaned from private conversations that several people use marijuana. I would follow this line of questioning by asking my respondent if they considered themselves religious or spiritual. Several people discussed experiences they had had which could be considered religious or spiritual in nature. They also discussed the sense of social support and belonging they felt as a result of being a member of a church or other religious organization. I would conclude the interview by asking if they believed people with bipolar disorder could manage their disorder. Everyone I interviewed said that "yes" people could manage their disorder, but at times because of the severity of symptomology it could be difficult if not impossible.

All of my fieldnotes and interviews were recorded and transcribed by hand. The comment function on Microsoft Word was used to designate and label themes and data. My main areas of focus were the management strategies people were incorporating into their lives, any mentions of marijuana use as a mood stabilizer, and discussions about religious or spiritual experiences. Each theme or data point was named and then grouped together on a separate document. Relationships were then examined among the different themes. Using the data I obtained from my participant observation, casual conversations, and semi structured interviews I settled on nine main management strategies, in addition to marijuana use and religion/spirituality, that were most mentioned by the group participants. The management strategies included: getting advice from participants in group, sharing stories in group, hearing the stories of others in group, feeling accepted in group, eating healthy, getting enough sleep, limiting alcohol, exercising regularly, and taking medications regularly.

Survey Data

From my participant observation and interview data I produced a list of items which were mentioned as methods persons with bipolar disorder used to manage their disorder. I then created a pen and paper survey which I intended to distribute to as many people in the group as possible. To accomplish this, at the conclusion of each group I would ask if anybody was interested in filling out the survey. I chose to limit the distribution of the survey to persons who had been to group at least twice. I did this because some of the model questions were dependent on participation in the group. I also did not want to overwhelm new members with requests for interviews or responses to the survey. The attendance at the groups fluctuated greatly, so a wide variety of levels and consistency of attending were sampled. Respondents had the option of completing the survey immediately or taking it home in a self-addressed stamped envelope to be mailed to me. I obtained 21 completed surveys out of the approximately 30 people I'd met in group.

The first section of the survey asked the respondents to list the current diagnosis, medication, and how long and how often they attend group. In the next section I asked individuals to rate in importance on a five point Likert scale how they felt the *average* person with bipolar disorder would respond in rating the importance of each item on the list. To determine the level of cultural sharing of these items, I subjected responses to cultural consensus analysis using UCINET. This method of statistical analysis allows the researcher to quantify the extent to which knowledge across a series of statements and a set of respondents is shared. The results of the analysis, which will be discussed below, revealed that there was not consensus among all my respondents concerning the nine model items. This is not surprising because

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several people in group were of the opinion that it was not possible to manage their disorder, and therefore would not have agreed with all of the model items.

In the next section of the survey questionnaire respondents were asked to rate how *they* felt about the cultural model items. Following methods outlined by Dressler (2005) responses across the items were summed, allowing me to gauge each respondent's level of individual consonance with the potentially culturally shared model of *managing the disorder*. The responses of each item which were rated a four or above on a five point Likert scale suggest agreement with the model items. I was interested in possible relationships between consonance to the model, marijuana use, and religion and spirituality, to health outcomes such as stress, mania, anxiety, and depression. Correlations between agreement to the model and health outcomes were examined using the Spearman rho which measures the consistency of relationships between ordinal variables. Correlations between marijuana use, whether or not people considered themselves religious or spiritual, and the health outcomes were also examined using the Spearman rho.

For measuring depression and anxiety I used the Patient Reported Outcomes Measurement Information System (PROMIS), funded by the National Institutes of Health (NIH) (www.nihpromis.org 2012), which are both short, four item scales. I used the Cohen's Perceived Stress Scale, Short Form, to measure stress, which is also a four item scale. To measure mania I randomly chose 4 items from the Goldberg Mania Scale. These items were not intended for diagnosing, nor were they intended to compare symptomology across groups. These items were intended solely for comparing responses on the symptomology measures with the methods of managing. This methodology does not provide the data to determine temporal precedence; it is unclear if the behaviors come first and lead to symptom outcomes, or if those with lower

symptomology are better able to incorporate more methods to stay healthy. However, in my opinion management strategies and symptomology work together in a circular fashion. People who employed more management strategies experienced less symptomology and were therefore more able to continue engaging in various management techniques. Participants who felt that they adhered to a model of managing the disorder may also experience less stress and therefore improved symptomology. The results of this survey data will be discussed along with the qualitative results in the following section.

Summary

For this research project I used several methods of data collection. Using several methods of data collection in ethnographic research enables the researcher to cross check information in various ways. My initial perceptions were constructed through my participation in the peer support group. These perceptions were further clarified in the casual conversations and semi structured interviews I had with the participants. Finally, by using the survey questionnaire I was further able to examine the level of agreement to the model *managing the disorder* and obtain data on marijuana use and religion/spirituality which people may not have been comfortable talking about in group. The survey questionnaire also provides quantitative data which can then be used to examine correlations between management strategies and health outcomes. By employing various means of data collection the researcher can obtain a more complete picture of the people being studied.

Chapter VI- Results:

So after all my bad experience I decided I just better learn to manage my moods on my own and not rely on medications. [Rex December 29, 2011]

I absolutely think you can manage it, but it's no different than diabetes or Crohn's or something else, it doesn't mean you're not going to have an episode. And just because you do have an episode doesn't mean you're not managing it. Even while I'm managing it, it's still part of my life, and it has been for a long time. - And that's something I've noticed with both drugs and medication is that I built up a tolerance really fast and I had to take more for it to work. And it just got to the point where this is not working for me. The stuff that did work I couldn't afford. So I had to figure out something else. [John June 28, 2011]

Managing the Disorder Model

The main theme I arrived at during my time in the group was that most participants, although valuing the benefits they received from their medications, were looking for additional ways to stay balanced in their lives, and that these methods were often effective in improving symptomology. Both John and a lady from group talked about having been hospitalized due to lithium toxicity. When I interviewed John, he mentioned having to go on dialysis to clean out his liver because of lithium toxicity. He was on such a high dose of lithium, that if he messed up and took one extra pill, he would go into lithium overdose. Participants often discussed their problems with side effects, costs, and efficacy of their medications. Most everyone searched for other ways to manage their symptoms.

There's one thing that we always talk about. Health being like a three legged stool, that you need your medication and you need your therapy, and you need a support. So the support group to me fills that need. So if you don't have one of those legs the stools can tip over. If you don't have support at home, you have to have it from somewhere, and group really does that for people. [Lois June 23, 2011]

Another example is Chris, who is living in a halfway house. He has spent most of the last ten years in and out of jail and prison. He's only taking medication sporadically, because he

doesn't get a lot of good results from them. He does do a lot of other things to try to manage his disorder though, like getting amino acids in his diet, exercise, and therapy. Indeed, group participants agreed on several methods to help manage their disorder. I concluded that there existed among this population a *model* of what a person with BD could emulate to aid in *managing the disorder.* The cultural model of *managing the disorder* included aspects connected to group participation such as hearing the stories of others, getting advice from participants, sharing stories, and feeling accepted. Participants also suggested that keeping a schedule of sleep, medication, and exercise, as well as limiting alcohol and keeping a healthy diet were instrumental in managing their disorder. Two other factors, marijuana use and religion/spirituality were also mentioned mostly in private conversations and I surmised that they also were beneficial to managing the disorder. However, because marijuana use and religion/spirituality were not discussed openly in group, I did not include these two factors as part of the *managing the disorder* model, but rather examined their correlations to symptomology separately. As a result of my participant observation, interviews, and survey data I concluded that through the process of *managing the disorder* participants experience less stress, depression, anxiety, and mania.

Through the act of participating in group, people are able to engage in four of the nine factors of the model including hearing the stories of others, getting advice from participants, sharing stories, and feeling accepted. An infrequent participant, Sam, discussed the feeling of belonging and being able to relate to others in group. "Other people can relate to you and you're not just a crazy, wacked out person. You're not the only one around, you know, who feels that way…It helps me to know, hey this person can relate to me and I can relate to them" (May 30,

2011). This sharing was expressed over and over in discussions in and out of group and formed

the basis for much of the cultural model.

> When you meet somebody (who is bipolar) you just talk and talk and talk because it's like you've met a kindred spirit, I think it eases my need to disclose to my friends and to seek support through my friends and stuff like that… (it's good to) talk to a group of people who are going through the same things, somebody who can really understand what you're going through so you just talk like crazy. [Tom June 5, 2011]

These comments from Tom suggest that he feels a part of the group (consonance), and this also

lessened Tom's need to talk about his disorder with other people in his life. This may be

beneficial in that it eases the strain which may occur as a result of his friends having to be his

only support network. Brad summed this up well,

> It's more helpful for me at times when you're able, like in the last meeting, being able to talk about a problem you're having, express it, get it out there, and then, the most helpful thing is when someone has something to say about it because they've been through the same thing and they have something, whether it's direct advice, or just to say "yeah I've been there." [August 22, 2011]

 I concluded from my participation in group and interviews that participants felt the most helpful

things about group were being able to hear the stories of others, getting advice from participants,

being able to honestly share their own stories, and feeling accepted. These social support

variables formed the first part of the cultural model.

> I think the biggest part for group, and even for me, is the feeling that you're not alone. I'm not the only one dealing with this. And I get to see other people that, you know, that are dealing with issues and hear how they get by, how they deal with things. I can relate. And I know I'm not alone. Because for the longest time, I felt so alone. Nobody feels like this, nobody understands. No one relates to how I feel and I think the good thing about group is people get to share how they feel. And no matter what it is you know like even today we had someone talking about anxiety messing up his life and trying to deal with the wreckage, and man I so relate to all of that. And maybe that's not where I am today, but I relate to that. Everyone in there today you know have different diagnosis, different things going on in their life, but I can relate to every single person. And that's huge for me. Whether I feel like that right now or not, I have felt that way. So I can be very

empathetic, when someone says I don't know if you guys understand, I can say, "No I understand." [John June 28, 2011]

The second part of the *managing the disorder* model includes three items involving keeping a schedule. Participants suggested that keeping a schedule of sleep, medication, and exercise were important factors to staying balanced. Lois said she needed to wake up and eat on a schedule, "So I know I have to wake up at the same time every day, and not only that I need to eat breakfast at the same time, so I need to schedule. That's essential for me" (June 23, 2011). Sam (May 30, 2011) mentioned not only sleep, but also taking medications on a schedule, "Well I think trying to stay on a regular schedule, going to bed at the same time every night and getting up at the same time every morning, taking meds, I think that's a big part of it, making sure you take your meds, preferably at the same time." Exercise was also mentioned as a way to manage symptomology. Tom noted, "I try to work out every day, some kind of exercise. I notice that really helps release some of that pent-up energy I get when I'm manic. Because energy just builds and builds and builds until you explode, and if I work out every day I can release some of that energy. That's probably the most important thing. Is to work out every day" (June 5, 2011). Brad discussed "regularity" as having an effect on his anxiety and depression.

> Scheduling is a managing technique for sure… the more regular my schedule is the more regular I am. Scheduled meds, scheduled bed times and stuff. If I scheduled the bedtime, whenever that happens to be, even if it's six in the morning, if I make sure that's a regular thing and I make sure the meds happen on a regular basis then these swings that I feel- they level out big-time. So regularity is a huge thing. That's a big management technique. A lot of this I don't know if we really appreciate it. Just exactly how important just one little thing is in that it affects a lot of anxiety and depression and whatever. [Brad August 22, 2011]

The final two factors of the model can be considered biologically based. Participants suggested that in addition to taking medications, a person with BD should focus on eating healthy and limiting alcohol.

I am anal about watching my diet. I'm on a strictly vegetarian vegan diet, I don't eat any meat. I track my intake of vitamins, since September 21 of 2009. Every day I can show you how many calories I have eaten. I can look back and say, wow last week I was really out there. And now I can look at my diet and see if anything correlates. A lot of times it does. [John June 28, 2011]

Often group participants discussed how they struggled with alcohol, when they were feeling manic the desire to drink was increased and if the person gave in and drank too much this often led to a depressive episode.

So if I start feeling manicy, I try to avoid things like parties and going out late drinking. One of the things I do to help manage my manic episodes which last into the evening is to not eat any chocolate or caffeine before bed. I try to stay away from caffeine other than early in the morning. It's harder to control my mood if I don't get a solid eight hours of sleep. [Rex December 29, 2011]

I am suggesting that the factors of hearing the stories of others, getting advice from participants, sharing stories, feeling accepted, keeping a schedule of sleep, medication, and exercise, as well as limiting alcohol and keeping a healthy diet comprised a model of *managing the disorder* which lessened bipolar symptomology. This combination of management strategies was openly discussed both in group and in interviews. As Tom said,

I think I'm really honest with myself and very aware of what I'm doing and what's going on with me. I also think diet is very important; someone with bipolar disorder needs to eat a lot of protein, get fatty acids like Omega threes, and stay away from sugar, caffeine, and light-colored carbohydrates. So I think those are the main things; diet, exercise, therapy, and medication. Sleep is also very important; I try to go to bed and wake up at the same time every day. [June 5, 2011]

Although most of the people I met were actively practicing a variety of methods to help manage their BD, a small minority were not. Some participants I spoke with expressed their disappointment and frustration with "like some of the people who come to group that just don't take any effort or any energy to try to make things better for themselves" (Brad August 22, 2011). One night after group I was having a conversation with Morris who described his

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frustration with people who did not take a more active role in managing this illness. He talked

about a lady who had a suicide attempt; she had tried to list off the meds she was taking and

couldn't do it. "She doesn't even know what she's taking. And she didn't know what any of the

drugs were for! It drives me so crazy!" (ND 2011). Morris said people need know what they're

putting in their bodies and what it's supposed to be doing for them. He couldn't believe how

many people with this disorder just take whatever drugs their doctors tell them and don't even

think about it, don't look it up, don't find out about it.

Another participant spoke about his frustration with some people in group, "You know it

says right in the group norms that this group is for people who want to manage their disorder. It

seems like the people that are doing well are the people that are really trying to manage it" (Gary

November 8, 2011). He described people who aren't managing as having a "woe is me" attitude.

He suggested that they're the ones that aren't doing so well, the ones that aren't managing their

disorder. People I talked to also stated that when in the throes of mania or depression, it is very

difficult to implement their strategies for managing their disorder.

> Well, once you go into mania you just forget to manage yourself. Your whole life.
> You think you're managing it, and you think you're doing a good job, but in
> reality you're not. So that's probably about the only time recently when I haven't
> taken good care of myself. Now, when I was in a depression, I pretty much
> couldn't do anything to take care of myself either. Keeping the schedule is
> impossible. I would just be in bed all day. So when you're in a severe depression
> state or severe manic state it's really hard to manage your illness. Because you just
> don't see a light at the end of the tunnel. [Sam May 30, 2011]

It was obvious that the model was not shared by all the participants that I had met, and

that the ability to adhere to the model was effected by the very symptomology that they were

attempting to control. This notion was cross checked with survey data. On the survey

questionnaire only 11 out of 21 respondents agreed with the statement "I believe people with BD

can manage their disorder," suggesting that there does not exist within the group agreement even that the disorder can be managed.

The results of the consensus analysis using the UCINET program echoed these results calculating an eigenratio of 1.41, which suggests that there was not a shared model. The UCINET programs measures agreement among participants on items of the model. A score of 3.0 or less suggests there is a lack of consensus (or agreement) within the group on the model. This could be a result of a low number of respondents to both the interviews, which formed the basis of the items chosen for the analysis, and the survey questionnaire. It also supports that there does not exist within the group agreement that the disorder can be managed and there is not a consensus on a model of what it looks like to be managing the disorder. This is important because if people do not believe they can manage their disorder they most likely will not actively engage in those techniques that those who believe in managing incorporate into their treatment program. As we see below, people who were consonant with the model experience less severe symptomology than those who were not consonant.

I was still interested in whether or not agreement with the items of the model were associated with better health outcomes, measured by items designed to determine levels of stress, depression, anxiety, and mania, which were drawn from the established scales previously mentioned. To examine these relationships I calculated individual consonance with the model items by adding the total of their scores and then comparing those scores to their scores on the stress, anxiety, depression, and mania scales. The Spearman rho statistic (which examines correlations between ordinal data) was calculated. The direction of the correlation between level of consonance with the model items and anxiety, depression, stress, and mania were all negative, which suggest that persons who reported adherence to the model items experience less

symptomology (Figure 1). This lends support to the idea that these methods of managing may be effective in decreasing stress, depression, anxiety and mania. I also suggest that experiencing less symptomology enables the person to better adhere to the model, interacting in a circular fashion. I suggest that these factors should be discussed with friends and family members, in support groups, and encouraged by mental health professionals.

			Consonance_avg#	Anxiety	Depression	Stress	Mania
Spearman rho	Consonance_avg#	Correlation Coefficient	1.000	-.153	-.063	-.341	-.017
		Sig. (2-tailed)	.	.508	.787	.131	.940
	Anxiety	Correlation Coefficient	-.153	1.000	.655[**]	.399	.159
		Sig. (2-tailed)	.508	.	.001	.073	.492
	Depression	Correlation Coefficient	-.063	.655[**]	1.000	.486[*]	.070
		Sig. (2-tailed)	.787	.001	.	.025	.763
	Stress	Correlation Coefficient	-.341	.399	.486[*]	1.000	-.300
		Sig. (2-tailed)	.131	.073	.025	.	.186
	Mania	Correlation Coefficient	-.017	.159	.070	-.300	1.000
		Sig. (2-tailed)	.940	.492	.763	.186	.

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

c. Listwise N = 21

Figure 1, Spearman rho Correlations

Marijuana Use

> *I also find that marijuana helps me balance my mood swings as well, but I do consider that a type of medication.* [Rex December 29, 2011]

> *Increased drug and alcohol abuse in manic-depressive patients has been related to changes in mood states, genetic factors, and self-medication of affective symptoms (both to diminish painful or unpleasant states and to induce, sustain, or exacerbate hypomanic states).* [Goodwin & Jamison, 1990:226]

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Marijuana use was rarely discussed openly in group, but several of the people I met discussed their use of marijuana with me outside of group. A few of these people had their medical marijuana license and a couple did not. One day Alice told me, "You know pot, I've heard it works. There's this one lady that used to come to group, that's all she does for it. She was an older lady, she had her license for it, and that's all she did. She would openly talk about it in group, to her that was her medication" (ND 2011). One night in group, a lady I had never seen before spoke up and said the only medication she uses to manage her disorder is marijuana. She only came to group once, so I was not able to discuss it with her further. Another person that came to group frequently, Brad, never discussed his marijuana use, but the night before the vote to ban medical marijuana dispensaries in Fort Collins, he called me urging me to vote against the ban. In my interview with Tom, he spoke openly about his past drug use and his current use of marijuana, but he also never mentioned it in group. Many people said they did not use marijuana, but knew someone who did, as Lois said, "I don't. I know a lot of people do. I have a friend that's got a medical marijuana license for depression. That's how he manages his depression. Actually it's bipolar" (June 23, 2011). It appeared that using marijuana, even though legal for some people in the state of Colorado, still carried enough stigma with it that people did not want to discuss it openly in group.

There were 7 out of 21 respondents who admitted to using marijuana on the survey questionnaire (a score of 4 or above on a 5-point Likert scale). To examine the relationship between marijuana use and health outcomes with survey data, again the Spearman rho statistic was calculated. The direction of the correlation between marijuana use (MMJ) and anxiety,

depression, stress, and mania were all negative (figure 2), which suggests that persons who

reported using marijuana experience less symptomology.

			Anxiety	Depression	Stress	Mania	MMJ
Spearman rho	Anxiety	Correlation Coefficient	1.000	.655**	.399	.159	-.548*
		Sig. (2-tailed)	.	.001	.073	.492	.010
	Depression	Correlation Coefficient	.655**	1.000	.486*	.070	-.236
		Sig. (2-tailed)	.001	.	.025	.763	.302
	Stress	Correlation Coefficient	.399	.486*	1.000	-.300	-.250
		Sig. (2-tailed)	.073	.025	.	.186	.275
	Mania	Correlation Coefficient	.159	.070	-.300	1.000	-.055
		Sig. (2-tailed)	.492	.763	.186	.	.813
	MMJ	Correlation Coefficient	-.548*	-.236	-.250	-.055	1.000
		Sig. (2-tailed)	.010	.302	.275	.813	.

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

c. Listwise N = 21

Figure 2, Spearman rho Correlations

This suggests that the possibilities for using marijuana as a mood stabilizer should be

further researched with clinical trials. Further ethnographic research could examine social and

cultural contexts of marijuana use by people with mood disorders to illuminate what contributes

to beneficial as opposed to problematic use. I am suggesting that controlled use of marijuana

may be effective in helping to minimize bipolar symptomology in some people. The altered

cognitive states achieved as a result of using marijuana, including dissociation, may help the

person relax and minimize stress. Marijuana may also help to balance the highs of mania and the

lows of depression. I would caution however, that as with any medications care should be taken

to avoid overuse or misuse. I would also encourage patients and their doctors to have an open dialogue about the possibilities of incorporating marijuana use as part of the treatment regimen.

Religion/Spirituality

> *There are so many people that come to group and either hold on really tightly to God and that's a refuge for them or they hate God because he turned his back on them and gave them this disease.* [Lois June 23, 2011]

In addition to the more mundane methods of attempting to manage their disorder, many group participants discussed their spirituality or relationship with God. Many of the group participants were in a 12-Step program, or had been in the past; many of these people discussed their relationship with a higher power. "And actually the beauty and just drawing close to God gives me comfort. Even in the worst times. We take a saint when we become Orthodox and that's our guardian angel someone who watches over us and the one that I chose is called the healer of depression" (Lois June 23, 2011). One person, Jean, who attend the group frequently discussed her participation in the Dances for Universal Peace, and noted that it was a good way for her to feel connected to other people and also to her spiritual self. John rarely mentioned his spiritual beliefs in group, but spoke to me in depth about his belief in a higher power and his time spent in prayer and meditation. Lois also spoke to me in depth outside of group about her spiritual beliefs, but rarely mentioned it in group, "So you walk out of church and you're like we are all one. One big church all across the globe and it really gives you a universal understanding" (June 23, 2011).

One of my first interviewees, Sam, had experienced a manic episode which may have occurred as the result of a change in medication. This manic episode had many religious themes

which became problematic. As I was to discover through the literature and speaking with people

from group, manic episodes containing religious themes are common in people with BD.

> Sure. There was a lot a hyper religiosity. My first manic episode I thought I was
> Jesus Christ. Seriously thought I was Jesus Christ. And this one pretty much the
> same. I thought I was, then I realized I wasn't, so I thought my son was. And then
> I thought I was married. I thought I was pregnant with an immaculate conception.
> There is one thing after another that I thought. I mean I did things like go to the
> church and talked to some of the pastors there about my son being Jesus Christ.
> Very embarrassing. Things like that. [Sam May 30, 2011]

Many of the people I met in support group talked about doing prayer or meditation as part

of their managing strategy. The following came from my conversation with Lois,

> I do prayerful meditation too. Repeating something holy that somebody has
> written down puts you in a good heart space, and then I do more of that
> conversational type of prayer, and the goal in the Orthodox faith is to have what
> they call pure prayer where you are thinking nothing but just existing with God. I
> think it's useful for staying stable. [June 23, 2011]

When Lois talks about meditative prayer, in my opinion she is describing a dissociative state,

and it is clear that the relaxation she derives from it affects her well-being. This was echoed by

John,

> The big thing for me has been to stop using my head and start using my heart and
> as goofy as that sounds it's what's working for me. As far as meditation goes I try
> to be quiet, it's about breath and flow, going through the motions and trying to
> quiet up here- (points to head) -Because that's the hardest thing to do is to quiet
> what's up there and I don't ever make it. Every once in a while though there will
> be like a moment, oh I was quiet. That doesn't happen that often. But that's okay.
> It's something to work on. I listen to a lot of music, I just try to be quiet. And it's
> hard for me, my brain doesn't stop very much. [June 28, 2011]

John talks about quieting his mind, which again is an example of dissociation. I

discussed this with Tom and although I didn't have my recorder, but caught the gist of his

statement. He said that many people in group discuss being addicted to the TV, and he thinks the

same way about the TV that John feels about meditation. He thinks maybe it's comforting to

people with BD. It is kind of mind-numbing and when you're manic or when you're depressed

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and you have a lot anxiety, and you're ruminating, it's relaxing to just focus on something that's just mindless. He said he thinks it is beneficial. Like John said in group, it's all about moderation and being aware of what you're doing. He suggested that sometimes by isolating you can really focus on yourself and try to get your energy and your resources and your mind together, so you can be around other people. He concluded by saying he thinks sometimes zoning out on the TV can be beneficial, "it just lets you relax and relaxation is really important" (ND 2011).

John talked extensively about his spirituality, but he stated he was not a part of any organized religion,

> To whom I pray to, I couldn't tell you. Something bigger than me is all I know. It's like the spirit of the universe, even mother-nature. I know there's something bigger than me. But it's not a Judeo-Christian God. That's not my conception. If I try to make God something you can put in a box and explain, then it's not big enough to solve my problems. [June 28, 2011]

This was echoed by Tom, who after describing a lifelong exploration of various religious traditions said, "It was all very interesting. But as years went by I became more and more disillusioned with all religion, now I don't even believe in a God. I believe everything is created in the brain. All the interesting experiences I had, all the miracles I saw, and they're all byproducts of brain activity" (June 5, 2011).

On the survey questionnaire 14 respondents out of 21 said that they considered themselves religious or spiritual (a score of 4 or above on a 5-point Likert Scale). Relationships between levels of religion/spirituality were examined using the Spearman rho statistic. The direction of the correlation between religion/spirituality and anxiety and depression were both negative (figure 3). This may illustrate that persons who have the social support from belonging to a religious or spiritual tradition experience less anxiety and depression. I also suggest that the practice of meditation or prayer may aid in achieving relaxed states which decrease stress and the

individual, in turn diminishing depression and anxiety. The framing of mood fluctuations in a religious or spiritual manner may also benefit the individual by providing a socially accepted manner in which to discuss and ultimately experience the symptoms of mania, anxiety, and depression.

			Anxiety	Depression	Stress	Mania	Religious Spiritual
Spearman rho	Anxiety	Correlation Coefficient	1.000	.655[**]	.399	.159	-.169
		Sig. (2-tailed)	.	.001	.073	.492	.463
	Depression	Correlation Coefficient	.655[**]	1.000	.486[*]	.070	-.141
		Sig. (2-tailed)	.001	.	.025	.763	.541
	Stress	Correlation Coefficient	.399	.486[*]	1.000	-.300	.094
		Sig. (2-tailed)	.073	.025	.	.186	.685
	Mania	Correlation Coefficient	.159	.070	-.300	1.000	.000
		Sig. (2-tailed)	.492	.763	.186	.	.999
	Religious Spiritual	Correlation Coefficient	-.169	-.141	.094	.000	1.000
		Sig. (2-tailed)	.463	.541	.685	.999	.

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

c. Listwise N = 21

Figure 3, Spearman rho Correlations

It is interesting to note that in the analysis a religious or spiritual orientation and stress were slightly positively correlated. I suggest that this may be the result of social commitments and expectations which go along with belonging to a church or other religious organization. Oftentimes social commitments are difficult for persons with bipolar disorder to keep because extreme mood fluctuations will affect their desire or ability to function in a group affectively. The correlation between being religious/spiritual and reported mania was neutral. This could be the result of a low number of respondents or possibly a reflection of manic states being framed as

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religious or spiritual. It is possible that the people who report higher levels of mania also report a religious or spiritual orientation. There also is the issue of religiosity co-occurring with a manic episode and the implications for treating it as a Brief Psychotic Episode or as a spiritual emergency or emergence. I suggest that clinicians should be aware of the possibility that this hyper religiosity may occur with an episode of mania. These episodes may actually be a transformative process and alternatives to hospital lock up and heavy dosing with drugs should be examined. Ultimately, the cultural framing is important and may affect health outcomes, again suggesting the value of the anthropological research paradigm.

Summary

As a result of my participant observation, interviews, and survey data I concluded that through the process of managing the disorder participants experience less stress, depression, anxiety, and mania. The cultural model of *managing the disorder* included aspects connected to group participation such as hearing the stories of others, getting advice from participants, sharing stories, and feeling accepted. Participants also suggested that keeping a schedule of sleep, medication, and exercise, as well as limiting alcohol and keeping a healthy diet were important to managing their disorder. Two other factors, marijuana use and religion/spirituality were also mentioned mostly in private conversations and I conclude that they also were beneficial to managing the disorder. I am suggesting that this process works in two ways. The first is that the specific management techniques benefit the person with bipolar disorder by strengthening social support, providing structure by keeping a strict schedule, and helping to maintain a biologically healthy body. The second part of the process is that by feeling as if they are adhering to a model of managing the disorder (consonance), people feel more in control and therefore experience less stress connected to being diagnosed with bipolar disorder. This stress reduction ultimately

contributes to the person experiencing less mania, anxiety, and depression. Ultimately this data points to the importance of examining how groups of people conceptualize their illness and how it should be treated. The people I met in the support group were creating their own models of what it means to be bipolar and what they could do to manage the disorder, influenced in part by the cultural constructions of mental illness and its treatments advocated by the sponsoring agency of the support groups. Through my time with the support group it became obvious to me that the people who were managing their disorder were incorporating multiple techniques, usually along with medication, as a means to minimize the effects that having bipolar disorder had on their lives. These results, I believe, support the idea that culture matters in the conceptualization and treatment of mental disorders. The particular culture of this peer support group on the Front Range of Colorado is creating its own conceptualization of bipolar disorder and how best to go about treating it. I also believe that this supports the value of conducting ethnographic research into how various groups conceptualize mental illness.

<u>Chapter VII - Conclusions and Limitations:</u>

As a result of my participant observation, interviews, and survey data I conclude that through the process of managing the disorder participants in this peer support group for persons with bipolar disorder and depression experience less stress, depression, anxiety, and mania. The cultural model of *managing the disorder* includes aspects which are connected to group participation such as hearing the stories of others, getting advice from participants, sharing stories, and feeling accepted. People in the group also suggested that keeping a schedule of sleep, medication, and exercise, as well as limiting alcohol and keeping a healthy diet were important to managing their disorder. Two other factors, marijuana use and religion/spirituality were also mentioned as being beneficial to managing depression and bipolar disorder.

I am suggesting that this process works in two ways. The first is that the specific management techniques benefit the person with bipolar disorder by strengthening social support, providing structure by keeping a strict schedule, and contributes to maintaining a biologically healthy body. The second part of the process is that by feeling as if they are adhering to a model of managing the disorder (consonance), people feel more in control and therefore experience less stress connected to being diagnosed with bipolar disorder. This stress reduction also contributes to the person experiencing less mania, anxiety, and depression. Ultimately this data points to the importance of examining how groups of people conceptualize their illness and how it should be treated. The people I met in the support group were creating their own models of what it means to be bipolar and what they could do to manage the disorder, as they were influenced by the sponsoring agency of their support groups. Through my time with the support group I learned that the people who were managing their disorder were incorporating multiple techniques,

usually along with medication, as a means to minimize the effects that having bipolar disorder had on their lives.

This research project had several limitations. First of all were the small number of respondents I was able to get for interviews and to complete survey data. This was a product of a short time in the field, the small number of individuals who participated in the group, and the transitory nature of participation in the group. Because I was not able to gather baseline data concerning symptomology on participants before they started attending group, I was not able to determine temporal precedence. This means I was not able to absolutely determine what comes first, managing or improved symptomology. I assume however that managing techniques and improved symptomology work in a circular fashion, those who practice management techniques experience improved symptomology which in turn enables them to practice more management techniques. Results are also tempered by the fact that only well-functioning individuals were interviewed. However, this is balanced by hearing the opinions of all group participants while in group and the fact that I gave everyone an opportunity to complete the survey questionnaire.

Further research should be conducted in various cultural settings to illustrate deviations in this model among various cultural contexts. For example, in the Mexican-American community it may be more important to focus on family interdependence and self-responsibility then on independence as in this Anglo-American sample. I also believe it is important to spend a longer period of time in the field in order to examine peoples' symptomology longitudinally as well as provide more participants for the sample. It is my opinion that ethnographic methods can provide unique insights into persons' experience with mental illness, in particular how these experiences are modeled by culture and how this determines the treatment methods that people choose and ultimately how effective those treatments are.

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APPENDICES

Appendix A:

Survey Questionnaire-

Bipolar Support Group Survey
Greg Batchelder, contact- greg.batchelder@colostate.edu
Colorado State University

Please answer as accurately as possible. Your identity will be kept confidential.

1.   Please list any current diagnosis._____.

2.   Are you currently taking any medication?   Yes   No
2a. Please list._____.

3.   How long have you been attending the support group?
1-4 months   4-8 months   8-12 months   more than 12 months

4.   How often do you attend support groups?
Every week   every 2 weeks   every 3 weeks   every 4 weeks   less

5.   How many times have you attended group in the last 4 weeks?
Once   twice   three times   four times

Please indicate how you think *the average* person with bipolar disorder (BD) would respond.

Strongly Disagree   Neutral   Strongly Agree
(1)-------------(2)-------------(3)-------------(4)-------------(5)

6.   Hearing the stories of others helps manage BD.   1   2   3   4   5

7.   Getting advice from participants helps manage BD.   1   2   3   4   5

8.   Sharing stories in group helps manage BD.   1   2   3   4   5

9.   Feeling accepted in group helps manage BD.   1   2   3   4   5

10.   It is important to eat healthy to help manage BD.   1   2   3   4   5

11.   It is important to get enough sleep to help manage BD.   1   2   3   4   5

12.   It is important to limit alcohol to help manage BD.   1   2   3   4   5

13.   It is important to exercise regularly to help manage BD.   1   2   3   4   5

14.   It is important to take your meds regularly.   1   2   3   4   5

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Now answer how _you_ feel about the following statements.

         Strongly Disagree   Neutral   Strongly Agree
         (1)------------(2)------------(3)------------(4)------------(5)

15.   Hearing the stories of others helps me manage my BD.   1   2   3   4   5

16.   Getting advice from participants helps me manage my BD. 1   2   3   4   5

17.   Sharing stories in group helps me manage my BD.   1   2   3   4   5

18.   Feeling accepted in group helps me manage my BD.   1   2   3   4   5

19.   I try to eat healthy to help manage my BD.   1   2   3   4   5

20.   I try to get enough sleep to help manage my BD.   1   2   3   4   5

21.   I try to limit alcohol to help manage my BD.   1   2   3   4   5

22.   I try to exercise regularly to help manage my BD.   1   2   3   4   5

23.   I try to take my meds regularly to manage my BD.   1   2   3   4   5

In this section, indicate if you felt this way in the past 7 days.

Never   Rarely   Sometimes   Often   Always
         (1)-------(2)----------(3)-----------(4)--------(5)
24.   I felt fearful.   1   2   3   4   5
25.   I found it hard to focus on anything other than my anxiety.   1   2   3   4   5
26.   My worries overwhelmed me.   1   2   3   4   5
27.   I felt uneasy.   1   2   3   4   5
28.   I felt worthless.   1   2   3   4   5
29.   I felt helpless.   1   2   3   4   5
30.   I felt depressed.   1   2   3   4   5
31.   I felt hopeless.   1   2   3   4   5

         Never Almost Never   Sometimes Fairly Often   Very Often
         (1)---------(2)----------------(3)------------(4)---------------(5)
32. In the last month, how often have you felt that you were unable to control the important things in your life?   1   2   3   4   5
33. In the last month, how often have you felt confident about your ability to handle your personal problems?   1   2   3   4   5
    34. In the last month, how often have you felt that things were going your way? 1 2 3 4 5
35. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?   1   2   3   4   5

         Strongly Disagree   Neutral   Strongly Agree
         (1)------------(2)------------(3)------------(4)------------(5)

36. In the last month, I have so many plans and new ideas that it is hard for me to work.
 1   2   3   4   5
37. In the last month, I feel a pressure to talk and talk.   1   2   3   4   5
38. In the last month, I have been irritable.   1   2   3   4   5
39. In the last month, I have felt restless.   1   2   3   4   5

Strongly Disagree	Neutral	Strongly Agree

(1)-------------(2)-------------(3)------------(4)-------------(5)

40. I consider myself religious or spiritual.   1   2   3   4   5
41. I meditate or pray regularly.   1   2   3   4   5
42. I believe in a "higher power."   1   2   3   4   5
43. I have had special religious or spiritual experiences.   1   2   3   4   5
44. I attend church regularly.   1   2   3   4   5

Marijuana- In my research I have found that some people use marijuana as a mood stabilizer. *If the following questions do not apply to you, or if you don't want to answer, you can leave blank.*

Strongly Disagree	Neutral	Strongly Agree

(1)-------------(2)-------------(3)------------(4)-------------(5)

45. I currently use or have used marijuana.   1   2   3   4   5
46. Using marijuana helps me to relax.   1   2   3   4   5
47. Using marijuana helps me to "zone out".   1   2   3   4   5
48. Using marijuana helps to stabilize my moods.   1   2   3   4   5
49. My doctor discourages my use of marijuana.   1   2   3   4   5

Almost done! Please answer all the rest.
50. I am currently satisfied with my quality of life.   1   2   3   4   5
51. I believe people with BD can manage their disorder.   1   2   3   4   5
52. Age._____
53. Gender._____
54. Married?   Yes   No
55. Children?   Yes   No
56. Education._____
57. Approximate current annual income._____

Thank you so much for helping me with this research. Contact me with any questions; 970-361-2402.Greg

Appendix B:

Interview Questions-

Questions about disorder/diagnosis:
1.   When were you first diagnosed?
2.   What is your diagnosis?
3.   Probe- Do you agree with it?
4.   When did you first start having mental health issues?
5.   Probe- How would you describe your "disorder?"
6.   Tell me about your experience with medication.
7.   Tell me about your family's understanding of BPD.
8.   Probe- Are there others in your family with mental health issues?

Questions about Support Group:
1.   How often do you attend the support group?
2.   What led you join the support group?
3.   What do you think the benefits of attending are for most people?
4.   What are the benefits for you?
5.   Probe- Does that affect your attendance?
6.   Do you ever show a different part of who you are in group that you don't always show outside of group?
7.   Probe- If yes – why in group but not outside?
8.   Do you feel like attending group changes the way you feel about yourself – good or bad?
9.   Probe- If yes – what about it?
10.   Probe- If not – why do you think that is?
11.   How do you see the group affecting your quality of life?
12.   Does attending group affect the stress you experience in life in any way?
13.   What changes have you experienced in life since starting to attend group?
14.   Do you see yourself continuing attending group?
15.   Probe- If so- for how long?

Model Questions:

1.   Do you feel a person with BPD can do things to manage their illness?
2.   Probe- If so, what?
3.   What have you done, or are currently doing to manage your illness?
4.   Has there been a time when you were not managing your illness?
5.   Probe- What did that look like?

Dissociation/Religion:

1.   Do you consider yourself religious or spiritual? Could you describe your experiences to me?
2.   Do you use any drugs besides your medication? Would you talk about why you use them and what they do for you?

Demographics:

Age, Gender, Born, Raised, Current Employment, Marital Status, Children, Education, SES current and past.

Appendix C:

Symptom Scales-

PROMIS Item Bank v1.0 – Emotional Distress-Depression – Short Form 4a
Participant Format © 2009 PROMIS Health Organization and PROMIS Cooperative Group
Please respond to each question or statement by marking one box per row.
In the past 7 days...

                                      Never Rarely Sometimes Often Always
1 I felt worthless .... ☐ ☐ ☐ ☐ ☐
2 I felt helpless .... ☐ ☐ ☐ ☐ ☐
3 I felt depressed .... ☐ ☐ ☐ ☐ ☐
4 I felt hopeless .... ☐ ☐ ☐ ☐ ☐

PROMIS Item Bank v1.0-Emotional Distress-Anxiety – Short Form 4a
Participant Format © 2009 PROMIS Health Organization and PROMIS Cooperative Group
Please respond to each question or statement by marking one box per row.
In the past 7 days…

                                        Never Rarely Sometimes Often Always
1 I felt fearful .... ☐ ☐ ☐ ☐ ☐
2 I found it hard to focus on anything other than my anxiety .... ☐ ☐ ☐ ☐ ☐
3 My worries overwhelmed me .... ☐ ☐ ☐ ☐ ☐
4 I felt uneasy .... ☐ ☐ ☐ ☐ ☐

INSTRUCTIONS:

The questions in this scale ask you about your feelings and thoughts during THE LAST
MONTH.   In each case, please indicate your response by placing an "X" over the circle
representing HOW OFTEN you felt or thought a certain way.

1.   In the last month, how often have you felt that you were unable to control the important
things in your life?
2.   In the last month, how often have you felt confident about your ability to handle your
personal problems?
3.   In the last month, how often have you felt that things were going your way?
4.   In the last month, how often have you felt difficulties were piling up so high that you
could not overcome them?

        Never Almost Never Sometimes   Fairly Often   Very Often
          0   1   2   3   4

Goldberg Mania Scale - ©1993 Dr. Ivan Goldberg - All Rights Reserved

Name: _____ Date: _____

0 = Not at all 1 = Just a little 2 = Somewhat 3 = Moderately 4 = Quite a lot 5 = Very much

My mind has never been sharper. 0 1 2 3 4 5

I need less sleep than usual. 0 1 2 3 4 5

I have so many plans and new ideas that it is hard for me to work. 0 1 2 3 4 5

I feel a pressure to talk and talk. 0 1 2 3 4 5

I have been particularly happy. 0 1 2 3 4 5

I have been more active than usual. 0 1 2 3 4 5

I talk so fast that people have a hard time keeping up with me. 0 1 2 3 4 5

I have more new ideas than I can handle. 0 1 2 3 4 5

I have been irritable. 0 1 2 3 4 5

It's easy for me to think of jokes and funny stories. 0 1 2 3 4 5

I have been feeling like "the life of the party." 0 1 2 3 4 5

I have been full of energy. 0 1 2 3 4 5

I have been thinking about sex. 0 1 2 3 4 5

I have been feeling particularly playful. 0 1 2 3 4 5

I have special plans for the world. 0 1 2 3 4 5

I have been spending too much money. 0 1 2 3 4 5

My attention keeps jumping from one idea to another. 0 1 2 3 4 5

I find it hard to slow down and stay in one place. 0 1 2 3 4 5

Appendix D:

Bipolar Support Group Recruitment Script-

TITLE OF STUDY: Perceived Quality of Life of Persons with Bipolar Disorder: Effects of Attending a Peer Support Group.

PRINCIPAL INVESTIGATOR: SNODGRASS, JEFFREY, ANTHROPOLOGY, PHD., JEFFREY.SNODGRASS@COLOSTATE.EDU

CO-PRINCIPAL INVESTIGATOR: BATCHELDER, GREG, ANTHROPOLOGY, GRADUATE STUDENT, GREG.BATCHELDER@COLOSTATE.EDU

  Hi, my name is Greg Batchelder, as you know, I am a member of this group, but I am also conducting research on the effect of attending peer support groups for people with Bipolar disorder. I would like to ask you to help me with my research, Perceived Quality of Life of Persons with Bipolar Disorder: Effects of Attending a Peer Support Group. I would like you to be in an interview that will last 1-2 hours and perhaps take a survey that will take 10-15 minutes. The interviews will be recorded and I will ask questions about your experience with Bipolar Disorder and the support group. Your participation is voluntary and you should not be experiencing any psychological discomfort at this time if you want to participate. We will keep all your responses confidential and they will not be reported back to the group or the facilitators. If you are interested, please talk to me after the group.

Appendix E:

Consent to Participate in a Research Study
Colorado State University-

TITLE OF STUDY: Perceived Quality of Life of Persons with Bipolar Disorder: Effects of Attending a peer Support Group.

Principal Investigator: Snodgrass, Jeffrey, Anthropology, PHD.,
jeffrey.snodgrass@colostate.edu

Co-Principal Investigator: Batchelder, Greg, Anthropology, graduate student,
greg.batchelder@colostate.edu: Greg is also a member of the support group and will be conducting the interviews and administering the surveys..

WHY AM I BEING INVITED TO TAKE PART IN THIS RESEARCH? As a member of the peer support group, who is an adult, and not currently in a psychologically vulnerable state, the researchers are interested in your thoughts concerning bipolar disorder and the peer support group.

WHO IS DOING THE STUDY? Greg Batchelder who is a graduate student at CSU and a member of the peer support group, under the direction of Dr. Jeff Snodgrass.
.

WHAT IS THE PURPOSE OF THIS STUDY? To examine the effects of attending the peer support group on perceived quality of life.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST? Interviews will take place at a location of your choice. Interviews will last between 1 and 2 hours. You may be asked to fill out a survey which will take 10-15 minutes.

WHAT WILL I BE ASKED TO DO? You will be asked to discuss your experience with bipolar disorder and effects of attending group. Interviews will be digitally recorded. You may be asked to complete a survey also.

ARE THERE REASONS WHY I SHOULD NOT TAKE PART IN THIS STUDY? If you are under the age of 18 or are currently experiencing psychological discomfort which may be increased due to the interview process, you will not be asked to participate.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?
➢ It is not possible to identify all potential risks in research procedures, but the researcher(s) have taken reasonable safeguards to minimize any known and potential, but unknown, risks. The only foreseeable risk would be the psychological discomfort which may be experienced as a result of the interview. You will not be subject to any risk above and beyond what would occur in discussions with family members or group. Participation is voluntary and you can quit the

interview at any time. You are already attending the support group and have the contact information of helping agencies if you experience excessive discomfort.

ARE THERE ANY BENEFITS FROM TAKING PART IN THIS STUDY? There is no direct benefit to you except being able to share your ideas. This research may however benefit persons with bipolar disorder and the field of mental health.

DO I HAVE TO TAKE PART IN THE STUDY? Your participation in this research is voluntary. If you decide to participate in the study, you may withdraw your consent and stop participating at any time without penalty or loss of benefits to which you are otherwise entitled.

WHO WILL SEE THE INFORMATION THAT I GIVE? We will keep private all research records that identify you, to the extent allowed by law.
A copy of the final report will be given to the group coordinator and access to said report will be made available to you if you would like to read it.

Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private.
.
We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from your research records and these two things will be stored in different places under lock and key.
You should know, however, that there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court OR *to tell authorities if we believe you have abused a child, or you pose a danger to yourself or someone else.*

WILL I RECEIVE ANY COMPENSATION FOR TAKING PART IN THIS STUDY? No

WHAT IF I HAVE QUESTIONS?
Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Greg Batchelder at 970-361-2402. If you have any questions about your rights as a volunteer in this research, contact Janell Barker, Human Research Administrator at 970-491-1655. We will give you a copy of this consent form to take with you.

This consent form was approved by the CSU Institutional Review Board for the protection of human subjects in research on (Approval Date).

Your signature acknowledges that you have read the information stated and willingly sign this consent form. Your signature also acknowledges that you have received, on the date signed, a copy of this document containing ___ pages.

_____ _____
Signature of person agreeing to take part in the study   Date

_____
Printed name of person agreeing to take part in the study

_____   _____
Name of person providing information to participant   Date

_____
Signature of Research Staff

Appendix F:

Diagnostic Criteria-

DSM-IV-TR Diagnostic Criteria for Major Depressive Episode

A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.
Note: Do not include symptoms that are clearly due to a general medical condition, or mood-incongruent delusions or hallucinations.
depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). Note: In children and adolescents, can be irritable mood.
markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others)
significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day. Note: In children, consider failure to make expected weight gains.
insomnia or hypersomnia nearly every day
psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)
fatigue or loss of energy nearly every day
feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick)
diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)
recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide
B. The symptoms do not meet criteria for a Mixed Episode.
C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
D. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).
E. The symptoms are not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

DSM-IV-TR Criteria for Manic Episode

A) A distinct period of abnormally and persistently elevated, expansive or irritable mood, lasting at least 1 week (or any duration if hospitalization is necessary)
B) During the period of mood disturbance, three (or more) of the following symptoms have persisted (four if the mood is only irritable) and have been present to a significant degree:
1) inflated self-esteem or grandiosity

2) decreased need for sleep (e.g., feels rested after only 3 hours of sleep)
3) more talkative than usual or pressure to keep talking
4) flight of ideas or subjective experience that thoughts are racing
5) distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli)
6) increase in goal-directed activity (at work, at school, or sexually) or psychomotor agitation
7) excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments)
C) The symptoms do not meet criteria for a Mixed Episode
D) The mood disturbance is sufficiently severe to cause marked impairment in occupational functioning or in usual social activities or relationships with others, or to necessitate hospitalization to prevent harm to self or others, or there are psychotic features.
E) The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication or other treatment) or a general medical condition (e.g., hyperthyroidism)
Note: Manic-like episodes that are clearly caused by somatic antidepressant treatment (e.g., medication, electroconvulsive therapy, light therapy) should not count toward a diagnosis of Bipolar I disorder.

DSM IV-TR Criteria for Mixed Episode

 (Note: this is often referred to as "rapidly cycling bipolar" - but technically Rapid Cycling refers to at least 4 episodes in the previous 12 months that meet criteria for a Major Depressive, Manic, Mixed or Hypomanic Episode, and the Episodes are demarcated either by partial or full remission for at least 2 months or a switch to an episode of opposite polarity - e.g., Major Depressive Episode to Manic Episode)
A. The criteria are met both for a Manic Episode and for a Major Depressive Episode (except for duration) nearly every day during at least a 1-week period.
B. The mood disturbance is sufficiently severe to cause marked impairment in occupational functioning or in usual social activities or relationships with others, or to necessitate hospitalization to prevent harm to self or others, or there are psychotic features.
C. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication, or other treatment), or a general medical condition (e.g., hyperthyroidism)
Note: Mixed-like episodes that are clearly caused by somatic antidepressant treatment (e.g., medication, electroconvulsive therapy, light therapy) should not count toward a diagnosis of Bipolar I Disorder.

DSM- IV-TR Criteria for Hypomanic Episode

A) A distinct period of persistently elevated, expansive or irritable mood, lasting throughout at least 4 days, that is clearly different from the usual nondepressed mood.
B) During the period of mood disturbance, three (or more) of the following symptoms have persisted (four if the mood is only irritable) and have been present to a significant degree:
1) inflated self-esteem or grandiosity
2) decreased need for sleep (e.g., feels rested after only 3 hours of sleep)
3) more talkative than usual or pressure to keep talking
4) flight of ideas or subjective experience that thoughts are racing

5) distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli)
6) increase in goal-directed activity (at work, at school, or sexually) or psychomotor agitation
7) excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments)
C) The episode is associated with an unequivocal change in functioning that is uncharacteristic of the person when not symptomatic.
D) The disturbance in mood and the change in functioning are observable by others.
E) The mood disturbance not severe enough to cause marked impairment in social or occupational functioning, or to necessitate hospitalization, and there are no psychotic features.
F) The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication or other treatment) or a general medical condition (e.g., hyperthyroidism)
Note: Hypomanic-like episodes that are clearly caused by somatic antidepressant treatment (e.g., medication, electroconvulsive therapy, light therapy) should not count toward a diagnosis of Bipolar II disorder.

Diagnostic criteria for 296.0x Bipolar I Disorder, Single Manic Episode

A. Presence of only one Manic Episode...and no past major Depressive Episodes.
    Note: Recurrence is defined as either a change in polarity from depression or an interval of at least 2 months without manic symptoms.
B. The Manic Episode is not better accounted for by Schizoaffective Disorder and is not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.
Specify if:
    Mixed: if symptoms meet criteria for a Mixed Episode...
Specify (for current or most recent episode).
    Severity/Psychotic/Remission Specifiers...
    With Catatonic Features...
    With Postpartum Onset...

Diagnostic criteria for 296.40 Bipolar I Disorder, Most Recent Episode Hypomanic

A. Currently (or most recently) in a Hypomanic Episode...
B. There has previously been at least one Manic Episode...or Mixed Episode...
C. The mood symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
D. The mood episodes in Criteria a and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.
Specify:
    Longitudinal Course Specifiers (With and Without Interepisode Recovery)...
    With Seasonal Pattern (applies only to the pattern of Major Depressive Episodes)...
    With Rapid Cycling...

Diagnostic criteria for 296.4x Bipolar I Disorder, Most Recent Episode Manic

A. Currently (or most recently) in a Manic Episode...
B. There has previously been at least one Major Depressive Episode..., Manic Episode...,or Mixed Episode...
C. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.
Specify (for current or most recent episode):
    Severity/Psychotic/Remission Specifiers...
    With Catatonic Features...
    With Postpartum Onset...
Specify
    Longitudinal Course Specifiers (With and Without Interepisode Recovery)...
    With Seasonal Pattern (applies only to the pattern of Major Depressive Episodes)...
    With Rapid Cycling...

Diagnostic criteria for 196.6x Bipolar I Disorder, Most Recent Episode Mixed

A. Currently (or most recently) in a Mixed Episode...
B. There has previously been at least one Major Depressive episode..., Manic Episode...,or Mixed Episode...
C. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.
Specify (for current or most recent episode):
    Severity/Psychotic/Remission Specifiers...
    With Catatonic Features...
    With Postpartum Onset...
Specify:
    Longitudinal Course Specifiers (With and Without Interepisode Recovery)...
    With Seasonal Pattern (applies only to the pattern of Major Depressive Episodes)...
    With Rapid Cycling...

Diagnostic criteria for 296.5x Bipolar I Disorder, most Recent Episode Depressed

A. Currently (or most recently) in a Major Depressive Episode...
B. There has previously been at least one Manic Episode...or Mixed Episode...
C. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.
Specify (for current or most recent episode)
    Severity/Psychotic/Remission Specifiers...
    Chronic...
    With Catatonic Features...
    With Melancholic Features...

With Atypical Features...
    With Postpartum Onset...
Specify:
    Longitudinal Course Specifiers (With and Without Interepisode Recovery)...
    With Seasonal Pattern (applies only to the pattern of major Depressive Episodes)...
    With Rapid Cycling...
Diagnostic criteria for 296.7 Bipolar I Disorder, most Recent Episode Unspecified
A. Criteria, except for duration, are currently (or most recently) met for a Manic..., a hypomanic..., or a Major Depressive Episode...
B. There has previously been at least one Manic Episode

DSM-IV-TR Criteria Bipolar II Disorder

A) Presence (or history) of one or more Major Depressive Episodes
B) Presence (or history) or at least one Hypomanic Episode
C) There has never been a Manic Episode or a Mixed Episode
D) The mood symptoms in Criteria A and B not better accounted for by Schizoaffective Disorder and is not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.
E) The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
Note: there are additional ways of coding for billing and diagnostic features such as severity and additional symptoms, but the fundamental diagnostic criteria for Bipolar remain the same.

Diagnostic criteria for 301.13 Cyclothymic Disorder
A) For at least 2 years, the presence of numerous periods with hypomanic symptoms and numerous periods with depressive symptoms that do not meet criteria for a Major Depressive Episode. Note: In children and adolescents, the duration must be at least 1 year.
B) During the above 2-year period (1 year in children and adolescents), the person has not been without the symptoms in Criterion A for more than 2 months at a time.
C) No Major Depressive Episode, Manic Episode, or Mixed Episode has been present during the first 2 years of the disturbance
Note: After the initial 2 years (1 year in children and adolescents) of Cyclothymic Disorder, there may be superimposed Manic or Mixed Episodes (in which case both Bipolar I disorder and Cyclothymic Disorder may be diagnosed) or Major Depressive Episodes (in which case both Bipolar II Disorder and Cyclothymic Disorder may be diagnosed)
D) The symptoms in Criterion are not better accounted for by Schizoaffective Disorder and is not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.
E) The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hyperthyroidism).
F) The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.