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## Identifying the Complexity of Bipolar Disorder: A Focused Ethnography

By

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# Dedication

I would like to dedicate this dissertation to my mom, who taught me from a very young age that I can do anything if I work hard. My mom would constantly tell me "the cream always rises to the top." She said this to me to keep me going despite all the obstacles that stood in my way. She is an amazing person, friend, mom, and nurse.

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In memory of my twins, Kathleen Elizabeth and Samuel James.

#### Abstract

Bipolar disorder is a complex illness that is difficult to correctly diagnosis and treat. Experts estimate that a correct diagnosis and treatment for bipolar disorder may be delayed for up to 7-10 years after symptoms become problematic. The primary purpose of this study was to identify the complexity of diagnosing bipolar disorder, including diagnostic patterns, recommended treatment, and patient response. A focused ethnography, including in-depth interviews and a retrospective chart review, were completed to answer the research questions: 1) What is the nature of the experience of receiving a diagnosis of bipolar disorder? 2) What are the diagnostic and treatment patterns for patients switched from depressive disorder to bipolar disorder during a psychiatric hospitalization? For the in-depth interviews, adults, 18-65 years of age and newly diagnosed with bipolar disorder during psychiatric hospitalization (n=10), were interviewed. Transcripts of audio recorded interviews were analyzed using thematic analysis. Two patterns and five themes were identified. The first pattern, Living with undiagnosed bipolar disorder included three themes: Distinguishing impulsive moods and behavior, Suffering life challenges, and Seeking relief. The second pattern, Receiving a new diagnosis of bipolar disorder, included two themes: Understanding the diagnosis and Reconciling the diagnosis. For the retrospective chart review, inclusion criteria were: adults age 18-65, diagnosis of major depression disorder upon admission and switched to bipolar disorder by discharge, and had complete data. The results showed that out of 3,092 patients admitted to the psychiatric hospital over a 1.5-year timeframe, 16.9% (525) had their diagnosis switched from major depression disorder to bipolar disorder. Out of 525 patients, only 5.2% (n=100) were screened for bipolar disorder on admission.

The interview data corroborated what was identified in the retrospective chart review, indicating that appropriate diagnosis and subsequent treatment opportunities are frequently missed in bipolar disorder. These findings offer clinicians and researchers a new way to think about the condition of bipolar disorder, including understanding barriers to proper diagnosis and using the diagnostic event to instigate meaningful life change.

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#### **CHAPTER I: Introduction**

#### Introduction

Chapter I contains specific detail regarding the problem, the problem statement, and the purpose. It includes a discussion of the background and significance of the misdiagnosis of bipolar disorder. This chapter concludes with the research questions. **Problem** 

Bipolar disorder is a progressive neurobiological brain disorder that affects 5.5 million individuals in the United States (National Alliance for Mental Illness, 2015). It is one of the leading causes of disability worldwide (Ratheesh et al., 2015). Also, it is estimated that the number of veterans diagnosed with bipolar disorder is almost double that of the general population (Ilgen et al., 2010). Bipolar disorder is often misdiagnosed as major depression disorder because patients experience depressive episodes much more frequently than manic episodes (Altamura et al., 2015; Cardoso de Almeida & Phillips, 2013). This is one of the major reasons that only 20% of patients with bipolar disorder receive the correct diagnosis within the first year of seeking treatment. In fact, it is estimated that the time it takes a patient to get a correct diagnosis of bipolar disorder and start on the correct treatment is five to ten years (Nasrallah, 2015).

Correctly diagnosing bipolar disorder is imperative because the treatment of major depression disorder (the disorder that is commonly diagnosed first) has completely different treatment protocols and can actually make bipolar symptoms worse. For example, the recommended treatment for major depression disorder are a classification of medications called antidepressants. In contrast, mood stabilizers and antipsychotic medications are the recommended treatment for bipolar disorder (APA, 2015). Therefore, a patient who has bipolar disorder and is treated with antidepressants is at an increased risk for poorer outcomes in social functioning, more annual hospitalizations, and more lifetime suicide attempts (Altamura et al., 2015; Baldessarini et al., 2013; Etain et al., 2012; Goldberg & Eernst, 2002; Goodwin & Jamison, 2007; Igor, Shwizer, & Stolovy, 2015; Offidani, Fava, Tomba, Ross, & Baldessarini, 2013; Oyffe, Schizer, & Stolovy, 2015). Without the correct treatment, as many as one in five patients with bipolar disorder complete suicide (Ilgen et al., 2010; Lemaire & Graham, 2011).

Bipolar disorder is a chronic, highly debilitating disorder that is the sixth leading worldwide cause of psychosocial disability, morbidity, and suicide (Altamura et al., 2015; Levy, Medina, Manove, & Weiss, 2011). In addition, patients with bipolar disorder have high rates of co-morbid conditions (obesity, heart disease, smoking, and sedentary lifestyle), which is one of the major reasons why patients with bipolar disorder have a seven to ten year reduction in expected life span as compared to patients without bipolar disorder (Homish, Marshall, Dubovsky, & Leonard, 2013; Jansen et al., 2011; Nock, Borges, Bromet, Chas, & Kessler, 2008).

One of the most common reasons for misdiagnosis of bipolar disorder is that patients do not report the manic symptoms (Oliveira, Esteves, & Carvalho, 2015). Patients with manic symptoms feel embarrassed and do not share this information with the health care provider (Michalak, Livingston, Maxwell, Hole, Hawke, & Parikh, 2014). People with more self-stigma about their diagnosis are less inclined to seek professional help, less likely to adhere to treatment when they do seek help, and more likely to experience a very poor alliance with health care providers (Michalak, et al.; Poole, Smith, & Simpson, 2015). Due to the social stigma and lack of education about bipolar disorder, patients lack the support and knowledge to get the treatment they need to help achieve mood stability.

Screening to rule out a bipolar disorder is imperative because of the complexity of the illness. If the patient does not present in a manic state, then screening instruments are very helpful to assess for any mania symptoms that the patient may be having and not reporting. Although several screening instruments exist, the two most commonly used are the Mood Disorder Questionnaire (MDQ) and the Hypomanic Checklist-32 (HCL-32); Feng et al., 2016). The MDQ (Appendix B) and HCL-32 (Appendix C) specifically screen for manic symptoms, family history, and level of impaired functioning. As many as eight out of ten times, routine screening for bipolar disorder is not a standard practice in the office setting. Therefore, the patient's mania symptoms may go unnoticed (Feng et al., 2016; Ghaemi, Ko, & Goodwin, 2002; Solomon et al., 2006). Patients were more likely to be screened for bipolar disorder in a psychiatrist's office rather than in a primary care visit (Cerimele, Chwastiak, Dodson, & Katon, 2014).

Veterans with bipolar disorder are at a higher risk of suicide when compared to the general population because they are more likely to have a comorbid mental illness, such as posttraumatic stress disorder (Ilgen et al., 2010). In male veterans, the risk of suicide was the highest for those with a diagnosis of bipolar disorder. In female veterans, the risk of suicide was the highest with those diagnosed with substance induced disorders, followed closely by bipolar disorder (Ilgen et al., 2010). Decreasing thoughts of suicide is imperative in veterans because they may own firearms, which is the most common way of attempting suicide in veterans (Byran, Ray-Sannerud, Morrow, & Etienne, 2013; Kirsch, 2014; McCarten, Hoffmire, & Bossarte, 2015). If mandatory screening for bipolar disorder was implemented, it might help drastically reduce the number of suicide attempts and completed suicides, not only in the veteran population but in the general population as well.

#### **Problem Statement**

Since many symptoms of psychiatric disorders overlap, some patients may not be very accepting of a bipolar disorder diagnosis, believing their symptoms point to a different psychiatric disorder (Poole, Smith, Simpson, 2013). Patients with bipolar disorder do feel more stigmatized than people with other forms of mental illness (Bassirnia et al., 2015; Uhlmann et al., 2014). Questions remain regarding how accepting patients are of the bipolar disorder diagnosis, the manner in which the bipolar disorder diagnosis is made, and how having a diagnosis of bipolar disorder affects their lifestyle and feelings of self-worth.

Several major factors have been recognized as contributing to the misdiagnosis of bipolar disorder. Patients not reporting mania symptoms is one of the largest barriers to making a correct diagnosis (Hirschfeld, Lewis, & Vornik, 2003). Manic symptoms affect each patient differently and therefore each patient has various reasons why they do not report their mania symptoms. For example, patients may feel embarrassed due to the social stigma surrounding bipolar disorder (Owen, Gooding, Dempsey, & Jones, 2015). From a patient's perspective, hypomania, a less extreme form of mania, can be enjoyable and productive in the beginning of the episode, so these patients purposely will not report their hypomanic/manic symptoms in fear of having less energy when their mood stabilizes (Lim, Nathan, O'Brien-Malone, & Williams, 2004). There is a paucity of research about (a) why patients who have not yet been diagnosed with bipolar disorder will not report their mania symptoms, and (b) if their primary health care providers accurately screened for the mania symptoms.

Veterans with bipolar disorder are at an increased risk of poor patient outcomes and are at in increased risk for suicide than in the general population (Sharp et al., 2015). Approximately 60% of veterans who have been diagnosed with mental illnesses, such as bipolar disorder, do not seek professional help. One of the most frequently reported barriers to seeking professional help is concerns about stigma (Sharp et al., 2015). Reducing stigma in veterans may be more difficult than the general population because military organizations have fostered certain stigmatizing beliefs in relation to helpseeking for mental health problems. These beliefs may be related to military culture, rules, and conduct learned and experienced in the service (Sharp et al., 2015; Greene-Shortridge, Britt, & Castro, 2007). Therefore, understanding more about the accentuated needs of this subset of patients with bipolar disorder could lead to understandings about the disorder in the general population. Conversely, understanding the needs of the general population could lead to identifying gaps in knowledge specific to veterans.

Medication compliance is also a concern for patients with bipolar disorder. They have a low rate of medication compliance because of a belief that they do not need the medication, and because of the fact that mood stabilizers and antipsychotic medications can have uncomfortable side effects (Thase, 2012). However, more research is needed to examine, from a patient's perspective, specific concerns about prescribed medication and compliance. In addition, research is needed in the area of how having a diagnosis of bipolar can impact a patient's daily living and self-worth.

Dual diagnosis is a term that is used when a patient has bipolar disorder and a cooccurring substance use disorder. Patients who suffer from a substance abuse disorder are five to six times more likely to have a history of bipolar disorder than the general population (Balanza-Martinez, Crespo-Facooro, Gonzalez-Pinto, & Vieta, 2015). Strong evidence in the literature indicates that 60% of patients with alcoholism also have bipolar disorder. In fact, Nery, Miranda-Scippa, Nery-Fernandes, Kapczinski, and Lafer (2014) discovered that patients that had both bipolar disorder and alcohol use disorder began their mood disorder at an earlier age and had more suicidal behaviors than patients with bipolar disorder without the alcohol use disorder. When a patient is under the influence of a substance at the time of diagnosis, it makes getting a correct diagnosis even more difficult because it is unknown whether the behavioral symptoms are the result of a substance or an underlying bipolar disorder (Østergaard, Bertelsen, Nielsen, Mors, & Petrides, 2013).

According to the American Psychiatric Association Practice Guidelines (2015), the standard of treatment for bipolar disorder is a mood stabilizer and/or an antipsychotic medication (APA, 2015). During an inpatient hospitalization, when a patient screens positive for bipolar disorder and the correct diagnosis of bipolar is made, the patient then should be started on a mood stabilizer and/or antipsychotic medication. In cases of acute mania, the recommendation is to start the patient on both types of medication to help achieve mood stability more quickly. Despite these recommendations, literature is scarce on how often these guidelines are put into practice.

In summary, bipolar disorder is a complex illness that is difficult to correctly diagnosis and treat. With bipolar disorder being highly stigmatized, patients often do not

report their manic symptoms, which contributes to the misdiagnosis. Increased screening for the mania symptoms of bipolar disorder can help the health care provider identify the disorder and prescribe the appropriate diagnosis. Medication compliance is a concern because patients may not feel like they need the medication. Patients will stop taking the medication due to uncomfortable side effects. The high incidence of co-occurring substance use in patients with bipolar disorder adds to the complexity of the illness. Due to the increasing number of patients that have been misdiagnosed, there is reason to believe there is a breakdown in the process. Further research is needed that examines diagnosis and treatment patterns.

#### Purpose

The overall aim of the study is to identify the complexity of diagnosing bipolar disorder, including diagnostic patterns, recommended treatment, and patient response. The purpose of the focused ethnography is to provide a description of experiences of patients who have been newly diagnosed with bipolar disorder at 4-6 weeks after discharge, using a semi-structured interview. A subset of veterans will be interviewed to identify any veteran-specific experiences in relation to being newly diagnosed with bipolar disorder. The purpose of the retrospective chart review is to determine the percentage of patients in the database who are diagnosed with major depression disorder and then correctly diagnosed with bipolar disorder, clinical characteristics of the patients who are misdiagnosed, and the screening, diagnosis, and treatment patterns for bipolar disorder.

#### Rationale

The proposed research study will use a multi-method approach, which will include a focused ethnography and a retrospective chart review. A multi-method approach was chosen to increase the completeness of the findings and add depth to the understanding of the complex issue of the misdiagnosis of bipolar disorder. Authors, such as Seaton (2005), recommend combining methodologies to enrich findings especially when questions are complex. A focused ethnography provides information within a subculture of a culture to provide insight on a specific topic or shared experience (Morse & Richards, 2013). This research study was funded by the Jonas Veteran Healthcare Foundation and include a subset of veterans. Veterans will be studied to identify any differences within the culture of patients with bipolar disorder to determine if the healthcare needs of veterans are similar to the general population. The focused ethnography approach, includes in-depth semi-structured interviews to gain understanding from a patient's perspective. A retrospective chart review will analyze existing inpatient hospital records to extract data of adult patients that had a diagnosis of major depression disorder upon admission and were switched to a bipolar disorder diagnosis by discharge in a psychiatric hospital in St. Charles, Missouri.

#### Background

Bipolar disorder is a lifelong mood disorder characterized by episodes of mania, with alternating episodes of depression (Drago, Crisafulli, Calabro, & Serretti, 2015; Gutierrez-Rojas, Jurado, Martinez-Ortega, & Gurpegui, 2010; Igor, Shwizer, & Stolovy, 2015). The Diagnostic and Statistical Manual of Mental Disorders [DSM-5] defines mania as a distinct period which a patient has an abnormally and persistently elevated, expansive, or irritable mood. The episode must last at least a week and have three out of the seven following symptoms: inflated self-esteem, little need for sleep, pressure of speech, flight of ideas, easily distracted, psychomotor agitation, and excess pursuit of pleasure with a high risk of danger (American Psychiatric Association [APA], 2013). Patients with bipolar disorder do not stay in the manic phase all the time, but can switch to a deep depression phase that can very easily lead to suicide (Isometsa, Sund, & Pirkola, 2014). The DSM-5 defines the depression episodes with bipolar disorder as having as least four of the following symptoms: changes in appetite or weight, sleep, or psychomotor activity; decreased energy; feelings of worthlessness or guilt; trouble thinking, concentrating, or making decisions; and thoughts of death or suicidal plans or attempts (APA, 2013).

Bipolar disorder can be very difficult to stabilize and manage due to characteristics related to the patient, such as lack of insight of the illness, therapeutic noncompliance, self-medication using nonprescribed psychoactive substances, inadequate family support, poor social support, and distrust of medical, pharmacological, and nonpharmacological therapy. When hospitalization is required, the main treatment goal is mood stability. The APA (2015) has standard practice guidelines for the treatment of bipolar disorder. Treatment recommendations include starting the patient on a mood stabilizer and if needed, for preventing and treating acute mania symptoms, also an antipsychotic medication. Clinical data has shown that starting a mood stabilizer helps the mood become more even, while the antipsychotic medication helps treat and prevent manic episodes (Rybakowski, 2013).

### Significance

Bipolar disorder is one of the leading causes of disability in the United States. This results in a significant loss of quality of life as well as an increase of suicidal behavior. The loss of productivity is an added burden to society. Due to the comorbid mental health disorders, veterans are at an increased risk of poor outcomes, including a higher risk of suicide than the general population. The misdiagnosis of bipolar disorder prevents proper treatment that could reduce the incidence and severity of these outcomes. It is important to understand influencing factors and phenomena that surround the diagnosis of this intricate disorder. The high suicide rates particularly in veterans can no longer be ignored. This study will add valuable insight into the complexity of diagnosing bipolar disorder that will help improve screening, diagnosis, and treatment.

#### **Research Questions**

RQ1: What is the nature of the experience of receiving a diagnosis of bipolar disorder? RQ2: What are the shared experiences of a subset of veterans within the population? RQ3: Out of a total of patients from age 18-65 admitted to the psychiatric hospital between 01/01/2015-08/ 31/2016 what percentage of patients were admitted with a diagnosis of major depression disorder and then bipolar disorder, suggesting a misdiagnosis?

RQ3a: Out of the total of patients that were switched from major depression disorder to bipolar disorder, what percentage of patients were screened for bipolar disorder? **Out of the total number of patients who were misdiagnosed with bipolar disorder** 

#### and screened for bipolar disorder:

#### **Prior to admission to a psychiatric hospital:**

RQ4: What were the clinical characteristics of the patients who were misdiagnosed and screened?

RQ4a: What percentage of patients that were misdiagnosed and screened for bipolar disorder had prior suicide attempts? If yes, how many?

#### Upon admission to a psychiatric hospital:

RQ4b: What percentage of patients had a positive urine drug screen to identify if the patient was under the influence of a substance at the time of the admission?

#### **During inpatient hospitalization:**

RQ5: What were the screening, diagnosis, and treatment patterns for patients with bipolar disorder that were misdiagnosed with major depression disorder?

RQ5a: Screened positive for bipolar disorder, diagnosed with bipolar disorder, and switched from and an antidepressant to a mood stabilizer (lithium, carbamazepine, lamotrigine, or valproate) and/or antipsychotic (quetiapine, lurasidone, or aripiprazole)? RQ5b: Screened positive for bipolar disorder, diagnosed with bipolar disorder, and kept on the same or different antidepressant medication?

RQ5c: (Pre-hospital diagnosis of major depression disorder and previously prescribed mood stabilizers) Screened positive for bipolar disorder, diagnosed with bipolar disorder, and were kept on the same mood stabilizer previously prescribed?

RQ5d: Screened negative for bipolar disorder, diagnosed with bipolar disorder, and switched from an antidepressant to a mood stabilizer (lithium, carbamazepine,

lamotrigine, or valproate) and/or antipsychotic (quetiapine, lurasidone, or aripiprazole)?

RQ5e: Screened negative for bipolar disorder, diagnosed with bipolar disorder, and kept on the same or different antidepressant medication?

RQ5f: (Pre-hospital diagnosis of major depression disorder and previously prescribed mood stabilizers) Screened negative for bipolar disorder, were diagnosed with bipolar disorder, and kept on the same mood stabilizer previously prescribed?

RQ6: What day of inpatient hospitalization were patients switched from an antidepressant to a mood stabilizer and/or an antipsychotic?

RQ7: What differences are there regarding RQ4-6 when comparing veterans to nonveterans?

#### **CHAPTER II: Literature Review**

#### Introduction

In this chapter, the theoretical definitions, the review of literature, and the theoretical framework for the current study are presented. The literature review is discussed along with a summary of the literature as it relates to the misdiagnosis of bipolar disorder and the social stigma of patients with bipolar disorder.

#### **Theoretical Definitions**

#### **Bipolar Disorder**

Bipolar disorder is mood disorder that is characterized by the occurrence of at least one manic episode during a patient's lifetime (Oxford English Dictionary, 2010).

#### **Misdiagnosis of Bipolar Disorder**

To make an incorrect diagnosis of the illness from which someone is suffering (Oxford English Dictionary, 2010).

#### Social Stigma of Bipolar Disorder

Social stigma is the disapproval of, or discontent with, a person on the grounds of characteristics that distinguish them from other members of society. Stigma can be attached to a person who differs from social or cultural norms. One form of social stigma is the imposition of having mental illness (Goffman, 1963).

#### Self-Stigma

Self-stigma is the perception held by the individual that he or she is socially unacceptable, which can lead to a reduction in self-worth if the person seeks psychological help (Vogel, Wade, & Haake, 2006).

## Self-Worth

Self-worth is the sense of one's own value or worth as a person (Oxford English Dictionary, 2010).

#### **Suicidal Ideations**

Suicidal ideations are part of a suicidal continuum ranging from thoughts of death, passive or active ideations with planning the suicide attempts, to suicide completion (Pfeffer, 2002).

# Suicidal Attempt

A suicide attempt is a non-fatal self-directed potentially injurious behavior (may or may not result in injury) with any intent to die as a result of the behavior (Beck, Kovacs, & Weissman, 1979).

#### **Substance Use Disorders**

Substance use disorders are defined as mild, moderate, or severe to indicate the level of severity, which is determined by the number of diagnostic criteria met by an individual (APA, 2013). Substance use disorders occur when the recurrent use of alcohol and/or drugs causes clinically and functionally significant impairment, such as health problems, disability, and failure to meet major responsibilities at work, school, or home. In addition, a diagnosis of substance use disorder is based on evidence of impaired control, social impairment, risky use, and pharmacological criteria (APA, 2013).

#### **Review of Literature on Bipolar Disorder**

#### Introduction

Having bipolar disorder is a struggle for the patient; it also profoundly affects family members, and health care providers. Bipolar disorder is a complex illness that can have a very high mortality rate if not treated appropriately. It is generally accepted that mental illness, as compared to physical illness, has a greater social stigma. Bipolar disorder is recognized as the most stigmatized of the already stigmatized mental illnesses (Bassirnia et al., 2015). Patients often will disagree with the diagnosis, become very defensive about being labeled as having bipolar disorder, and feel worthless and more "crazy" than if they were diagnosed with less stigmatized mental illnesses, such as major depression disorder and general anxiety disorder. This chapter will summarize the current state of the literature on bipolar disorder, the screening and instruments for bipolar disorder, the contributing factors to the misdiagnosis of bipolar disorder, the consequences of misdiagnosing bipolar disorder, the practice guidelines for medication management, and the theoretical framework used to guide the study.

This review of literature was completed using both health-related and educational databases. Databases were searched for pertinent research studies as well as current health information. The key words used in these searches included bipolar disorder, mood disorder, misdiagnosis, misdiagnosis of bipolar disorder, mood stabilizers, mania, social stigma and mental illness, social stigma and bipolar disorder, suicide, and suicide and bipolar disorder. The databases searched included Psych Info, ERIC, CINAHL, Medline, Google Scholar, and PubMed. All articles were in English. To identify appropriate articles, abstracts were read to determine the degree of relevance to the topic. Pertinent

articles were then used to identify both seminal and additional works. Approximately 60% of the articles found were research articles and the remaining 40% of articles consisted of expert opinion. Of all the research articles, only five articles were qualitative. It is apparent through this comprehensive literature search that research is lacking in specific areas such as bipolar disorder treatment, misdiagnosis of bipolar disorder, and the social and self-stigma of the disorder.

#### **Types of Bipolar Disorder**

Providers diagnose bipolar disorder using guidelines from set criteria of the DSM-5. To be diagnosed with bipolar disorder, patients must present with symptoms that are a major change from their normal mood or behavior. The DSM has classified bipolar disorder in four different categories: bipolar I disorder, bipolar II disorder, bipolar disorder not otherwise specified, and cyclothymic disorder. Bipolar I disorder is defined by a patient having manic or mixed episodes (mania and depression) that last at least 7 days (APA, 2013). Bipolar II disorder is defined by a pattern of depressive episodes and hypomanic episodes, but no full-blown manic or mixed episodes. Hypomanic episodes are episodes in which the patient will have a persistently elevated, expansive, or irritable mood. The episode lasts at least 4 or more days and must meet at least three of the manic symptom criteria (APA, 2013). The next type of bipolar disorder is bipolar disorder not otherwise specified. This diagnosis is given to a patient when the symptoms of illness exist, they do not meet diagnostic criteria for either bipolar I or II, and they are clearly out of the person's normal range of behavior (APA, 2013). Lastly, cyclothymic disorder is a mild form of bipolar disorder and is diagnosed when a patient has episodes of hypomania as well as mild depression for at least 2 years. To be diagnosed with

cyclothymic disorder, a patient's symptoms must not meet the diagnostic requirements for any other bipolar disorder (APA, 2013). For the purpose of this study, bipolar disorder will refer to bipolar type I, unless otherwise stated.

#### **Bipolar Disorder**

Bipolar disorder is a mood disorder that includes at least one manic episode. Although the term bipolar disorder was adopted by the psychiatric community for only 30 years, bipolar disorder symptoms have been recognized for over a century (Angst & Sellaro, 2000). The categorization of bipolar disorder as an illness was first conducted by psychiatrist Jean-Pierre Falret in 1851. He called the illness "folie circulaire," which means circular madness due to the illness's manic and depression episodes separated by symptom-free intervals (Angst & Sellaro, 2000; Pichot, 1995). In 1854, psychiatrist Jules Baillarger used the term manic-melancholic illness. Both psychiatrists, along with the psychiatric community at that time, considered this illness to be "desperate, terrible, and incurable" (Angst & Sellaro, 2000; Pichot, 1995). At the turn of the 19th century, the psychiatric community sought to unify the approach to classifying mood disorders. This resulted in the manic-melancholic illness being renamed manic-depressive insanity, which included single episodes of mania and depression and recurrent depression (Angst & Sellaro, 2000). Manic-depression insanity remained the name of the illness until 1980 when the name was changed to bipolar disorder.

Although the name of the condition has changed over time, the symptoms have remained the same. Patients diagnosed with bipolar disorder experience recurrent extreme emotional states that occur in separate periods defined as mood episodes (Angst & Sellaro, 2000). The drastic mood changes are very different from a person's usual attitude and behavior. Mania is defined as an overly joyful or overexcited state. The cluster of symptoms that a patient in mania might exhibit are increased restlessness, insomnia, extreme anger, hypersexuality, irritability, lack of impulse control, lack of concentration, racing thoughts, and reckless behavior (APA, 2013). Many times patients will enjoy being in a manic state because of the increased energy that it gives them. Although, the biological mechanism by which mania occurs is not known, there are theories that suggest over activity of the dopamine receptor, protein kinase, and inositol monophosphatase in the brain (Li, Liu, Wang, & Li, 2010; Yildiz, Guleryuz, Ankerst, Ongur, & Renshaw, 2008). The human mind does not stay in the manic state for longer than two weeks, and that is usually when the depressive episode will start (APA, 2013). The depression episodes are characterized by an overly long period of feeling sad or hopeless; loss of interest in activities once enjoyed; feelings of tiredness; a lack of concentration, remembering, and decision-making; an increase or decrease in eating and sleeping habits; and suicidal ideations or attempts (APA, 2013).

All patients differ in frequency of how often they go into manic or depressive episodes. Rapid cycling is a term used for patients who have four or more episodes of depression or mania lasting at least 2 weeks' duration in a 12-month period (APA, 2013). Patients who were first diagnosed with bipolar at a younger age have a greater incidence of having rapid cycling. Also, rapid cycling affects women more than men (APA, 2013; El-Mallakh et al., 2015; Kupka et al., 2005; Valenti et al., 2015). When comparing patients who have rapid cycling bipolar disorder and patients who have non-rapid cycling bipolar disorder, patients who had rapid cycling experienced more manic episodes, had a higher incidence of childhood physical and/or sexual abuse, and were more likely to have a history of drug use (El-Mallakh et al., 2015; Kupka et al; Valenti et al., 2015).

Veterans with bipolar disorder are almost always diagnosed with another mental illness, most often PTSD (Quarantini et al., 2010). Having co-occurring mental health diagnoses can worsen the symptoms of bipolar disorder and can trigger manic episodes, as well as periods of depression (Quarantini et al; Orsillo et al., 1996). For example, if the veteran was in combat, wartime flashbacks can act as a trigger and place the patient in mania (Orsillo et al., 1996). Patients with PTSD and bipolar disorder have more mood instability than patients with only bipolar disorder (Quarantini et al). This is important because it puts this population at an even greater risk for suicide, mandating that health care providers must be even more vigilant at correctly diagnosing and treating these patients.

Bipolar disorder is a very debilitating illness with a significant morbidity and mortality risk due to suicide. Although the reason why suicidality is high in patients with bipolar remains unknown, available research suggests it is the impulsivity behavior that patients have when in the manic state (Bauer, Meyer, Sanches, Zunta-Soares, & Soares, 2015). The risk of suicide attempts is 3.9% annually with a corresponding rate of completed suicide at 1% annually (Baldessarini, Pompili, & Tondo, 2006; Benedetti et al., 2011; Coryell et al. 2016; Goodman, Roiff, Oakes, & Paris, 2012). Although, having a mental illness does increase the risk for suicide, specifically having bipolar disorder puts a patient at the most risk for suicide (Tondo, Lepri, & Baldessarini, 2007; Goodman et al.). The exact reason for this remains unclear, however, some researchers postulate that the increase risk for suicide is due to the rapid changes in mood states at the beginning and toward the end of a depressive episode (Jamison, 2001).

Bipolar is highly heritable and multiple research studies have found that the heritability rates are between 60-79% (Antypa & Serretti, 2014; Smoller & Finn, 2003). More research is being done to examine how much a family history affects the severity of bipolar disorder. For example, Antypa and Serretti (2014) found that patients with bipolar disorder who reported a family history of bipolar disorder had an earlier age of onset of a manic or a depressive episode, a higher number of manic or depressive phases, a higher occurrence of rapid cycling, and more suicide attempts. In addition, Goldstein et al. (2012) found that a family history of depression or bipolar disorder with a high severity of depressive episodes was the most compelling predictors of prospective suicide attempts in young patients with bipolar disorder. In addition, patients with bipolar disorder have a high incidence of comorbid substance use disorders as well, with a lifetime prevalence as high as 50% to 60%. In fact, substance use disorder comorbidity is associated with worse bipolar disorder outcomes and a higher suicide risk (Balanza-Martinez, Crespo-Facorro, Gonzalez-Pinto, & Vieta, 2015; Wilens, Yule, Martelon, Zulauf, & Faraone, 2014). Of all the substances, alcohol is the most prevalent among patients with bipolar disorder, and it is estimated that up to 60% of patients with bipolar disorder will develop an alcohol use disorder at some point in their lives (Balanza et al.; Nery et al., 2013).

#### **Screening Instruments for Bipolar Disorder**

Mandatory screening for bipolar disorder is not included in standard practice, despite the fact that screening has been shown to help identify manic symptoms and

distinguish major depression disorder from bipolar disorder (Feng et al., 2016). For example in the veteran population, health care providers are mandated to screen for symptoms of post-traumatic stress disorder (PTSD) and major depression disorder (McCarten, Hoffmire & Bossarte, 2015). This new mandated screening protocol was put into place to address the increase of suicide attempts and completed suicides (Dobscha et al., 2013). In addition, the Department of Veterans Affairs mandated assessment for possible suicidal ideations among veterans who have positive depression or PTSD screens as a national performance goal (Dobscha et al., 2013; McCarten, Hoffmire & Bossarte, 2015). Despite these efforts, the rate of suicide attempts and completed suicides has only increased. Kang et al. (2015) found that in the veteran population, the suicide risk was 41% higher than in the general population. The use of clinical predictors and screening instruments can improve the recognition of bipolar disorder (Cerimele et al., 2014). When screening for bipolar disorder, the most widely used screening instruments are the Mood Disorder Questionnaire (MDQ; Appendix B) and the Hypomania Checklist-32 (HCL-32; Appendix C) (Abhari et al., 2013; Meyer et al., 2011; Poon, Chung, Tso, Chang, & Tang, 2012).

#### Mood Disorder Questionnaire (MDQ)

The MDQ is a self-report, single page measure used to determine lifetime history of mania or hypomania. It consists of 13 yes/no symptom questions based on the DSM-IV criteria for bipolar disorder and includes three sections of symptom endorsement, symptom clustering, and level of functional impairment. The symptom questions are followed by a single yes/no question about whether symptoms clustered during the same period of time. The final question evaluates the level of impairment resulting from the symptoms and provides a rating on a 4-point scale: no problem, minor problem, moderate problem, or serious problem (Clark et al., 2015; Waleeprakhon et al., 2014). In clinical settings, the MDQ has shown strong sensitivity and specificity (73% and 90%, respectively), and it has been translated into multiple languages and validated in multiple countries (Waleeprakhon et al., 2014).

#### Hypomania Checklist-32 (HCL-32)

The HCL-32 is a self-report, single page measure used to determine hypomanic symptoms. The instrument has 32 yes/no questions and is one of the most widely used scales because it is particularly sensitive in detecting hypomania (He et al., 2014). The HCL-32 was developed as a sensitive instrument to detect if patients had a previous history of hypomanic symptoms in clinical and nonclinical settings. The standard cut-off score is 14, and it has a sensitivity of 0.80 and a specificity of 0.51 (Miller, Klugman, Berv, Rosenquist, & Ghaemi, 2004; Poon et al., 2012). It proved to be a reliable instrument with acceptable psychometric properties and transcultural stability in many languages, including Spanish (Bech, Christensen, Vinberg, Beck-Anderson, & Kessing, 2011; Hidalgo-Mazzei et al., 2015). In addition, a shortened version of 16 items based on the HCL-32 scale has been recently developed and has shown similar psychometric properties (Bech et al., 2011).

#### **Contributing Factors of the Misdiagnosis of Bipolar Disorder**

#### **Social Stigma**

The most often cited reason for why people do not seek mental health treatment is the self-stigma associated with bipolar disorder (Corrigan, 2004; Vogel et al., 2006). While the general public endorses stigmatizing attitudes towards patients with bipolar

disorder, few studies have focused exclusively on why patients with bipolar disorder feel so stigmatized or examined stigma experiences of people diagnosed with it (Bonnington & Rose, 2014). Psychiatric evaluations are completed to obtain the most accurate history and assess the current symptoms that the patient is presenting. In fear of getting diagnosed with bipolar disorder, patients may make a conscience decision not to report their symptoms of hypomania or mania (Bassirnia et al., 2015; Cerit et al., 2012; Ellison, Mason, & Scior, 2013; Griffiths, Carron-Arthur, Parsons, & Reid, 2014; Hawke, Parikh, & Michalak, 2013; Vazquez et al., 2011). In addition, when patients with bipolar disorder feel socially stigmatized, they are more prone to deny their symptoms and have a low adherence to their treatment (Bassirnia et al., 2015; Uhlmann et al., 2014). A diagnosis of depression is generally more tolerable for patients than bipolar disorder (Bonnington & Rose, 2014). Providers may be reluctant to diagnose bipolar disorder unless there is absolute certainty due to the high stigma surrounding this disorder (Bonnington & Rose, 2014; Griffiths et al.; Nasrallah, 2015). The high level of stigma of bipolar disorder has been shown to have negative associations on self-esteem, social adjustment, perceived social support and lead to functional impairment (Ellison et al., 2013; Hawke et al., 2013).

#### Self-Stigma

Living in a culture steeped in stigmatizing images, patients with bipolar disorder may accept these notions and suffer diminished self-esteem, self-efficacy, and confidence in one's self. When this happens, a patient will develop self-stigma. When the negative views expressed by society toward patients with bipolar disorder is internalized, then self-stigma develops (Corrigan, 2004; Thomé et al., 2012). This leads to patients perceiving themselves as inferior, inadequate, or weak. As a result, patients higher in self-stigma may decide to forego mental health treatment to maintain a positive image of themselves (Corrigan, 2004; Vogel et al., 2006). Self-stigma can also affect social support because research has shown that patients with bipolar disorder are less likely to ask for help from nonprofessional sources, such as friends or family, due to embarrassment (Vogel et al., 2006).

#### Stigma in the Military

Many of the same stigma barriers exist in the veteran population as they do in the general population, however, veterans and active duty service members may experience somewhat unique barriers. For example, the culture of the military has a long history of having strict rules and conduct expected of their service men (Kulesza, Pedersen, Corrigan, & Marshall, 2015). There are many reasons why veterans do not routinely seek mental health treatment from professionals including, the value placed on the actions of the group to achieve military objectives above all else, the cultures of dependence upon each other, masculinity, self-sufficiency, and the stigmas of going sick (Kulesza, Pedersen, Corrigan, & Marshall, 2015; Sharp et al., 2015).

#### Difficulty Differentiating Bipolar Disorder from Other Mental Illnesses

Bipolar disorder can be misdiagnosed as several different psychiatric disorders, including attention-deficit hyperactivity disorder, general anxiety disorder, and schizophrenia. However, major depression disorder is the most common misdiagnosis (Nasrallah, 2015). One of the major reasons for this is that providers do not assess for mania symptoms. The depressive symptoms of bipolar disorder are very similar to the diagnosis of major depression disorder. Lish et al. (1994) conducted a survey of patients with bipolar disorder and discovered that 73% of the patients in the study had initially

been misdiagnosed with major depression disorder and to be correctly diagnosed had to wait as long as 10 years. In 2000, the survey was reproduced and yet still 69% of patients reported being misdiagnosed with major depression disorder before bipolar disorder was correctly diagnosed (Hirschfeld et al., 2003).

Currently, there are no available lab tests that can diagnose mental illnesses. This means that mental health providers rely on patients' giving the symptomatology of their illness so the correct diagnosis can be made. However, patients may provide a poor history, particularly during acute mood episodes. For example, many times patients with depression will state that they "always" feel depressed or that they cannot recall ever feeling better (Nasrallah, 2015). This will lead the provider to start thinking about a major depression disorder diagnosis and not assess further symptoms, such as mania (Nasrallah, 2015; Perlis, 2005). Diagnosing bipolar disorder is very complex to diagnose because more than 50% of patients experience at least one comorbid mental illness, such as anxiety disorder (Simon et al., 2004; Nasrallah, 2015). Moreover, making a differential diagnosis can be very difficult because many symptoms for different psychiatric disorders overlap (Nasrallah, 2015). For example, some of the features of anxiety and depression or hypomania/mania, such as impaired concentration and sleep disruption, can be associated with all three disorders (Perlis, 2005).

Patients with bipolar disorder can have severe manic episodes, in which they experience psychotic symptoms, such as hallucinations or delusions. When a patient has psychotic symptoms during a manic episode, it makes getting a correct diagnosis even more difficult (Altamura et al., 2015). For example, schizophrenia and substance use disorders can both have psychotic symptoms. The health care provider needs a detailed history and proper screening on these patients to accurately distinguish between bipolar disorder and other mental illnesses. This subgroup of patients with bipolar disorder who have psychotic symptoms tend to have a worse prognosis than patients with bipolar disorder without a history of hallucinations or delusions (Østergaard et al., 2013).

Since multiple mental illnesses have overlapping symptoms, a thorough psychiatric assessment needs to be completed in order to make a correct diagnosis. However, patients are more likely to present to a primary care provider first before going to a mental health provider. This is in part due to the fact that patients with bipolar disorder also have high rates of anxiety and substance use disorders that often lead to seeking medical treatment for somatic symptoms (Merikangas et al., 2007). Furthermore, few patients with bipolar disorder receive consistent care from mental health providers, making it even more likely that patients experiencing recurring depressive symptoms will present to primary care (Abed Faghri, Boisvert, & Faghi, 2010; Cerimele et al., 2014). With this in mind, much effort was given by mental health providers to investigate if screening assessments and/or instruments were being used in primary care settings to try to obtain an earlier correct diagnosis (Abed Faghri et al.; Cerimele et al.). The results of this effort indicated that primary care providers have not agreed on a standard method for assessing or documenting a patient's psychiatric symptoms or complaints, so there is a wide range of how bipolar disorder is screened for and diagnosed (Abed et al; Cerimele et al.).

The comorbidity of PTSD and bipolar disorder in veterans has important implications both for the classification of PTSD and for the diagnosis and treatment of bipolar disorder. To add to the complexity of diagnosing bipolar disorder, warzones can easily cause adrenaline surges, periods of depression, and sometimes extreme impulsivity, all of which can mimic the course of bipolar disorder (Hernandez et al., 2013; Rakofsky, Ressler, & Dunlop, 2012). The presence of multiple mental health diagnoses makes getting a correct diagnosis even more difficult and requires health care providers to make complex decisions regarding differential diagnosis (Rakofsky et al.). In addition, the comorbidity complicates the course the course of treatment, necessitating additional interventions for a complex, hierarchical approach to selecting target symptoms for change (Hernandez et al., 2013). This means that since the patients have multiple symptomatologies from several diagnoses, finding the correct treatment can be difficult.

### **Consequences of Misdiagnosing Bipolar Disorder**

#### **Suicidal Behavior**

With suicidal behavior strongly linked to bipolar disorder, many research efforts have focused on understanding the factors that increase suicide risk in an effort to curb the excessive mortality rates for bipolar disorder. Those research studies have shown that a delayed diagnosis or misdiagnosis is one major contributor to death by suicide in patients who have bipolar disorder (Ahearn et al., 2013; Goodwin & Jamison, 2007). For example, Shi, Thiebaud, and McCombs (2004) provided evidence that the risk of suicide attempts in people with undiagnosed bipolar disorder was significantly higher than it was in people with diagnosed bipolar disorder who were receiving treatment. One of the main causes, many researchers postulate is that patients are more likely to be prescribed antidepressants than mood stabilizing agents when bipolar disorder is misdiagnosed, and that can significantly increase the risk for suicide (Birnbaum et al., 2003; Matza, Rajagopalan, Thompson, & de Lissovoy, 2005; Meyer & Meyer, 2009; Meyer et al., 2011; Tondo, Vazquez, & Baldessarini, 2010).

# **Social and Cognitive Impairments**

Untreated bipolar disorder has long been associated with cognitive impairments, even in a normal mood state. Severe manic episodes and frequent psychiatric hospitalizations have been associated with high work, social, and family life impairments (Gutierrez-Rojas, Jurado, & Gurpegui, 2011). The major sources of social and cognitive impairments are due to psychotic features, subclinical depression, sustained neurocognitive deficits, comorbidities, medication side effects, low premorbid functioning, and weak social support (Balanza-Martinez et al., 2015). A meta-analysis of cognitive functioning in bipolar disorder suggests that most domains of cognition exhibit some impairment, but that the largest deficits tend to be found in executive control and verbal learning and memory (Bourne et al., 2013, 2015). When a patient's moods are not stabilized, the severity of cognitive impairment worsens. Specifically, attention, mental flexibility, decision-making, verbal fluency, and memory (Buoli, Caldirolo, Caletti, Zugno, & Altamura, 2014). Although discovering more efficient treatments to reduce cognitive impairments would be beneficial for patients with bipolar disorder, cognitive impairments will not be examined in the current study.

# Practice Guidelines for Medication Management of Bipolar Disorder

Bipolar disorder does not have a cure, however, appropriate medications can drastically decrease the associated morbidity and mortality. According to the American Psychiatric Association (APA, 2015) practice guidelines, the first-line pharmacological treatment for mania or manic and depressive episodes is the initiation of either lithium plus an atypical antipsychotic or valproate plus an antipsychotic (APA, 2015).

#### **Mood Stabilizers**

For the treatment of bipolar disorder, drugs, collectively known as mood stabilizers, are the first line treatment. A mood stabilizer can be defined as a drug that (a) acts therapeutically in mania and/or in depression, (b) acts prophylactically against manic and/or depressive episodes, and (c) does not worsen any therapeutic or prophylactically aspect of the illness outlined above (Rybakowski, 2013). Lithium, valproate, carbamazepine, and lamotrigine are the only medications classified as mood stabilizers. Of the four mood stabilizers used in treatment of bipolar disorder, lithium is the drug of choice (APA, 2015).

Lithium has been used since the 1950s for the treatment of bipolar disorder and is the archetypal mood stabilizer. Lithium has a wealth of empirical evidence supporting its efficacy in this role. One of the reasons that lithium is prescribed more frequently in patients with bipolar disorder is that numerous research studies have shown that taking lithium long term has significantly decreased the rate of suicidal behavior (Ahearn et al., 2013; Alda, 2015; APA, 2015; Baldessarini et al., 2006; Cipriani, Pretty, Hawton, & Geddes, 2005; Cipriani, Reid, Young, Macritchie, & Geddes, 2015; Malhi, Tanious, Das, Coulston, & Berk, 2013). In addition to reducing suicidal behavior, several studies have suggested that lithium may reduce cognitive decline in patients (Malhi et al.). However, the benefits of lithium are restricted by its adverse effects and low therapeutic index. For example, the kidneys and thyroid can be significantly and adversely affected by longterm use of lithium, and lab work should be done routinely to ensure the lithium level in the blood does not rise above the therapeutic level and become toxic (Geddes & Miklowitz, 2013).

In 1980, research began looking at links between anticonvulsant medication and the treatment of mood disorders. Valproate, carbamazepine, and lamotrigine proved to be effective treatments for mood stability when lithium was not tolerated (Ahearn et al., 2013; Geddes & Miklowitz, 2013). Despite the dramatic increase in the use of valproate, carbamazepine, and lamotrigine in the past two decades, placebo-controlled evidence showing their efficacy remains scarce (Geddes & Miklowitz, 2013). All three of these mood stabilizers are associated with a serious rash as part of Stevens-Johnson syndrome and toxic necrolysis. Both Stevens-Johnson syndrome and toxic necrolysis can be fatal if not treated. Close monitoring and slow titration of these medications are required to help reduce the risk for these deadly adverse reactions. In addition, patients taking valproate and carbamazepine need routine lab work to ensure toxic blood levels are not reached (Dols et al., 2013).

# **Antipsychotic Medications**

Antipsychotic medications are commonly used for the initial treatment of acute mania, both as monotherapy and as adjunctive therapy to mood stabilizers. In acute mania, antipsychotic medications show similar efficacy to lithium but have a faster onset of action (Ahearn et al., 2013; Rascati et al., 2015; Tohen et al., 2005). Despite the frequent use of antipsychotic medications, few studies have examined their effect on suicide risk. Atypical antipsychotics, the newer classification of antipsychotic medication, have been studied in regard to bipolar depression with variable results (Buoli, Serati, & Altamura, 2014). Olanzapine, an atypical antipsychotic has demonstrated efficacy in multiple randomized control trials in treating acute mania in bipolar disorder (Tohen et al., 1999, 2000, 2005). Because more antipsychotic medications are being used today, the side effect profile of this classification of medications warrants close monitoring. For example, weight gain is a well-established side effect, and more studies are showing a link to diabetes as well as cardiovascular and metabolic side effects (DeHert, Yu, Detraux, Sweers, van Winkel, & Correll, 2012).

# **Theoretical Framework**

### Leininger's Transcultural Care Theory

This research study will be conducted in part through the use of focused ethnography approach by observing and interviewing patients with a new diagnosis of bipolar disorder. The theoretical framework for this study is based on Leininger's transcultural care theory and conceptual model (Leininger, 1978; Leininger & McFarland, 2002; Leininger & McFarland, 2006). This theory provides a context for understanding patients who were misdiagnosed and given a new diagnoses of bipolar disorder. Leininger's transcultural care theory recognizes that a specific group of people in a culture hold values, beliefs, and traditions (Leininger & McFarland, 2006). For example, members within a culture share similar values, beliefs, and practices that are particular to that population of people. Major concepts of Leininger's theory (1991) are that a variety of factors shape illness and wellness, including perception and coping skills and the social level of the patient. The patient must accept the diagnosis and learn positive coping skills to achieve mood stability. The current study will focus on patients with bipolar disorder as a culture. Along with concepts involving racial, cultural, and ethnic differences, Leininger's theory also recognizes the need for non-judgmental, quality nursing care (Leininger & McFarland, 2006). Leininger described nursing as a transcultural humanistic and caring science profession with the purpose to serve other human beings (Fawcett, 1993; Leininger & McFarland). This concept is extremely important when working with patients with bipolar disorder because of the already high social stigma that they encounter in their daily lives. Leininger (1978) defined ethnonursing as a "systematic study and classification of nursing care beliefs, values, and practices as cognitively perceived by a designated culture through their local language, experiences, beliefs, and value system." Leininger (1985) further defined ethnonursing as a systematic process to observe, describe, document, and analyze the way of life and life patterns of people in their environment. In an effort to handle the challenges of the misdiagnosis of bipolar disorder, Leininger's Transcultural Care Theory was chosen as the theoretical framework for this study.

Leininger's Transcultural Care Theory Conceptual Model was founded in the belief of ethnoscience. According to Leininger (1978), ethnoscience refers to a formalized and systematic study of people from their viewpoint in order to obtain an accurate account how the people know, classify, and interpret their lifeways and the universe. The application of this model will help the graduate nurse researcher gain knowledge by encompassing the language, beliefs, and experiences of patients newly diagnosed with bipolar disorder.

The overall goal of using the Sunrise Model is for the health care provider to deliver culturally competent care to all populations. Providing culturally based care to

various populations has universal features that health care providers need to utilize in their practice when caring for patients with bipolar disorder (Daly & Jackson, 2003; Gennaro, 2000; Messias, 2001). The Sunrise Model (Leininger, 2002; Appendix A) has four theory tenets that encompass culture care which include (a) worldview, (b) cultural and social structure dimensions, (c) influences, and (d) transcultural care decisions and actions (Leininger, 2002).

# **Application of Leininger's Transcultural Care Theory Conceptual Model**

At the top of the Sunrise Model is the tenet of worldview. This model greatly expands the worldview of health care providers by motivating them to look for the overt and covert factors that influence the views of members of a culture on mental health (Leininger, 2002). Using this model helps reinforce the perspective of mind-body-spirit holism. In a general sense, health encompasses a wide spectrum of conditions, including well-being, illness, disability, and handicap (Leininger, 1978; 1988). Health care providers need to understand the disparity that patients with bipolar disorder have and form a plan of care than emphasizes the interaction of the environment and worldview with the importance of flexibility and adaptability.

The next tenet addresses the cultural and social structure dimensions, which include technological factors, religious and philosophical factors, kinship and social factors, cultural values, beliefs, and lifeways, political and legal factors, economic factors, and educational factors. For the purpose of this study, the cultural and social structure dimensions were categorized into internal and external patient factors. The internal factors are religious and philosophical factors; kinship and social factors; and cultural values, beliefs, and lifeways. Each of these dimensions are factors that influence care from the patient's perspective. External factors include technological factors, political and legal factors, economic factors, and educational factors. The external factors are societal obstacles that the patient has to handle to overcome the stigma of mental illness. These dimensions can be applied in the psychosocial assessments to identify the patient's health needs and what actions should be followed (de Melo, 2013).

At the center of the model is the tenet of influence. How the patient and society views bipolar disorder influences the guidelines for treatment. The standard care for patients with mental illness, specifically with bipolar disorder, have emerged over the last decade, however, there is room for progress. By examining the current practices and patient outcomes, it is clear that improvements are needed, understanding that human care practices are discovered by studying the person's own conceptions-local, insider, generic folk, or emic- and doing so from their perspective. This study will use focused ethnography to increase the health care provider's outsider, or etic, knowledge about patients with bipolar disorder.

The last tenet of the model is transcultural care decisions and actions. Establishing a therapeutic relationship with a patient and providing non-judgmental and non-biased care is an example of implementing culturally competent care accommodations to patients with bipolar disorder. For example, a patient's behavior is culturally determined, and behavior influences mental health. With this in mind, it is imperative for the health care provider to understand that patients are not viewed as self-contained social and cultural beings, but as patients whose perceptions and behavior are influenced by their families, by the socioeconomic realities of their lives, by ethnicity or race, and by legal and political factors of their environment. In summary, applying Leininger's Sunrise Model (2002) gives a direct transformation from an abstract idea of cultural and social structure dimensions to a concrete perspective when caring for patients with bipolar disorder. By having the knowledge to give culturally sound, non-judgmental care, patients can have a strong sense of security and therefore, enhance the patient-nurse relationship and strengthen the therapeutic relationship.

# **Focused Ethnography**

As the oldest form of research methodology, ethnography stems back to ancient Greece and today has become very popular in nursing research (Higginbottom, Pillay, & Boadu, 2013). Ethnography has been defined as the work of describing culture using a process of learning about people by learning from them (Roper & Shapira, 2000). Ethnography is the process of recording, describing, and studying a particular culture through participation and observation of that given culture (Leininger, 1978).

Leininger (1978) helped culture become a focus in nursing, and nursing in turn, branched into transcultural care and ethnonursing. Leininger described two types of ethnography: mini ethnography and maxi ethnography. Mini ethnography focuses on the health care practices of a small number of participants in a culture. It is limited to a narrow selection of a particular group in a specific environment. Maxi ethnography is a larger and more comprehensive study and is not popular in the nursing field because of its long time commitment (Leininger, 1978). What Leininger called mini ethnography is now called focused ethnography. Focused ethnography is an appropriate fit for nursing research because patients with a particular illness may be considered as a cultural group (Muecke, 1994). Focused ethnography was selected due to its focus on understanding a specific aspect of the culture of patients with bipolar disorder. There is a paucity of research related to understanding a patient's perspective about being newly diagnosed with bipolar disorder. By using focused ethnography, this phenomenon was explored in depth, rendering a fuller understanding of what occurs after discharge from the psychiatric hospital with a patient with bipolar disorder.

# Summary

This chapter summarized research and theoretical aspects about the misdiagnosis of bipolar disorder and provided a framework for the study. Bipolar disorder is a complex, chronic, and debilitating mental illness; consequently, there must be a coordinated effort to help fill the clinical gaps and help improve the life of patients with bipolar disorder. By using a subset of veterans, issues surrounding this unique population have been identified. A comprehensive literature review was completed that resulted in understanding the factors that contribute to and consequences of the misdiagnosis of bipolar disorder. In addition, appropriate medication used to treat bipolar disorder, along with screening instruments used to make the correct diagnosis were examined.

# **Chapter III: Methodology**

# Introduction

Chapter III contains specific detail regarding the research design used to answer the research questions. Included in this chapter are the methodologies and methods used for this study. This was a focused ethnographic multi-method study to identify the complexity of diagnosing bipolar disorder, including diagnostic patterns, recommended treatment, and patient response. Data collection methods included in depth face to face interviews and a retrospective chart review, each grounded in a post-positivist foundation. Finally, a discussion of the protection of human subjects is presented.

## **Research Questions**

RQ1: What is the nature of the experience of receiving a diagnosis of bipolar disorder? RQ2: What are the shared experiences of a subset of veterans within the population? RQ3: Out of a total of patients from age 18-65 admitted to the psychiatric hospital between 01/01/2015-08/ 31/2016 what percentage of patients were admitted with a diagnosis of major depression disorder and then bipolar disorder, suggesting a misdiagnosis?

RQ3a: Out of the total of patients that were switched from major depression disorder to bipolar disorder, what percentage of patients were screened for bipolar disorder?

Out of the total number of patients who were misdiagnosed with bipolar disorder and screened for bipolar disorder:

# Prior to admission to a psychiatric hospital:

RQ4: What were the clinical characteristics of the patients who were misdiagnosed and screened?

RQ4a: What percentage of patients that were misdiagnosed and screened for bipolar disorder had prior suicide attempts? If yes, how many?

# Upon admission to a psychiatric hospital:

RQ4b: What percentage of patients had a positive urine drug screen to identify if the patient was under the influence of a substance at the time of the admission?

### **During inpatient hospitalization:**

RQ5: What were the screening, diagnosis, and treatment patterns for patients with bipolar disorder that were misdiagnosed with major depression disorder?

RQ5a: Screened positive for bipolar disorder, diagnosed with bipolar disorder, and switched from and an antidepressant to a mood stabilizer (lithium, carbamazepine, lamotrigine, or valproate) and/or antipsychotic (quetiapine, lurasidone, or aripiprazole)? RQ5b: Screened positive for bipolar disorder, diagnosed with bipolar disorder, and kept on the same or different antidepressant medication?

RQ5c: (Pre-hospital diagnosis of major depression disorder and previously prescribed mood stabilizers) Screened positive for bipolar disorder, diagnosed with bipolar disorder, and were kept on the same mood stabilizer previously prescribed?

RQ5d: Screened negative for bipolar disorder, diagnosed with bipolar disorder, and switched from an antidepressant to a mood stabilizer (lithium, carbamazepine, lamotrigine, or valproate) and/or antipsychotic (quetiapine, lurasidone, or aripiprazole)? RQ5e: Screened negative for bipolar disorder, diagnosed with bipolar disorder, and kept on the same or different antidepressant medication? RQ5f: (Pre-hospital diagnosis of major depression disorder and previously prescribed mood stabilizers) Screened negative for bipolar disorder, were diagnosed with bipolar disorder, and kept on the same mood stabilizer previously prescribed?

RQ6: What day of inpatient hospitalization were patients switched from an antidepressant to a mood stabilizer and/or an antipsychotic?

RQ7: What differences are there regarding RQ4-6 when comparing veterans to nonveterans?

#### **Associated Assumptions**

The first assumption is that patients diagnosed with bipolar disorder are embarrassed to report their manic symptoms because they feel more "crazy" than having other mental illness symptoms, such as depression or anxiety. The second assumption is that patients with bipolar disorder have an unrealistic expectation of medications for the treatment of bipolar disorder.

# **Focused Ethnography**

As the ethnography research design has advanced, it has become the method of choice in understanding more detailed characteristics of life and cultural experiences relevant to their disciplines (Erickson, 2011). To assist with making ethnography a useful tool, Polit and Beck (2008) categorized ethnography into two types: macroethnography and microethography. Macroethnography is concerned with broadly defined cultures and microethnography focuses on narrowly defined cultures. Microethnography is also known as focused ethnography (Polit & Beck, 2008). As nursing practice has expanded so have the research methods used to study the meanings of illness and health (Roper & Shapira, 2000; Speziale, Streubert & Carpenter, 2011).

A focused ethnography was chosen for this study because it concentrated on a particular aspect of a subculture, patients that have been newly diagnosed with bipolar disorder. It is mostly useful in assessing or prompting information on a special topic or shared experience (Richards & Morse, 2007). In addition, focused ethnography allows the researcher to understand better the complexities surrounding issues from the participants' perspective, while bringing the researcher's (who is an outsider) framework to the study (Roper and Shapira, 2000). Nurse researchers have used focused ethnography to study the experiences of being diagnosed with tuberculosis in Somali patients (Gerrish, Naisby, & Ismail, 2013), the quality of life after heart transplantation in children (Green, McSweeney, Ainley, & Bryant, 2007), the social awkwardness in morbidly obese patients (Hales, de Vries, & Coombs, 2016), and the nature of attachment in a NICU (Bialoskurski, Cox, & Hayes, 1999).

Ethnography is a research methodology where the aim is to gain understanding of how people experience their culture. This research methodology is rooted in anthropology, the study of human cultures, as the researcher becomes engrossed in the culture to know and identify the behaviors within a culture (Streubert & Carpenter, 2007). Ethnography delivers an honest account of people's stories in their own words and brings a local context as researchers plunge themselves in the world of the participants' social behavior in their culture (Roper and Shapira, 2000; Fetterman, 2010). When using ethnography as a research design, the researcher will use three data collection strategies: participant observation, formal and informal interviews, and examination of relevant documents. These three strategies are essential in helping the researcher to gain a better understanding of the culture being studied. Fetterman (2010) regards the interviews as the most important data-gathering technique because it allows the research to map participants' responses, which are essential to subsequent coding and analysis.

The research questions, not the researcher, determine the research design. In this study, both qualitative and quantitative methods were used to gain a more complete understanding of the concerns about the misdiagnosis of bipolar disorder, and also to hear the voices of the patients that have been newly diagnosed with bipolar disorder. By definition, a multi-method research approach is the collection and analysis of both qualitative and quantitative data and its combination, drawing on the strengths of both approaches (Guetterman, Fetters, & Creswell, 2015). The graduate nurse researcher used a meaningful integration of methods that produced a completeness that may not have been understood using only one of the research designs. Fetters and Freshwater (2015) state that the benefit of using a multi-method approach is to "produce a whole through integration that is greater than the sum of the individual qualitative and quantitative parts."

### In-depth interviews.

### Design.

The purpose of obtaining in-depth face to face interviews was to provide a description of the shared experiences of patients that have been newly diagnosed with bipolar disorder at six weeks post hospital discharge. In addition, a subset of veterans were interviewed to identify any veteran-specific experiences in relation to being newly diagnosed with bipolar disorder. The main area of inquiry for the semi-structured interview was for the patient to state what it is like to be newly diagnosed with bipolar disorder. Other queries included asking the patient to compare their life before admission

to the hospital and after, how having bipolar disorder has impacted their life, and cound been done, anything differently in terms of their diagnosis. The interview sessions varied in length, ranging from 45 minutes to 90 minutes. All interviews included an introduction at the beginning and a debriefing session at the end. The graduate nurse researcher provided a truthful account of the patients' experiences through observations, field notes, and interviews. Confidentially and privacy was maintained throughout the study.

# Setting and sample.

Patients in this study were interviewed in a private room at one of six psychiatric physicians' offices in the greater St. Louis area. The sample size was ten patients, which included a subset of one patient who was a veteran. Patients were recruited until saturation was reached. The reason for ten patients for the semi-structured interview is that this study has an idiographic aim, which means that the graduate nurse researcher strives for a sample that is sufficiently small for individual cases to have a locatable voice within the study so an intensive analysis of each case can be conducted (Robinson, 2014). Inclusion criteria for the focused ethnography are: (a) patients, a subset of which are veterans, 18-65 years of age, (b) newly diagnosed with bipolar disorder during an inpatient psychiatric admission that occurred 29-42 days prior, and (c) willingness to participate in an interview session.

#### Data collection procedures.

The chief executive officer of the hospital gave the graduate nurse researcher a letter of administrative approval (Appendix K) for her to use at the site. After IRB approval was obtained, the graduate nurse researcher recruited patients from an inpatient unit at a free standing psychiatric hospital in St. Charles, Missouri. To help reduce personal bias, a reflective journal was maintained by the graduate nurse researcher. The purpose of this journal was to record her reactions to the patients in the study and the setting, as well as the feelings and emotions. These personal and intimate notes were used to evaluate the graduate nurse researcher's response to specific observations and interviews (Speziale et al.). In addition, memoing was incorporated in order to record ideas and insights the graduate nurse researcher had about the data. Memos are reflective notes about what is learned from the data. Memos are written to assist with pulling together notations that have shared meaning and allow the graduate nurse to make connections between pieces of information. These reflections help the graduate nurse researcher to recognize any gaps that may warrant further research (Roper & Shapira, 2000). Prominent materials from the fieldwork journal and memoing were integrated into the data analysis process for consideration as part of the data.

The graduate nurse researcher educated three nurse practitioners and two psychiatrists at the psychiatric hospital about the inclusion criteria. The graduate nurse researcher gave them flyers to give to potential participants. The flyers contained the study information as well as the investigator's contact information (Appendix A). The investigator used the telephone script (Appendix B) when responding to potential participants who called her. When the potential participant expressed interest in volunteering to participate in the study, the graduate nurse researcher scheduled an interview session, 29-42 days after discharge at a Psych Care Consultants physician office in the St. Louis/St. Louis County area most convenient to the participant. Prior to the interviews, the study procedures were explained in detail, confidentiality was assured, and written informed consent (Appendix L) was obtained from all participants. During the semi-structured interview that was voice-recorded, questions were asked regarding their experience of being diagnosed with bipolar disorder (Appendix D). An interview guide, based on the Ethnographic Interview (Spradley, 1979), was used. This guide consists of broad questions supplemented by probes (e.g. Please tell me more. What was the experience like for you?). According to Spradley (1979), an ethnographic interview should be a series of friendly conversations in which the informant may forget they are being interviewed due to the researcher's ability to interject ethnographic questions without the informant's awareness. For example, the semi-structured interviews were guided by the research questions, with specific questions within each topic to help serve as prompts during the interview if the patient did not discuss the topic in enough depth to gather comprehensive data. Following the semi-structured interview, a \$20 Target gift card and a \$5 Quick Trip gas gift card was given to the patient.

Once the patient left the semi-structure interview, field notes were written to reflect the personal account of what was learned during the patient interview (Wolfinger, 2002). Field notes consisted of a variety of materials, such as a running description of observed events and people; conversations with and among people; the researcher's interpretations, analyses, and thoughts for future questions; and personal feelings about the experience (Roper &Shapira, 2000). Recording the graduate nurse researcher's reflections helped clarify what the graduate nurse researcher was thinking and experiencing during the semi-structure interview (Wolfinger, 2002).

## Transcript analysis.

Data analysis occurred concurrently with data collection. The voice-recordings were transcribed verbatim by a professional transcriptionist and were verified by the graduate nurse researcher and a member of the dissertation committee. All interview and field note data were read by the researcher and a member of the dissertation committee to gain a general overview of the data (Wolfinger, 2002). Next, the data were reread and coded to reflect units of meaning, recurring themes, and descriptions of experiences related to the research questions.

Once interviews and field notes were entered into a word document, data analysis was conducted using Spradley's (1979) research sequence. In Spradley's method (1979), there are four levels of data analysis, including domain analysis, taxonomic analysis, componential analysis, and cultural themes. In the first level, the domain analysis, the graduate nurse researcher identified relational patterns among terms in the domains that were used by members of the culture. Domains are connections of cultural symbols that are interrelated together. For example, the graduate nurse researcher focused on the cultural meaning of terms and symbols used in patients with bipolar disorder that were misdiagnosed, and their interrelationships.

In the taxonomic analysis level, the graduate nurse researcher organized and categorized the items from the semi-structured interview into a domain to identify subsets of cultural knowledge. This level involved a more in-depth analysis of the domains that the graduate nurse researcher selected. In the componential analyses, multiple relationships among the terms in the domains were examined. Similarities and differences among cultural units of meaning were examined. Boyle (1994) indicates that this level of analysis should have two objectives: (a) to specify the conditions under which informants' name something; and (b) to understand under what conditions the informants give something a specific name. Finally, in the cultural themes domain, cultural themes were identified and uncovered. The graduate nurse researcher connected the domains into cultural themes, which helped to provide a holistic view of the veterans that have been misdiagnosed and then correctly diagnosed with bipolar disorder (Polit & Beck, 2008). This is part of the process to discover some of the patient factors that contribute to the misdiagnosis and to identify the gaps that the health care providers in the future can fill through proper screening.

The first step in the analysis procedure was to read the de-identified transcripts in their entirety. After the de-identified transcripts were read once, they were each re-read to identify particular words, phrases, structure of conversations, and manner of responses from the questions asked in the interview. Next, the identified concepts were extracted that related to the research focus and named for working themes. The process of identifying themes started with the development of a blank table that was constructed by analyzing and readying each individual transcript and comparing it to the research questions. The graduate nurse researcher and member of the committee each separately created a table that identified working themes, definition of the themes, and an exemplar of the theme via direct quotes from the transcript. During the process of reviewing each transcript, key information was transferred to the large table under the appropriate theme and pattern. After the table was completed and all interviews analyzed, the table was reviewed for recurring themes across participant interviews.

The next step in the analysis procedure was the identification of exemplars. Exemplars are used as stories to help capture the meaning of an experience (Benner, 1994). This is critical in qualitative data analysis because it can identify similarities and differences in the data. Also, exemplars are beneficial in recognizing characteristics or working definitions occurring in the text (Benner, 1994). Exemplars are an additional technique for the researcher to gain an understanding of the participant's experience.

Interpretive sessions were held to review the transcripts, themes, and patterns. These sessions included the graduate nurse researcher and a member of the committee. The raw transcripts were provided before the sessions for review. During the interpretive session, dialogue took place concerning the themes and meanings of the data. These sessions were imperative because it reinforced the design of the study and verified the results of the analysis.

Member checking was initiated after five transcripts were analyzed and working themes were identified. Member checking involves taking data and interpretations back to the participants in the study so that they can confirm the credibility of the information and narrative account (Creswell & Miller, 2000). In this study, the graduate nurse researcher asked two participants to view raw data (one transcript and a list of working themes) and comment on their accuracy. Throughout this process, the graduate nurse researcher asked the participants if the themes made sense, whether they were established with adequate evidence, and whether the overall account was genuine and accurate. Next, the graduate nurse researcher incorporated participants' comments into the final narrative. This established credibility by having a change to react to both the data and the final narrative (Creswell & Miller, 2000). This process was repeated for the remaining five transcripts.

## Thematic analysis of the data.

Once the interviews were completed, the transcripts of the interviews, field notes, and journal entries were read, studied as a whole, and summarized. The texts were then re-read by the graduate nurse researcher and a member of the committee independently to identify working themes. During the first round of the thematic data analysis, any words, expressions, or notations about changes in voice, emotions, or behaviors that were interesting, unanticipated, or seemed in other ways to be noteworthy to answering the research questions were highlighted. The highlighted quotations that communicated a similar meaning were grouped together. These groups of highlighted text resulted in a preliminary list of 18 themes:

- Issue of recognizing past symptoms as abnormal
- Issue of reconciling diagnosis
- Issue of agreeing with the bipolar disorder
- Issue of normalcy
- Issue of seeking relief
- Issue of seeking treatment
- Issue of worsening of moods after previous treatment
- Issue of getting relief after starting on mood stabilizers
- Issue of self-harm
- Issue of social stigma
- Issue of self-stigma

- Naming "bipolar disorder"
- Questioning the diagnosis
- Hinting acceptance of diagnosis
- Desiring normalcy
- Recognizing past symptoms
- Reconciling symptoms, diagnosis, and treatment
- Getting initial help

The transcripts were read a third time and it became clear that there was overlap between the themes of *Issue of recognizing past symptoms as abnormal, Issue of* normalcy, Recognizing past symptoms, and Naming "bipolar disorder." These four themes were collapsed under the theme of *Extremities of emotion*. Also during the third analysis meeting, the graduate nurse researcher and member of the committee expanded the theme Issue of worsening of moods after previous treatment into a broader theme of *Life consequences* because many of the participants endured intense consequences due to their moods and behaviors. Next, the themes *Issue of seeking* treatment, Issue of self-harm, and Getting initial help were combined under Seeking *relief.* The participants voiced actions that they had done to get relief from the symptoms of bipolar disorder, which included substance abuse, self-harm, and seeking treatment from healthcare providers. Recurring conversations about having a previous diagnosis prior to the bipolar disorder diagnosis re-formed the following themes: Misdiagnosis and Correct Diagnosis: Reconciling symptoms, diagnosis, and treatment and Issue of getting relief after starting on mood stabilizers. By the end of the third reading, there was a clear range of differences in how each participant

agreed or disagreed with being diagnosed with bipolar disorder. Therefore, the following themes of *Issue of reconciling diagnosis*, *Issue of social stigma*, *Issue of social stigma*, *Questioning the diagnosis*, and *Hinting acceptance of diagnosis* were categorized into a pattern called *Range of Acceptance* with working themes of *Approval*, *Challenging*, *and Stigma*. After much discussion and further dissection of themes, re-reading of text, and re-categorization between the graduate nurse researcher and the committee member, the following two overarching patterns and themes emerged:

- Living with Undiagnosed bipolar disorder
  - Extremities of emotion
  - Life consequences
  - Seeking relief
- Obtaining a diagnosis
  - Misdiagnosis
  - Correct diagnosis
  - o Stigma

The transcripts were read for a fourth time and phrases, words, and sentences were highlighted according to the existing list of themes. It was determined after the fourth reading, the theme *Extremities of emotion* was changed to better describe the emotions that the participants expressed. Many of the participants had unpredictable emotions that were better described as labile. The next theme of *Life consequences* was changed to *Life challenges* because not all participants suffered consequences, but all of them described additional challenges they went through that people without

mental illness may not have had to experience. Also, the second pattern of *Obtaining* a diagnosis was not found to fully represent the participants once the diagnosis was made. The words "misdiagnosis" and "correct diagnosis" were not necessarily expressed by the participants in those words, so the graduate nurse researcher and member of the committee examined each interview again as a whole to determine what these participants were saying and what their experience was like once the diagnosis of bipolar disorder was given. When examining all the transcripts, the reactions of getting the diagnosis of bipolar disorder resulted in two themes: understanding and reconciling the diagnosis. Understanding the diagnosis includes the lack of education regarding bipolar disorder as well as the social stigma that accompanies the diagnosis. Included in the theme *Reconciling the diagnosis*, the participants had a wide-range of acceptance with the diagnosis. Even the participants who were more accepting of the diagnosis had issues of self-stigma regarding themselves as having bipolar disorder. As a result of the fourth reading, the following patterns and themes emerged:

- Living with undiagnosed bipolar disorder
  - Experiencing labile emotions
  - Suffering life challenges
  - Seeking relief
- Receiving a new diagnosis of bipolar disorder
  - Understanding the diagnosis
  - *Reconciling the diagnosis*

Peer and member checks were completed at this point to determine whether the identified patterns and themes were represented in the transcript, and if they saw see any additional issues that the patterns and themes do not address. The peer checks consisted of one researcher assistant and two faculty members, all of whom agreed with the patterns and themes. When the first member check was done, the participant felt that *Seeking relief* should not include medication seeking behaviors. The participant's text demonstrated that the seeking relief by self-harm was different than seeking relief from medication. After clarifying the definitions of both, the graduate nurse researcher and committee member made a preliminary decision to keep the theme *Seeking relief* to encompass all types of relief seeking behavior in one theme.

The transcripts from each of the participants were read for a fifth time and statements were once again highlighted and coded by themes and placed into appropriate patterns and themes. On the fifth reading, it became clear that *Experiencing labile emotions* did not permeate throughout the majority of the participants' accounts. This was due to the participants describing their behaviors as well as their emotions. Also, the participants reported impulsive behaviors and many of them included specific behaviors such as promiscuity, excessive spending, and extreme gambling. After a long discussion, it became apparent that the theme should be changed to *Distinguishing impulsive moods and behaviors*.

A table was constructed to assure that each theme was, in fact, present in each of the participant's experiences. Also, another peer and member check was done to help validate the new changes to the patterns and themes. The peer check was done by a graduate research assistant and the member check was done by a different participant from the study. The member indicated that the themes and overall meaning of the experience mirrored the experience of getting newly diagnosed bipolar as they lived it. The final list of the two patterns and five themes include:

- Living with undiagnosed bipolar disorder
  - Distinguishing impulsive moods and behavior
  - Suffering life challenges
  - Seeking relief
- Receiving a new diagnosis of bipolar disorder
  - Understanding the diagnosis
  - *Reconciling the diagnosis*

# Rigor.

Rigor in qualitative methods is measured in terms of primary and secondary criteria of validity (Whittemore, Chase, & Mandle, 2001). Primary criteria include credibility, authenticity, criticality, and integrity. Secondary criteria include explicitness, creativity, thoroughness, congruence, and sensitivity (Whittemore et al). Strategies recommended by Whittemore et al. were employed during and following this study to ensure rigor and validity. Credibility is the faithful depiction of the patient's lived experiences that would be recognizable to themselves, as opposed to the verification of a preconception of those events. Authenticity is a representation of the emic perspectives that exhibit awareness to the subtle differences in the voices of all the patients. Using the emic approach means that the graduate nurse researcher disregarded theories and concepts and focused on the actual data from the participants and to the themes or patterns that appeared from the participants. Criticality involves a process that demonstrates evidence of a critical appraisal. The last criterion in the primary criteria is integrity, which is a process that reflects recursive and repetitive checks of validity, as well as an accurate presentation of findings.

The secondary criteria are additional guiding principles that contribute to the development of validity in qualitative research (Whittemore et al). The first criterion in the secondary criteria is explicitness. To achieve this, methodological decisions, interpretations, and investigator biases were addressed. Vividness is the process of having thick and faithful descriptions portrayed with artfulness and clarity. Thoroughness is ensuring the findings convincingly address the questions posed through completeness and saturation. Congruence is the step in which the graduate nurse researcher confirmed the process and that the findings were congruent, the themes fit together, and the findings fit into a context outside the study situation. Lastly, sensitivity was implemented by ensuring that the research process was sensitive to the nature of human, cultural, and social contexts.

Peer and member checks were used in this study to validate the identified themes. The graduate nurse researcher and a member of her committee asked four peers and two study participants to each read one de-identified transcript to determine whether the identified patterns and themes represent what the graduate nurse researcher and committee member saw in the transcript, and if they had any additional issues that the patterns and themes did not address.

### **Retrospective chart review.**

### Design.

The purpose of the retrospective chart review was to determine the percentage of patients that were diagnosed with major depression disorder and then correctly diagnosed with bipolar disorder, clinical characteristics of the patients that were misdiagnosed, and the diagnosis and treatment patterns for bipolar disorder. This study is a retrospective chart review that analyzed existing inpatient hospital records to extract data of adult patients that had a diagnosis of major depression disorder upon admission and were switched to a bipolar disorder diagnosis by discharge in a psychiatric hospital in St. Charles, Missouri.

# Setting and Sample.

The data were extracted through a retrospective chart review from a psychiatric hospital in St. Charles, Missouri. Inclusion criteria for the retrospective chart review was: (a) adults age 18-65, (b) had a diagnosis of major depression disorder upon admission and was switched to a bipolar disorder by discharge, and (c) have complete data on the database of patients admitted, 01/01/2015 through 08/31/2016.

#### Outcomes.

The percentage of patients who were misdiagnosed with major depression and then correctly diagnosed with bipolar disorder were analyzed by looking at the admitting diagnosis and the discharge diagnosis from the patient's electronic medical record. The clinical characteristics of the patients that were misdiagnosed were obtained through the admission demographic data from the patient's electronic medical record. Prior suicide attempts were obtained through the past psychiatric history intake assessment from the patient's electronic medical record. The results of the urine drug screen were obtained from the lab results section from the patient's electronic medical record. Diagnostic and treatment patterns of the patients were obtained through the medication administration record, physician order sheets, and the progress notes from the patient's electronic medical record.

### Data Collection Procedures.

Clinical information that is documented by health care providers during the course of hospitalization included admitting diagnosis, urine drug screen results, psychiatric intake admission, psychiatric evaluation by the health care provider, medication administration record, discharge summary, and demographics.

# Data Analysis.

The data collected from the inpatient charts were de-identified by the hospital data manager, then coded and put in an excel spreadsheet and exported in SPSS version 18. An in-depth analysis of the data was accomplished using inferential statistics (means and standard deviations, frequencies and percentages).

### Limitations

There were several limitations associated with this study. The first is that the data, from both the in-depth interviews and the retrospective chart review, were collected from one geographical site using convenience sampling techniques. Despite the use of one geographical site, multiple physician offices throughout St. Louis and St. Louis County were used. Next, some of the interview questions were leading and participants generally responded with affirmations or explanations that were testimonial so that the responses were trustworthy. However, had questions taken a less structured form, there may have been additional disclosures.

# **Protection of Human Subjects**

For both the focused ethnography and the retrospective chart review, confidentiality was maintained by keeping all data in a password protected computer. The only person with the password was the graduate nurse researcher. The participants' names, contact phone numbers, and any data printouts that were on paper was kept in a locked file for which only the graduate nurse researcher has a key. Participants were assigned an identification number. The list of names and code numbers were kept in a locked file for which only the graduate nurse researcher has a key. All names and contact information were shredded after the end of data collection. The graduate nurse researcher provided participants with a copy of the informed consent form and the graduate nurse researcher's contact information, in addition to contact information for the Human Subjects Committee. The graduate nurse researcher followed the University of Missouri-St. Louis (UMSL) IRB, the UMSL Office of Compliance, the Health Insurance Portability Accountability (HIPPA), and Code of Federal Regulations Concerning Informed Consent guidelines for the protection of human subjects.

Specifically for the focused ethnography, the sessions were voice recorded. When the participant did not want the session recorded, the graduate nurse researcher instead took field notes. At the beginning of the interview session, participants were informed that sometimes answering questions about one's personal experiences may be uncomfortable. The graduate nurse researcher explained that participants could stop answering the questions and withdraw from the study at any point without any consequences and that they would still be compensated with a \$5 Quik Trip gas gift card. The graduate nurse researcher would have ended the session if she felt the participant's judgment was impaired. Examples of this include if the participant becomes too upset or too tired to finish the session. If this would have occurred, the graduate nurse researcher would have provided the debriefing session and destroyed the audiotape.

Also, the graduate nurse researcher informed participants that she is a psychiatric mental health nurse practitioner and that her collaborating physician and clinical expert is Dr. Azfar Malik, a psychiatrist that has over 30 years of experience in mental health. The graduate nurse researcher is board certified and routinely screens, diagnoses, treats, and debriefs patients with mental illness in her office practice at the Centerpointe Hospital in the South County Branch. Although the graduate nurse researcher is employed at Centerpointe Hospital South County Branch, she had not met the participants had no access to their identifiable medical records, and was not involved in their inpatient care at the hospital in St. Charles.

For the focused ethnography, the potential risks included possibility of psychological effects. Any potential risks were reduced because of the planned steps undertaken to minimize risk. Although the participant was not directly asked about suicidal behavior during the semi-structured interview, there was the possibility that patients might have expressed suicidal behavior. If this had occurred, the graduate nurse researcher would have put the Crisis Action Plan into effect. The Crisis Action Plan, an established hospital protocol, is outlined below.

Crisis Action Plan

1) To assess for suicidality, the investigator will give the Columbia-Suicide Severity Rating Scale, Screener/Recent-Self-Report form (Appendix I) to the participant to fill out. If the participant answers "yes" to question #2 on the rating scale, the graduate nurse researcher will immediately call the participant's mental health care provider. If the mental health care provider is not available, the graduate nurse researcher will call 911, and the EMS (following standard emergency services protocol) will take the participant to the closest emergency department for a psychiatric evaluation. However, if the graduate nurse researcher feels that the participant is a threat to himself/herself, but is unwilling to go to their preferred hospital for a psychiatric evaluation, the graduate nurse researcher will inform the participant that she will be admitting him/her to Centerpointe hospital to ensure safety. At that point if the participant leaves the session, the graduate nurse researcher (following standard protocol) will notify the police to follow through to ensure safety for the participant.

2) For any participant who had a crisis during the session, the graduate nurse researcher will call that participant 24 hours after the session to ensure safety. Also, she will call the participant 2 weeks after the session to check on the participant's wellbeing. During the follow-up call if the participant indicates any suicidal behavior, the graduate nurse researcher will call 911, and the EMS (following standard emergency services protocol) will take the participant to the closest emergency department for a psychiatric evaluation. At that point, the EMS is responsible for carrying out their protocols to ensure safety.
3) The graduate nurse researcher will notify Dr. Azfar Malik immediately of any participant who had a crisis during the session.

The audiotapes of any participant who need the Crisis Action Plan will be destroyed.

The study proceeded without the need to engage the Crisis Action Plan. No participant expressed suicidal intent.

### **Chapter IV: Findings**

### Introduction

Chapter IV presents the findings of the study. Included here are the voices of the participants telling their stories of their experience with being newly diagnosed with bipolar disorder. The particulars vary from patient to patient but their experiences bear many similarities. Also included in this chapter are the results from the retrospective chart review as well as the description of the overall sample for each part of the focused ethnography method, how missing data was handled, themes and patterns of the in-depth interviews, including quotes, and summary of results.

### **In-depth interviews**

The purpose of the in-depth interviews was to describe the experience of getting newly diagnosed with bipolar disorder. A second purpose was to identify if the experience was any different for a subgroup of veterans. The information presented in this section of the chapter describes the demographics of the study participants in the study and defines the thematic analysis of the data. Data from the individual interviews, a fieldwork journal, and a reflective journal are then presented as cultural themes and patterns identified out of a domain and taxonomic analyses. The participants were recruited to the study because they were recently diagnosed with bipolar disorder. Each participant chose to participate because they had a story to tell about their experience. It is only sensible to allow their voices to be heard in the telling of their stories. The names used in the telling are fictitious. Pseudonyms were used to protect the identities of the participants who participated in this study.

### Description of the participants.

The participants in this study included three males and seven females who were all admitted to the psychiatric hospital and given a new diagnosis of bipolar disorder. At the time of the study the ages ranges from 19 - 61 years of age, with the mean age 34.7 years old. There was one African American participant in the study and the rest of the participants were Caucasian. Two of the participants had Masters' degrees, one of the participants had a Bachelor degree, one of the participants had an Associate degree, three of the participants had high school diplomas and one participant had a 10<sup>th</sup> grade education level. Eight out of ten participants had a family history of mental illness. Four of the participants were unemployed, five were employed, and one was retired. Table 1 presents a summary of the demographic data.

### Prologue to the Stories.

The participants in the study were interviewed in a conversational format that occurred within the context of the visit. The first part of all the interviews included the process of determining eligibility (which included confirming with the participant that he or she was recently discharged from an inpatient hospitalization and was newly diagnosed with bipolar disorder) and obtaining informed consent. All the conversations were audio recorded. All the interviews followed the questions from the semi-structured interview guide and all the possible problems were used. The participants' words varied but the answers to the interview questions revealed common experiences. When the participants reflected on their lives, all of them indicated that their lives before getting the diagnosis of bipolar disorder were unpredictable. Some of the words they used to describe their life before the bipolar disorder diagnosis included: "up and down", "not being stable", "moody", "anger", and "all or nothing-all the time." Many of the participants have had mood symptoms since early adolescence. All the participants described multiple relationship difficulties, significant financial concerns, and relief seeking behavior. The relief seeking behavior included a variety of actions, including substance abuse, self-harm, and seeking treatment from previous healthcare providers. Although there was a range of accepting of the diagnosis among the participants, all of them reported relief from the mood stabilizers. The following results are presented in the form of patterns and themes.

### Results.

### Pattern: Living with undiagnosed bipolar disorder

Living with undiagnosed bipolar disorder was labeled based on the content of each participant's description of their lives before the diagnosis of bipolar disorder was made. The participants were asked to describe how their life was going before being diagnosed with bipolar disorder. By their accounts and descriptions of their experience living with either undiagnosed or misdiagnosed bipolar disorder, the following themes emerged: *Distinguishing impulsive moods and behavior, Suffering life challenges,* and *Seeking relief.* For many, the symptoms of bipolar disorder started very early in childhood and adolescence. All three of these themes were chosen because they captured how these participants lived prior to getting the correct treatment.

### Theme: Distinguishing impulsive moods and behaviors

Throughout the interviews, participants repeatedly reported moods and behaviors that they felt were not normal. Distinguishing is defined as "recognize or treat (someone or something) as different" (Oxford, 2010). This word was chosen because the

participants recalled their specific examples as different moods and behaviors than their friends, family, or co-workers. Although, several words could have been used to describe the moods and behavior, the word impulsive was used to exemplify the quick response without thinking of the consequences that these participants described. The word impulsive is defined as "acting or done without forethought" and "acting as an impulse" (Oxford, 2010). The word mood was chosen because many of the participants described their emotions as their moods in the transcripts. A mood is defined as "a temporary state of mind or feeling" or "an angry, irritable, or sullen state of mind" (Oxford, 2010). The more the transcripts were read, it became apparent that in addition to moods, behaviors were also reported and described. A person's behavior is defined as "the way in which one acts or conducts oneself, especially towards others" (Oxford, 2010). When a person is in the mania state of bipolar disorder, they can exhibit many of the moods and behaviors that the participants reported during their interview. In many of the interviews, the participants reported uncontrollable moods and behavior, which nobody knew, including themselves, would occur.

The participants in the study used the words: "up and down", "pissy", "angry", "irritable", and "unstable" to describe the way they felt prior to being diagnosed with bipolar disorder. All of these moods and behaviors the participants experienced in their everyday lives were so severe at times that it affected every aspect of their life. As Shelby described during our interview, "I felt like I was angry 'cause my mood swings were just all over the place. I – before I went into treatment, I was really unpredictable. I never know what I'm going to do next." This was a common theme among all participants. For example, Sophie described her moods and behavior as: Yeah. Periods of sadness. Periods of extreme anger where like I was very like physically violent. Like not to like people, but just like inanimate objects. You know, throwing things and slammin' doors.....But yeah, before going into the hospital, I was definitely just kind of out of my mind. Like getting angry all the time and then being really happy....(Ln 234-240).

When reflecting on their life prior to getting diagnosed with bipolar disorder, the participants in this study identified impulsive moods and behavior. Many of the participants could recall specific time points in their life that these impulsive moods and behavior have caused them problems in their relationships and employment. These participants often felt out of control over these symptoms and some felt guilty over the way they had treated their family members. During the interviews, many of the participants were tearful and one participant acknowledged that she should have gone for help sooner but was too embarrassed and ashamed. Shelby states "I always wanted to go to like talk to somebody or go to the doctor, but I was either scared to know the diagnosis myself 'cause then it would be real, you know" (Ln 151-153). When Stella was asked about what kind of symptoms of bipolar disorder she had prior to going in the hospital, she responded:

I think like the impulsiveness I want to say was one. Um, just being like up and down. Like little things made me snap. Just like nothin'. Like just like somebody looking at you the wrong way or something. Like – like you just kinda like flip all of a sudden from like being fine and okay and in a great mood, whistlin', to like just wantin' to punch somebody in their head. Like just so mad for no reason. I mean, it's just like – it's like uncontrollable sometimes. Like you

can't control it. But I don't know if – like being super sad maybe is one, too. Going from being like really happy to like nothing happening, and all of a sudden you're just crying (Ln 295-298).

### Theme: Suffering life challenges

Participants in the study described difficult life circumstances that appear to be more severe than in patients without bipolar disorder. Suffering is defined as "the state of undergoing pain, distress, or hardship" (Oxford, 2010). This word was chosen because all the participants described repeated hardships after enduring the consequences of their untreated moods and behaviors. Some of the participants have been having symptoms of bipolar disorder throughout their lifetime, starting in early childhood. The word challenges was used to describe the constant obstacles that these patients have endured as a result of their untreated illness.

The participants in study used phrases such as "repeated arguing," "a lot of relationship problems," "divorces," and "failed marriages." The life challenges vary in description from participant to participant, but all of the participants remember these challenges as standing out from other more manageable aspects of their lives. Both the depression and manic symptoms of bipolar disorder can create challenges for patients.

Severe life challenges, such as legal matters, relationship problems, and/or financial troubles, occurred in all of the stories that the participants reported. For instance, Stella recalled her life challenges started from a very young age: "So, you know, I was being truant – like truancy from school. And my parents were getting in trouble for that. I wasn't doing anything I was supposed to be doing, so I ended up in a residence facility" (Ln 120-122). Stella continued to say "Cause I did four years in prison and I was clean the whole time. I went for involuntary manslaughter" (Ln 226-127, 232). Relationship problems were also described in many of the participants, with many of the participants having been through multiple divorces. Maggie states "I've had two failed marriages and then I broke up with my boyfriend" (Maggie, Ln 102). In congruence with the manifestation of manic symptoms, many participants were forced to face money issues from the impulsive spending.

Participants described many challenges that have resulted from their impulsive moods and behavior. Many of these challenges were a direct result of class manic symptoms such as impulsive spending, hypersexuality, racing thoughts, and anger and irritability. For example, one of the participants was facing severe credit card debt due to her impulsive spending. Maggie reported how her spending habits when she was having a manic episode affected her life long after treatment was obtained: "My spending habits. I mean, I'm like in debt" (Ln 185). Although the veteran had more favorable outcomes in her job, she did report that family relationships suffered as a result of her "not being able to slow down." Many of these participants felt isolated and alone because of these challenges that they have faced. There was a sense of regret that was universally experienced by these participants.

### Theme: Seeking relief

With outcomes of impulsive behavior and an increase of challenges in life, the next reasonable step is to seek relief. Participants in the study had sought out different avenues for relief of the symptoms of bipolar disorder. The two definitions of the seeking that were explored when the words was used as a theme were a) "to attempt to find" and b) "ask for (something) from someone" (Oxford, 2010). Relief is defined as "a feeling of reassurance and relaxations following release from anxiety or distress" (Oxford, 2010). The participants had a variety of ways that relief from their mental illness was sought. Many of the participants sought relief from illegal and/or controlled substances. Some of the participants went to numerous healthcare providers seeking any kind of diagnosis and treatment that would help. In many cases, eight out of ten participants sought relief by self-harm as a last resort.

Seeking relief from substance abuse was the most common throughout the participants. Many of them had a substance addiction. Stella recalled "But I wasn't paying attention to like the things I knew were wrong. I just was kinda – pushed 'em to the back and lettin' 'em go. And then you turn to drugs and you turn to other ways you know how to cope" (Ln 404-497). Some participants used healthcare providers to get controlled prescription medications in order to seek relief. Sophie reported that she sought controlled substances through her medical doctor in order to use the medication as an "escape" "Yeah. But again, I was- I was lying about having it, you, cause I wanted to get Xanax"(Sophie, Ln 320-321).

Other participants sought legal and appropriate treatment for their symptoms. For example, many participants had prior mental health diagnoses and were given medications that were not effective. Ashley recalls the numerous medications that her medical provider tried her on before effective treatment was given: "So then he tried me – he must've tried about eight different things. "Well, you must be used to that one, so we'll give you that one. Well, this one might not be right. We'll give you that one." But it was just all out of my just regular general practice doctor, who knew absolutely nothing (Ashley, Ln 374-378). Self-harm was another form of seeking relief that many of the participants shared. Some participants have a long history of self-harm that started in adolescence. Avery always kept suicide in the back of his mind as a backup plan in case his moods never improved. For example, he reports "And a lot of the stuff that I've done was based on the contingency that I could just commit suicide and I wouldn't be in a particular situation and I wouldn't get stuck. You know? (Ln 181-183). Self-harm was also a recurring relief seeking behavior that many of the participants have had since adolescence. The best description of the moods and behaviors resulting in self-harm came from Bill:

Ah, the cutting was mostly angry. Like it wasn't a depressed, don't want to be here. Like it was always – like you can see the scars – some of 'em – on my arm. I would just get so mad. They're up there. And then even like the arguments with the, um, ex-girlfriend at the time – now, you know, current girlfriend. And I'd just – I'd get so mad I'd just need to hurt something. So I'd just, you know, take a knife to my arm. (Ln 221-227).

Whatever form of seeking relief the participants used, they were ineffective long term and some resulted in severe life changing consequences. For example, Stella recalled her experience of being in prison for years: "I actually went for involuntary manslaughter. It was – we were getting high together. And I bought the drugs and I shot him up, and he overdosed and died. And I called 9 - 1 - 1, and they charged me" (Stella, Ln 232-235).

What is most striking about listening to the participants describe their life experience prior to being diagnosed is the amount of repeated hardships that these participants went through. When symptoms of bipolar disorder are listed in a manual on a page, the list does not convey the severity of symptoms on a person's life. The literature focuses on suicide being the most severe consequence of having misdiagnosed or undiagnosed bipolar disorder (Birnbaum et al., 2003; Matza, Rajagopalan, Thompson, & de Lissovoy, 2005; Meyer & Meyer, 2009; Meyer et al., 2011; Tondo, Vazquez, & Baldessarini, 2010). Although, yes, suicide is the most severe consequence, the literature does not give insight to the lack of quality in the lives of these patients.

### Pattern: Receiving a new diagnosis of bipolar disorder

Participants were asked to describe how receiving a new diagnosis of bipolar disorder impacted their life, as compared to before the hospitalization. By their accounts and descriptions of their experience of receiving a new diagnosis of bipolar disorder, the following themes emerged: *Understanding the diagnosis* and *Reconciling the diagnosis*. Each participant in the study had experienced some form of relief in their bipolar disorder symptoms, since starting on the correct treatment. The two themes were chosen because they summarize the difficulties with social and self-stigma and the stages of acceptance that all the participants expressed in their interviews.

### Theme: Understanding the diagnosis

Bipolar disorder is a highly stigmatizing disorder and has led to patients not reporting or underreporting their symptoms due to fear of getting diagnosed. As in the literature, this was also true for the participants. The two definitions of understanding that were chosen were a) "an individual's perception or judgement of a situation" and b) "sympathetic awareness or tolerance" (Oxford, 2010). This word was chosen because many of the participants attributed lack of understanding about bipolar disorder to the stigma. Each participant in the study was newly diagnosed with bipolar disorder, however, many of them did not understand the illness. During many of the interviews, the graduate nurse researcher answered questions regarding what bipolar disorder is, how it is diagnosed, and how mania symptoms appear. In addition to asking for explanations about bipolar disorder, many of the participants described how they felt about people they knew who had bipolar disorder. As previously explained by Bonnington & Rose (2014) and supported by the results of this study, social stigma affects the way a person with bipolar disorder views the illness. For example, participants used phrases such as "you never know what to expect," "they are more crazy" and "people treat people differently if they know they have bipolar disorder."

Many of the participants described their own view of a person with bipolar disorder and did not think they had the same symptoms. Olivia, who worked in the field of mental health acknowledged the stigma that even mental health providers can have working with patients with bipolar disorder with the following statement: "As a (occupational reference) myself, I know the stigma where if you tell someone you're depressed versus tell somebody you're bipolar, even as a (occupational reference), you're viewed differently." In addition, three participants, during the interview, reported that did not understand terms related to their new diagnosis, such as "bipolar" and "mania." Sophie recalls her own experience with the stereotypical social stigma of bipolar disorder:

Well, I would say specifically like the bipolar. Because automatically I feel like my own stigma of bipolar is like, oh, man, this person's gonna be- they're up one minute, you know, and happy and they're gonna be awesome, and then they can be down like real fast" (Ln 343-346). Many of the participants reported feeling isolated and felt that people avoided them because of the disorder. For instance, Maggie stated in reference to how people treat people with bipolar disorder "they kind of stay distant from you (Ln 171).

The high level of stigma of bipolar disorder has been shown to have negative associations on self-esteem, social adjustment, perceived social support and lead to functional impairment (Ellison et al., 2013; Hawke et al., 2013). None of the participants described what they knew of bipolar disorder as positive. While these data support a perceived stigma towards patients of bipolar disorder, the myriad of phrases used represents new findings: Despite mental health awareness ads, campaigns, and community support groups in an effort to educate and reduce stigma, the social stigma of bipolar disorder has not been altered.

### Theme: Reconciling the diagnosis

All the participants had varying degrees of acceptance to the diagnosis of bipolar disorder. The definitions of reconcile are to "make or show to be compatible" and to "make someone accept (a disagreeable or unwelcome thing)" (Oxford, 2010). While none of the participants completely disagreed with the diagnosis, some reported mixed feelings and contributed their symptoms that lead to the diagnosis to drug use.

The terms "agreeing" and "disagreeing" were not chosen because all of the participants were in different stages of acceptance of the diagnosis. At the beginning of Sophie's interview, she heavily blamed the drug use as the reason for the diagnosis, however, toward the end of the interview she was more accepting of the diagnosis, she reported: "That'd be the only thing that I'd say. And I feel like the test, too, of taking it. Like I was on drugs, so I don't know if they took that into account or not. Like I – I wrote, "on drugs." You know? Cause, I mean- so , yeah, I think stuff like that should be taken into account. But other than that, I guess that's all" (Sophie, Ln 407-415). In contrast, several participants agreed that bipolar disorder fit their symptoms and explained years of impulsive moods and behavior. When asked if he agreed with the diagnosis, Sterling reported 'I agree one hundred percent" (Ln 26). Also, Maggie reported relief know that her symptoms could be explained and she reported "Um, it was – I guess it would be considered a relief knowing that there was a name to it (Ln 78-79).

Even when the participant identified with the symptoms and was starting to accept the diagnosis, the self-stigma was apparent in their stories. For example, Bill described his experience with going to the outpatient program as: "And even in the group and things, I would just – you know, "My name is so-and-so, and I'm here for this." And I'd be, "Oh, I'm here for depression" (Ln 53-55). Another example is Sophie's statement about actually putting her diagnosis on the daily mood survey in the outpatient program. She states:

You know, like I still- I just started writing on the paper here that have to fill out every morning. At the top where it says diagnosis, I just started putting bipolar on there. And I have been here like three weeks (Ln 191-194).

The participants in the study all had different levels of acceptance about their diagnosis. Recruitment for this study was done by posting flyers and patients contacting the graduate nurse researcher to sign up to participate in the study. This is important to note because all the participants had some basic level of acceptance to self-report they have been newly diagnosed with bipolar disorder. While the level of acceptance seemed

to be an individual phenomenon, there were similarities in the descriptions of how they felt once started on the mood stabilizers. Even if the participant did not agree with the diagnosis of bipolar disorder, all of the descriptions from the participants were positive when describing how the new medication was working comparative to previous medications or no medications at all.

### The Veteran's Story

Although veterans were heavily recruited, only one veteran volunteered and participated in the study. The veteran's (Ashley) description of her experience matching closely with the other nine participants, however, it is important to note that there were some differences. For example, Ashley reflected back on her career in the military and attributed much her success in her rank and status on undiagnosed manic symptoms. She gives examples of constantly wanting to do better in her job and please her boss, the commander in chief and working long hours, sometimes being in the office before anybody else and staying late in the evening after everybody was gone to ensure her job was done. Ashley does express hardships in other areas such as her marriage and family life suffered from her going constantly at her job and not having enough time for them. Ashley reports:

And somehow that worked, but it was a continuous fast-motion thing to where I had to feel like if I get that done, I get praised. But at the same time, everybody gets praised, but then that might mean that I can get my next stripe or I can get a better job. Which it did. Which it did. I was pulled from a base with a Colonel – with a General – no, with a Senior Mast Sergeant. He took me to every base

because I – I knew exactly how he worked. I knew what speech he needed – I could pull it (Ln 254-261).

Many of the participants, including Ashley, had excessive spending habits. However, the difference in Ashley, as compared to the rest of the participants is that Ashley made a lot of money during her manic episodes. Ashley reports that she bought her daughters brand new cars every year and \$100 outfits on a weekly basis. Looking back after being diagnosed and treated, she reports that she does not have any savings because of years of excessive spending. Ashley does admit that the military gave her structure and in the atmosphere of "going and going." She did not stand out and could function quite successfully. Another difference in Ashley as compared to the rest of the participants is that Ashley did not have current or a history of substance abuse. She did seek relief by going to different psychiatrists and healthcare providers to receive medical treatment and by starting multiple businesses to help her self-esteem when the depression episodes occurred. Ashley had many similarities, but also had differences in using some of the manic symptoms and behaviors to her advantage and success in one area of her life, the military.

### **Retrospective chart review**

The purpose of the retrospective chart review was to identify the incidence of how often patients are getting misdiagnosed with major depression disorder and switched to bipolar disorder. The occurrence of how often patients were screened and their treatment patterns were also explored. A second purpose was to identify if veterans had any difference in their diagnosis and treatments. The information presented in this section of the chapter describes the clinical characteristics of the patients were misdiagnosed and screened, as well as describing their specific treatment patterns.

### **Description of the sample**

One hundred patients were misdiagnosed with major depression disorder and switched to bipolar disorder and were screened for bipolar disorder once admitted to the psychiatric hospital. The sample ranged in age from 19 to 63 years of age with a mean age of 35.2 years (SD = 12.6). Fifty-one percent of the patients were men and 49% were women. The majority of the participants were Caucasian (87%). The remaining participants included African American (7%), Asian (3%), and unknown (3%). Education levels were as following: 11% of participants did not have a high school education or general education development (GED) certificate, 9% of participants only had a GED certificate, 20% only had a high school diploma, 39% of participants had some college, 4% of participants had an Associate's degree, 13% of participants had a Bachelor's degree, 2% had a graduate degree or high, and 2% did not answer. Majority of the sample were unemployed (41%), followed by employed (40%), disabled (8%), full-time student (8%), retired (2%), and homeless (1%) (See Table 2). Four percent of the sample were veterans.

#### Results

RQ3: Out of a total of patients from age 18-65 admitted to the psychiatric hospital between 01/01/2015-08/ 31/2016 what percentage of patients were admitted with a diagnosis of major depression disorder and then bipolar disorder, suggesting a misdiagnosis? Three thousand ninety-two patients were admitted to the psychiatric hospital between 01/01/2015-08/31/16. The total number of patients from this same time frame that were admitted with a diagnosis of major depression disorder and then were switched to bipolar disorder was 525. This means that 16.9% of patients had their diagnosis switched from major depression disorder to bipolar disorder.

RQ3a: Out of the total of patients that were switched from major depression disorder to bipolar disorder, what percentage of patients were screened for bipolar disorder?

Five hundred and twenty-five patients were admitted with a diagnosis of major depression disorder and switched to bipolar disorder. Out of that sample, only one hundred patients were screened for bipolar disorder. This means that only 5.2% of patients that had their diagnosis switched from major depression disorder to bipolar disorder were screened for bipolar disorder.

Out of the total number of patients who were misdiagnosed with bipolar disorder and screened for bipolar disorder:

Prior to admission to a psychiatric hospital:

**RQ4:** What were the clinical characteristics of the patients who were misdiagnosed and screened?

Descriptive statistics was utilized to determine the clinical characteristics of the sample (See Table 2).

**RQ4a:** What percentage of patients that were misdiagnosed and screened for bipolar disorder had prior suicide attempts? If yes, how many?

Fifty-two percent of patients did not have a prior suicide attempt. Of the 48% of patients that did have a prior suicide attempt, 30% of patients only had one attempt, 6% of patients had two prior attempts, 8% of patients had 3 attempts, 1% had six prior attempts, 1% had ten prior attempts, and one patient had twenty prior attempts.

### Upon admission to a psychiatric hospital:

RQ4b: What percentage of patients had a positive urine drug screen to identify if the patient was under the influence of a substance at the time of the admission? During inpatient hospitalization:

Majority of the patients had a positive urine drug screen upon admission. Fortynine percent had a positive urine drug screen upon admission, 35% had a negative urine drug screen and 16% of patients did not have a urine drug screen result in their chart. **RQ5:** What were the screening, diagnosis, and treatment patterns for patients with bipolar disorder that were misdiagnosed with major depression disorder? **RQ5a:** Screened positive for bipolar disorder, diagnosed with bipolar disorder, and switched from and an antidepressant to a mood stabilizer (lithium, carbamazepine, lamotrigine, or valproate) and/or antipsychotic (quetiapine, lurasidone, or aripiprazole)?

Fifty-one percent of patients screened positive for bipolar disorder and were switched from an antidepressant to at least one mood stabilizer.

**RQ5b:** Screened positive for bipolar disorder, diagnosed with bipolar disorder, and kept on the same or different antidepressant medication?

Four percent of patients screened positive and were not started on a mood stabilizer.

**RQ5c:** (Pre-hospital diagnosis of major depression disorder and previously prescribed mood stabilizers) Screened positive for bipolar disorder, diagnosed with bipolar disorder, and were kept on the same mood stabilizer previously prescribed?

Seven percent of patients who had a pre-hospital diagnosis of major depression disorder and previously prescribed mood stabilizers, screened positive for bipolar disorder, diagnosed with bipolar disorder, and were kept on the same mood stabilizer previously prescribed.

RQ5d: Screened negative for bipolar disorder, diagnosed with bipolar disorder, and switched from an antidepressant to a mood stabilizer (lithium, carbamazepine, lamotrigine, or valproate) and/or antipsychotic (quetiapine, lurasidone, or aripiprazole)?

Thirty-seven percent of patients were switched to a mood stabilizer who screened negative for bipolar disorder.

**RQ5e:** Screened negative for bipolar disorder, diagnosed with bipolar disorder, and kept on the same or different antidepressant medication?

None of the patients in the sample screened negative for bipolar disorder, diagnosed with bipolar disorder, and kept on the same or different antidepressant medication.

**RQ5f:** (Pre-hospital diagnosis of major depression disorder and previously prescribed mood stabilizers) Screened negative for bipolar disorder, were diagnosed with bipolar disorder, and kept on the same mood stabilizer previously prescribed?

One percent of patients had a pre-hospital diagnosis of major depression disorder and previously prescribed mood stabilizers, screened negative for bipolar disorder, were diagnosed with bipolar disorder, and kept on the same mood stabilizer previously prescribed.

## **RQ6:** What day of inpatient hospitalization were patients switched from an antidepressant to a mood stabilizer and/or an antipsychotic?

Of the patients who were switched from an antidepressant to a mood stabilizer and/or antipsychotic medication, 13% of patients were switched on the first day of admission, 34% were switched on admission day two, 44% of patients were switched on admission day three, 6% of patients were switched on admission day four, 2% were switched on admission day five and 1% of patients were switched on admission day six.

# **RQ7:** What differences are there regarding **RQ4-6** when comparing veterans to nonveterans?

There were no significant differences in treatment patterns in the veterans compared to non-veterans.

### **Summary of Results**

The findings of this focused ethnography supported and expanded existing knowledge about the experience of being newly diagnosed with bipolar disorder. Two patterns and five themes were validated from multiple peer and member checks throughout the thematic analysis. In addition, various treatment patterns were recognized in the retrospective chart review.

Living with undiagnosed bipolar disorder can be emotionally exhausting due to patients' uncertainty of moods and behavior. During the interview, participants distinguished their impulsive moods and behaviors as abnormal and uncontrollable. Many of them described their lives prior to receiving a diagnosis of bipolar disorder as chaotic and full of emotional instability. Due to these extreme periods of moods and behavior, participants in the study described severe consequences throughout their lives. The theme, suffering life challenges, emerged from the transcripts because participants had severe relationship, financial, and employment difficulties. The results from the retrospective chart review revealed that 41% was unemployed, a life challenge.

As a result of impulsive moods and behaviors and consequently severe life challenges caused by untreated bipolar disorder, the participants sought relief in various ways. For example, all but one of them sought relief through illicit drug use. In agreement with the in-depth interviews, 49% of patients in the retrospective chart review had positive drug screens upon admission. Both findings support the available literature that states that patients with bipolar disorder have a high percentage of co-occurring substance use (Balanza-Martinez, Crespo-Facooro, Gonzalez-Pinto, & Vieta, 2015). Another way that most participants sought relief was by acting on the impulse to selfharm. The retrospective chart review also found that almost half (48%) of the patients had at least one previous suicide attempt. Both of these findings support the literature that states that patients with bipolar disorder have a very high percentage of suicide attempts and completed suicides (Tondo, Lepri, & Baldessarini, 2007; Goodman et al.).

According to the literature, it takes patients 7-10 years on average to receive the correct diagnosis and treatment (Nasrallah, 2015). Both the in-depth interviews and retrospective chart review findings support this concept. For instance, most of the participants in the in-depth interviews had seen numerous health care providers and had multiple diagnoses over the course of their lifetime before receiving the diagnosis of bipolar disorder. In addition, the results from the retrospective chart review showed that

16.9% of all patients admitted to the psychiatric hospital over 1.5 years had a previous diagnosis of major depression disorder and, after a psychiatric assessment, their diagnosis was switched to bipolar disorder. The retrospective chart review showed that out of the total number of patients that had their diagnosis switched from major depression disorder to bipolar disorder, only 5.2% of patients were screened for bipolar disorder.

The introduction of the diagnosis of bipolar disorder leads to proper pharmacological treatment and management (Shi, Thiebaud, & McCombs, 2004). The retrospective chart review gave detailed results regarding the treatment patterns before and after the patient's diagnosis was switched to bipolar disorder. The best treatment pattern was for the patient to have a positive screening, receive the diagnosis of bipolar disorder, and then have their medication switched from an antidepressant to a mood stabilizer. The results showed that 51% of patients received this best treatment pattern. Regarding the next treatment pattern, a small percentage (4%) of patients screened positive for bipolar disorder, were diagnosed with bipolar disorder, yet were not given the preferred treatment, a mood stabilizer, in the hospital. According to their patient records, this was due to three patient-specific circumstances: (a) one patient refused all medications and was discharged without any home medication prescribed; (b) one patient had a positive pregnancy test and was kept on the same home antidepressant; and (c) one patient was only started on an anti-anxiety medication.

A third treatment pattern we examined showed that 7% of patients were found to be already on a mood stabilizer, screened positive for bipolar disorder, diagnosed with bipolar disorder, and were kept on the same mood stabilizer. Although this was not an expected finding, there is literature that could possibly explain this phenomenon. For instance, providers may be reluctant to diagnose bipolar disorder unless there is absolute certainty due to the high stigma surrounding this disorder (Bonnington & Rose, 2014; Griffiths et al.; Nasrallah, 2015). This would explain why a provider would diagnose a patient with major depression disorder, however, and treat their symptoms with a mood stabilizer.

There still appears to be ambiguity on how bipolar disorder is diagnosed and treated. For example, regarding a fourth treatment pattern, 37% of patients screened negative for bipolar disorder and diagnosed with bipolar disorder were still switched from an anti-depressant to a mood stabilizer. There are several reasons why this might have occurred. It is well documented in the literature that patients will feel embarrassed and ashamed of their moods and behavior and as a result do not report or underreport that symptoms. As a result, the screening instrument is only as valid as the truthfulness of the patient completing it. For example, one of the participants from the in-depth interview reported that she did not feel comfortable reporting her symptoms to her healthcare provider because she felt embarrassed and stated that she did not feel comfortable telling her healthcare provider. This puts the pressure on the mental health provider to do a thorough assessment and make a clinical judgement that is going to be best for the patient. Another reason for this occurrence could be that if the patient has failed multiple trials on antidepressants, that switching to a different category of medications could help minimize the symptoms. Many participants in the in-depth interviews reported that they were started on many different antidepressants without success; this is another reason to suspect bipolar disorder. Regarding a fifth treatment pattern, one patient (1%) was already on a mood stabilizer, screened negative for bipolar disorder, diagnosed with

bipolar disorder, and was kept on the same mood stabilizer. This could be case if the patient is not reporting or underreporting their symptoms and the healthcare provider makes a clinical judgement to treat for bipolar disorder anyway. This ambiguity can make it difficult for patients to reconcile the diagnosis of bipolar disorder.

Together the in-depth interviews and retrospective chart review add depth and richness to what is known about bipolar disorder. For example, 9 out of 10 participants reported that, in addition to major depression disorder, they had other previous mental health diagnoses such as attention deficit hyperactivity disorder and general anxiety disorder. Most literature on bipolar disorder is from the healthcare providers' perspective in regard to diagnosis and treatment. However, this focused ethnography concentrates on the patients' experience of receiving a diagnosis of bipolar disorder. By having both the in-depth interviews and retrospective chart review in this study, the data represents a more complete picture of the experience of receiving a new diagnosis of bipolar disorder. In many cases, both the in-depth interviews and retrospective chart review validated each other.

### **Chapter V: Discussion**

### Introduction

The findings of this study emerged from a process that included in-depth interviews and a retrospective chart review. Data collection occurred over a four-month period. In this final chapter, rethinking of the diagnosis of bipolar disorder; implications to research, practice, education, and policy; recommendations for future research; conclusions; and the epilogue are presented.

### **Rethinking the Diagnosis of Bipolar Disorder**

The DSM-5 defines bipolar disorder as periods of depression occurring interchangeably with periods of mania (APA, 2014). The healthcare provider uses a standard process and matches the periods of symptoms to the criteria from the DSM-5, confirming the diagnosis of bipolar disorder (APA, 2014). Also, the literature states that the average time it takes a patient to receive a diagnosis of bipolar disorder is 7-10 years. There is substantial body of literature that addresses the complexity of diagnosing bipolar disorder, such as difficulty deciphering symptoms that apply to multiple disorders, patients not reporting or underreporting their symptoms, and lack of appropriate screening by healthcare providers (Michalak, Livingston, Maxwell, Hole, Hawke, & Parikh, 2014). What this focused ethnography adds is new information about the experiences of persons eventually diagnosed with bipolar disorder, including how previously untreated or mistreated periods affects lives prior to the diagnosis. For instance, one of the symptoms of mania is excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., engaging in impulsive buying sprees, foolish business investments, or sexual indiscretions). One of the participants

described her experience of how she felt when she was impulsively buying and the regret and guilt she felt when the credit card statement came in. These data reinforce the importance of focusing on the holistic well-being of the patient, including the social interactions, and not just the diagnosis.

At the beginning of the study, the graduate nurse researcher believed that all of the participants would be in disagreement with the bipolar disorder diagnosis. However, data from the in-depth interviews showed varying degrees of accepting the diagnosis. Some participants felt relief that there was a name for their symptoms. In fact, one of the participants reported that she felt so strongly that she had bipolar disorder that she kept asking her psychiatrist if he thought she had bipolar disorder. However, a few participants attributed their manic symptoms to their substance use and were still reconciling the diagnosis of bipolar disorder. Recovery starts with the stages of reconciling the acceptance of the diagnosis. Above and beyond the issue of having a correct or incorrect diagnosis, the crux of the issue is how patients respond to the diagnosis. Therefore, it is not the diagnosis, but the diagnostic event that serves an opening for a better life.

From the patient's perspective, the diagnosis of bipolar disorder was not as important as the opportunity the diagnosis gave patients toward having more control over their moods and behavior. This was evident in the majority of the participants' accounts. They described how the diagnosis and treatment changed their outlook regarding their mental health. For instance, participants stated they are now on a better regimen to ensure they take her medication every day, keep a more structured schedule to increase medication compliance, slow down when getting angry, and recognize the triggers for periods of depression and mania. The data from the in-depth interviews also showed that receiving the diagnosis is the beginning to achieving better outcomes in mental health. Data from the in-depth interviews showed that the participants that had a higher level of acceptance of the diagnosis of bipolar disorder were already implementing improved choices for their mental health.

This study elucidated the experience of receiving a new diagnosis of bipolar disorder. The analysis of in-depth interviews revealed symptoms that are commonly found in patients with bipolar disorder and the severe life challenges that in many ways altered participants' life choices and life paths. The participants' stories and analyzing these texts along with the data from the retrospective chart review emphasized the point that receiving a diagnosis can change the trajectory of a condition. The diagnosis itself is a part but not the whole phenomenon demanding attention. Rendering an accurate diagnosis is insufficient in meeting the needs of members of this population. The question of accurate verses inaccurate diagnoses of bipolar disorder was overshadowed by the revelation of substantial experiential matters that characterized the lives of participants before and up to the diagnosis. Healthcare providers must assess the progress of treatment in patients and re-examine it frequently. What was learned in this analysis was that the correct diagnosis is important and is pivotal, but the subsequent management of symptoms and life circumstances are needed to alter the life courses of persons who reach the point of diagnosis.

### Implications

### Research

There is a paucity of qualitative research on patients with bipolar disorder. Of the research studies that are available, none of them explored the experience of a patient that was newly diagnosed with bipolar disorder. Not only was social and self-stigma identified in the current study, but also the daily life challenges and events that patients with bipolar disorder described before and after the diagnosis. This study should be replicated in different urban and rural geographical areas, as well in more current military and veterans. Once larger groups of patients with bipolar disorder are involved in studies, then an intervention study using Leininger's Sunrise Model could be proposed, funding obtained, and then implemented.

The experience of having bipolar disorder, including challenges and events that happened in a person's life before and after diagnosis has been virtually ignored in the research. Many questions remain such as: What percentage of patients with bipolar disorder stay on their medications continually? What are some of the reasons that patients with bipolar disorder feel that they can stop taking their medications? What do family members of patients with bipolar disorder experience at various time points after receiving the diagnosis of bipolar disorder? Answers to these questions will help health care providers understand patients' lifelong response to this illness after the initial diagnosis has been made.

### Practice

The results of this research have provided a new and rich description of the impact that bipolar disorder, whether undiagnosed or diagnosed, has on a person's life.

These experiences of the participants provide valuable information to nurses, healthcare providers, social workers, and therapists. While the general public endorses stigmatizing attitudes towards patients with bipolar disorder, few studies have focused exclusively on why patients with bipolar disorder feel so stigmatized or examined stigma experiences of people diagnosed with it (Bonnington & Rose, 2014). These individuals with bipolar disorder are at risk for serious physical and psychological consequences associated with their moods and behavior.

Patients with bipolar disorder needs to be seen in practice as a culture. Therefore, interventions must be culturally sound. As nurses and nurse practitioners assist with the designing and implementation of community mental health support programs, these programs need to be developed that target this vulnerable population, and interventions designed that address their specific concerns revealed in this study.

### Education

This research has implications for patient/family education, nursing staff education, and nursing curriculum. Education of patients is essential to help with medication and treatment compliance. Many participants in the in-depth interviews reported that they did not know what bipolar disorder and mania were. The more that the patient knows about bipolar disorder, including the periods of depression cycling with the periods of mania, the easier it will be to understand their moods and behaviors. Also, educating the family may help give the patient a stronger support system. Patients and families need to recognize causes that may trigger a depressive or manic episode, such as not getting enough sleep. Nursing staff need to be aware of the symptoms of bipolar disorder and recognize subtle symptoms that, if treated, may prevent a severe episode of depression or mania.

Psychiatric nursing curricula needs to be revised to educate students about the experiences of patients in response to receiving a new diagnosis of bipolar disorder. A major focus needs to be aimed at reducing stigma and helping raise awareness about bipolar disorder. Every patient has the potential of having bipolar disorder. By providing insight into how the patient experiences bipolar disorder, a nurse in any healthcare setting would have a baseline knowledge that could help him/her recognize early symptoms. In addition, signs and symptoms of suicidality need to be taught to students and reviewed every year.

### **Policy**

In light of these findings from both the in-depth interviews and retrospective chart review, a protocol in needed that requires screening to rule out bipolar disorder before any antidepressant is prescribed. Screening instruments, such as the MDQ, usually takes a patient 10 minutes to complete and can be independently filled out. In addition, recommended screening should be completed after any suicidal attempt and done annually if the patient is prescribed any psychiatric medications. These protocols should be implemented in both primary and mental health settings.

### **Recommendations for Future Research**

This study provided a voice for patients who have been newly diagnosed with bipolar disorder. The interviews revealed important challenges that patients are facing in their families, their relationships, the healthcare system, and society in general. The information that the participants shared gives healthcare providers an opportunity to adapt the delivery of care, starting from the first office visit, in order to promote more positive outcomes for this population.

Difficulties in their relationships was very apparent in participants' stories. In light of this, an interpretive research study focusing on the families of a person with bipolar disorder would be important. A study focused specifically on spouses or on parents of adult children might reveal differences in coping strategies as compared to the patients. This research may also increase understanding as to how the symptoms of bipolar disorder affect family dynamics.

An intervention study piloting the feasibility of screening tools by primary healthcare providers, as well as mental health providers, would also be useful. Although the data from the in-depth interviews indicate that most of the participants did see a provider before and obtained a diagnosis other than bipolar disorder, none of them recalled being screened for bipolar disorder. Additionally, obtaining data regarding how often inpatient healthcare providers use screening and if there are any barriers to the screening may identify the reasons why screening is inconsistent so necessary changes can be implemented in practice.

### Conclusion

The major findings in this focused ethnography supported and expanded the previously existing knowledge about the complexity of bipolar disorder. Their experiences have confirmed that patients with bipolar disorder have unique life circumstances that are not very well understood by themselves or society. The use of a focused ethnography was adept in acquiring new information on these participants who have been newly diagnosed with bipolar disorder. A deeper understanding of the social and cultural context was gained within this population.

### Epilogue

As a psychiatric mental health nurse practitioner, this study changed the way I diagnose and treat patients. This focused ethnography reminds me that every time I diagnose a patient, the patient is not just a list of symptoms, but a person that, because of the symptoms, may have been exposed to many difficult life challenges. It is an opportunity for me as a clinician, not only to prescribe medication, but to improve the life of patients with bipolar disorder. After hearing the stories of the participants, it reminds me that every day that patients sometimes go untreated, and that delay can have detrimental effects. A change that I have made in my practice since the completion of the study is that I screen every patient for bipolar disorder. In addition to screening, I ask about relationships, difficult situations where they felt out of control, and about suicidality. Instead of just looking at a positive or negative drug screen, I ask the patient what was going on when they decided to use the drug. By incorporating these changes, I am more prepared to recognize symptoms of bipolar disorder sooner and more effectively.

	%		%
Sex		Race	
Male	30%	Caucasian	90%
Female	70%	African American	10%
Age Range		Education Level	
19-29 years of age	40%	Below a high school education	10%
30-39 years of age	40%	High school	40%
40-49 years of age	10%	Associate's degree	20%
50-61 years of age	10%	Bachelor's degree	10%
Employment Status		Master's degree	20%
Unemployed	40%	Age at First Psychiatric Diagnosis	
Employed	50%	Before age 18 years old	30%
Retired	10%	19-25 years old	10%
Family History of Mental Illness		26-35 years old	40%
Yes	80%	36-46 years old	10%
No	20%	Unknown	10%

### Table 1: In-depth Interview Demographic Data

	%		%
Gender		Employment Status	
Male	51%	Disability	8%
Female	49%	Unemployed	41%
Race		Employed	40%
White	87%	Student	8%
African American	7%	Retired	2%
Asian	2%	Homeless	1%
Missing Data	4%	Veteran	
Education Level		No	96%
No GED or High school diploma	11%	Yes	4%
GED	9%		
High school diploma	20%		
Some college	39%		
Associate's degree	4%		
Bachelor's degree	13%		
Graduate degree or higher	2%		
Missing data	2%		

 Table 2: Retrospective Chart Review Patient Clinical Characteristics

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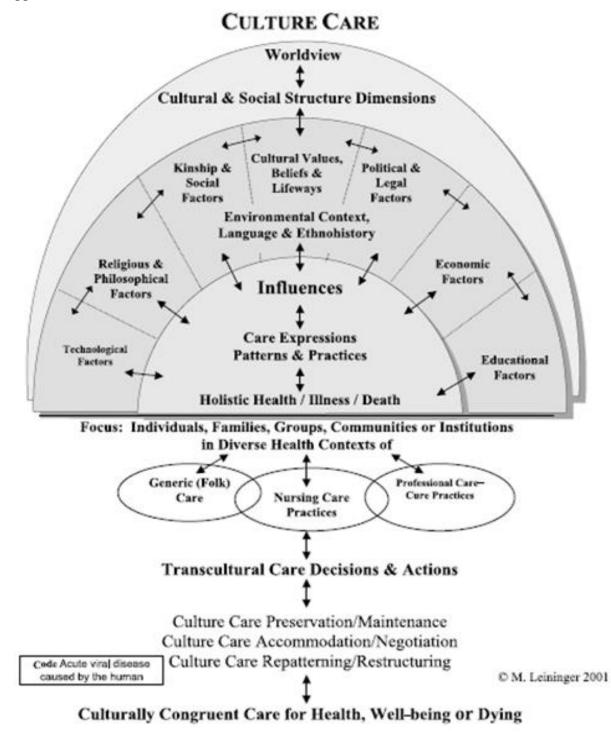
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Appendix A. The Sunrise Model

Appendix B. The Mood Disorder Questionnaire

Appendix B. The Mood Disorder Questionnaire		110
<b>1.</b> Has there ever been a period of time when you were not your usual self and	YES	NO
You felt so good/hyper that other people thought you were not your		
normal self or so much that you got in trouble?		
You were so irritable that you shouted at people or started fights or		
arguments?		
You felt much more self-confident than usual?		
You got much less sleep than usual and found you didn't really miss it?		
You were much more talkative or spoke much faster than usual?		
Your thoughts raced through your head or you couldn't slow your mind down?		
You were so easily distracted by things around you that you had trouble concentrating or staying on track?		
You had much more energy than usual?		
You were much more active or did many more things than usual?		
You were much more social or outgoing than usual, for example, you		
telephoned friends in the middle of the night?		
You were much more interested in sex than usual?		
You did things that were unusual for you or that other people might have		
thought were excessive, foolish, or risky?		
Spending money got you or your family into trouble?		
2. If you checked YES to more than one of the above, have several of		
these ever happened during the same period of time?		
3. How much of a problem did any of these cause you – like being	NA	NA
unable to work; having family, money or legal troubles; getting into		
arguments or fights? Please circle one response only.		
NO PROBLEM		
MINOR PROBLEM		
MODERATE PROBLEM		
SERIOUS PROBLEM		
<b>4.</b> Have any of your blood relatives (i.e. children, siblings, parents, grandparents, aunts, uncles) had manic-depressive illness or bipolar disorder?		
5. Has a health professional ever told you that you have manic- depressive illness?		

Appendix C. The Hypomanic Checklist-32

1) First of all, how are you feeling today compared to your usual state: (Please mark only one of the following)

		<b></b>				
Much	Worse	A little	Neither	A little	Better	Much
worse	than	worse	better nor	better	than	better
than	usual	than	worse	than	usual	than
usual		usual	than usual	usual		usual

2) How are you usually compared to other people? Independently of how you feel today, please tell us how you are normally compared to other people, by marking which of the following statements describes you best? Compared to other people my level of activity, energy, and mood.... (Please mark only one of the following)

is always rather stable and even	is generally higher	is generally lower	repeatedly shows periods of ups and downs

3) Please try to remember a period when you were in a "high or hyper" state. How did you feel then? Please check all the statements that happen during a high or hyper state.

In such a "high or hyper" state:

	YES	NO
1. I need less sleep		
2. I feel more energetic and more active		
3. I am more self- confident		
4. I enjoy my work more		
5. I am more sociable (make more phone calls, go out more)		
6. I want to travel and/or do travel		

moro	
more	
7. I tend to driver faster or take more risks when driving	
8. I spend more money/too much money	
9. I take more risks in my daily life (in my work and/or other activites)	
10. I am physically more active (sports, etc)	
11. I plan more activities or projects	
12. I have more ideas, I am more creative	
13. I am less shy or inhibited	
14. I wear more colorful and more extravagant clothes/make up	
15. I want to meet or actually do meet more people	
16. I am more interested in sex, and/or have increased sexual desire	
17. I am more flirtatious and/or am more sexually active	

18. I talk more	
19. I think more	
20. I make more jokes or puns when I am talking	
21. I am more easily distracted	
22. I engaged in lots of new things	
23. My thoughts jump from topic to topic	
24. I do things more quickly and/or more easily	
25. I am more impatient and/or get irritable more easily	
26. I can be exhausting or irritating to others	
27. I get into more quarrels	
28. My mood is higher, more optimistic	
29. I drink more coffee	
30. I smoke more cigarettes	
31. I drink more alcohol	
32. I take more drugs (sedatives, anxiolytics, stimulants)	

(Please mark only one of the following)	
sometimes?	If you mark this box, please answer all questions 5 to 9
most of the time?	If you mark this box, please answer only questions 5 and 6
I never experienced such a "high"	If you mark this box, please stop here

4) Did the previous chart, which characterize a "high", describe how you are... (Please mark only one of the following)

## 5) Impact of your "highs" on various aspects of your life:

	0		, ei j euei	
	Positive and negative	Positive	Negative	No Impact
Family Life				
Social Life				
Work				
Leisure				

6) How did people close to you react to or comment on your "highs"? (please mark one of the following)

Positively (encouraging or supportive)	Neutral	Negatively (concerned, annoyed, irritated, critical)	Positively and negatively	No reactions

7) Length of your "highs" as a rule (on the average): (please mark one of the following)

1 day	2-3 days	4-7 days	Longer than a week	Longer than a month	I can't judge/don't know

8) Have you experienced such "highs" in the past twelve months?

Yes	No

9) If yes, please estimate how many days you spent in "highs" during the last twelve months: Taking all together: about \_\_\_\_\_\_ days

#### Appendix D. Semi-Structure Interview Guide

ID# \_\_\_\_\_

### 1. Tell me what it is like to be newly diagnosed with bipolar disorder.

Possible subsequent queries:

Is there anything else that you remember about that experience?

Other possible queries:

Think about how your life was before you were admitted to the psychiatric hospital.

Compared to your life before being admitted, tell me what, if any, difference the new

diagnosis has made.

What events lead you to being admitted to the psychiatric hospital?

What kind of mood symptoms were you having before hospitalization?

What is your experience with medication?

Help me understand how this whole experience has impacted your life.

Is there anything that could have been done differently in terms of your diagnosis?

### The following query is for veterans only:

2. Tell me about what it is like to be a veteran with bipolar disorder.

Possible subsequent query:

How has the military impacted your mental health?

## WE NEED YOUR HELP!!

## Are you between the ages of 18 and 65?

# Have you recently been diagnosed with bipolar disorder?

Adults age 18-65 that have been newly diagnosed with bipolar disorder are wanted for participation in a study about bipolar disorder. This research study is being conducted by Centerpointe Hospital and University of Missouri-St. Louis. Participants will attend one 90 minute session. The session will include questions regarding your recent diagnosis of bipolar disorder. You will be compensated for your time. All information you provide as part of this study will be strictly confidential.

> *For more information, please call: Brandie Stiles, Nurse Practitioner 314-791-7346*

Appendix F: Telephone Script to be Used When Potential Participants Call

Hello, this is Brandie Stiles. Can I help you?

I am Brandie Stiles, a nurse practitioner from Centerpointe Hospital, but I am not involved in your care and will not be your health care provider. Are you calling today regarding the research study about bipolar disorder? I am wondering if you have an interest in hearing about the study.

Were you recently diagnosed with bipolar disorder?

If yes, proceed to the following script:

The purpose of the study is to understand patients' experiences with having bipolar disorder. The visit will be held at one of the many Psych Care Consultants physicians' offices. You can choose whichever one is closest to you. The visit will take 90 minutes and I will ask you some questions about yourself. All information will be confidential. The study compensation is a \$20 Target gift card and a \$5 Quik-Trip gas card.

Do you think you are interested in being part of the study? Do you have any questions? (pause)

Given you have shown an interest, I would like to set up the 90-minute visit with you. Let's talk about which office is the closest to you. (pause to give directions)

Do you have any questions? I would like to give you my cell phone number in case you wish to contact me.

or

(If not interested, thank the person).

Appendix G. Focused Ethnography Demographic and Clinical Data Form

ID#:	
Age:	
Sex: M F Race:	
Highest grade completed:	
Employment status:	
Age at first psychiatric diagnosis:	
Veteran: Y N	
Years of service:	
Age of military enrollment:	
Have you ever been diagnosed with posttraumatic stress disorder? Y N	-
Do you have a family history of mental illness? YN	
If yes, what relative and diagnosis:	

			Stiles, Brandie	e, 2016, UMSL, p. 139
Appendix H. Data Th	at Will be Obtain	ed From the D	atabase	
ID#:				
Age:				
Sex: M F		Race	:	
Highest grade comp	oleted:			
Employment status:	·			
Veteran: Y	N			
Prior suicide attemp	ots: Y	_ N	If yes, how many_	
Drug screen on adm	nission to the psy	ychiatric hosp	oital: Positive	_Negative
switched from and a lamotrigine, or valp Y N Screened positive for	proate) and/or an	tipsychotic (d	uetiapine, lurasido	ne, or aripiprazole)?
kept on the same or				
Y N				
Screened negative f switched from an ar lamotrigine, or valp	ntidepressant to a	a mood stabil	izer (lithium, carba	disorder, and were mazepine, ne, or aripiprazole)?
Y N	[			
Screened negative f the same or differen				disorder, and kept on
Y N	r			
Innatient hospital da	av natient switch	ned from an a	ntide <b>nr</b> essant to a n	nood stabilizer and/or

Inpatient hospital day patient switched from an antidepressant to a mood stabilizer and/or an antipsychotic?\_\_\_\_\_

Appendix I. COLUMBIA-SUICIDE SEVERITY RATING SCALE Screener/Recent – Self-Report

	In T Past Mon	_
Answer Questions 1 and 2	YE S	NO
1. Have you wished you were dead or wished you could go to sleep and not wake up?		
2. Have you actually had any thoughts about killing yourself?		-
If <b>YES</b> to 2, answer questions 3, 4, 5, and 6. If <b>NO</b> to 2, go directly to questions	stion 6	
3. Have you thought about how you might do this?	+	
<b>4.</b> Have you had any intention of acting on these thoughts of killing yourself, as opposed to you have the thoughts but you definitely would not act on them?		
5. Have you started to work out or worked out the details of how to kill yourself? Do you intend to carry out this plan?		
	In th Past Mon	3
6. Have you done anything, started to do anything, or prepared to do anything to end your life?		
Examples: Collected pills, obtained a gun, gave away valuables, wrote a will or suicide note, took out pills but didn't swallow any, held a gun but changed your mind or it was grabbed from your hand, went to the roof but didn't jump; or actually took pills, tried to shoot yourself, cut yourself, tried to hang yourself, etc.		
In your entire lifetime, how many times have you done any of these things?		

#### How CenterPointe Hospital May Use or Disclose Your Health Information:

For Treatment. CenterPointe Hospital may use your health information to provide you with medical treatment or services. For example, information obtained by a health care provider, such as a physician, nurse, or other person providing health services to you, will record information in your record that is related to your treatment.

CPH 9-SSL135A (4/11/14) Policy Reference: HC.028

for that person to be involved in your care or payment related to your care. CenterPointe Hospital may also disclose health information to those assisting in disaster relief efforts so that others can be notified about your condition, status and location.

 Fundraising. CenterPointe Hospital does not use your information for fundraising communications.

CenterPointe

NOTICE OF HEALTH INFORMATION PRIVACY PRACTICES Effective as of September 1, 2013

## This Notice Describes How Health Information About You May Be Used And Disclosed And How You Can Get Access To This Information. Please Review It Carefully.

If you have any questions about this notice, please contact the Privacy Officer at (636) 441-7300.

#### In the event that the patient is a minor, this notice describes how health information may be used and disclosed about the minor patient

#### This Notice Describes Our Practices and Those Of:

- Any health care professional allowed to enter information into your chart;
- Any volunteer we allow to help you while you are here; and
- All employees of any hospital, clinic, laboratory, or other facility affiliated with CenterPointe Hospital.
  - All of these people follow the terms of this notice. They may also share protected health information with each other for treatment. payment or health care operations as described in this notice

Our Pledge Regarding Health Information: CenterPointe Hospital uses health information about you for treatment, to obtain payment for treatment, for administrative purposes, and to evaluate the quality of care that you receive. Your health information is contained in a medical record that is the physical property of CenterPointe Hospital.

- We understand that health information about you and your health is personal.
- We are committed to protecting health information about you.
- This notice will tell you about the ways in which we may use and disclose health information about you.
- We also describe your rights and certain obligations we have regarding the use and disclosure of health information

#### CenterPointe Hospital Is Required By Law To:

- Make sure that health information that identifies you is kept private: Give you this notice of our legal duties and privacy
- practices with respect to medical information about you:
- Accommodate reasonable requests you may make to communicate health information by alternative means or at alternative locations:
- Follow the terms of the notice that is currently in effect.

#### How CenterPointe Hospital May Use or Disclose Your Health Information:

For Treatment. CenterPointe Hospital may use your health information to provide you with medical treatment or services. For example, information obtained by a health care provider, such as a physician, nurse, or other person providing health services to you, will record information in your record that is related to your treatm ant

CPH 9-SSL125A (4/11/14) Policy Reference: HC.028

This information is necessary for health care providers to determine what treatment you should receive. Health care providers will also record actions taken by them in the course of your treatment and note how you respond to the actions.

- For Payment. CenterPointe Hospital may use and disclose your health information to others for purposes of receiving payment for treatment and services th you receive. For example, a bill may be sent to you or a third-party payor, such as an insurance company, HMO or health plan. The information on the bill may contain information that identifies you, your diagnosis, and treatment or supplies used in the course of treatment. Or, unpaid service balances may be referred to a collection agency to obtain payment.
- For Health Care Operations. CenterPointe Hospital may use and disclose health information about you for operational purposes. For example, your health information may be disclosed to members of the medical staff, risk or quality improvement personnel, and others to:
  - Evaluate the performance of our staff; ۶ Assess the quality of care and outcomes in your case and similar cases;
  - Learn how to improve our facilities and services; × and
  - Determine how to continually improve the quality and effectiveness of the health care we provide.
- Facility Directory. CenterPointe Hospital does not use your information for a facility directory.
- Clergy. Unless you inform us that we should not do so. your religious affiliation may be released to a member of the clergy even if they do not ask for you by name.
- D Appointments/Health-Related Products and Services. CenterPointe Hospital may use your information to contact you to provide appointment reminders. CenterPointe Hospital may also contact you to tell you about treatment alternatives or other healthrelated benefits and services that may be of interest to vou
- Others Involved In Your Care. CenterPointe Hospital may release relevant health information to a family member, friend, or anyone else you designate in order for that person to be involved in your care or payment related to your care. CenterPointe Hospital may also disclose health information to those assisting in disaster relief efforts so that others can be notified about your condition, status and location.
- Fundraising. CenterPointe Hospital does not use your information for fundraising communications.

Appendix K: Administrative Letter of Approval



4801 Weldon Spring Parkway St. Charles, MO 63304

May 16,2016

To the Chair of the UMSL IRB:

I am pleased, as the Chief Medical Officer of Centerpointe Behavioral Health Systems, to provide this administrative approval letter in regard to the research study entitled, Identify the Complexity of Bipolar Disorder: A Focused Ethnography and Retrospective Chart Review conducted by Brandie Stiles, doctoral student at the University of Missouri-St. Louis. On behalf of the hospital and the administrative team, I give her permission to utilize patients 4-6 weeks post-discharge and the Psych Care Consultants physician offices for the sessions for the focused ethnography. This means that the permission is for the entire facility, including any providers' patients. In addition, she will be given access to a de-identified database for the retrospective chart review.

Thank you,

Azfar Malik, M.D., MBA CMO and President CenterPointe Behavioral Health Systems

Appendix L. Informed Consent

College of Nursing



8001 Natural Bridge Road St. Louis, Missouri 63121-4499 Telephone: 314-516-6066 Fax: 314-516-7082 E-mail: <u>stilesb@umsl.edu</u>

**Informed Consent for Participation in Research Activities** 

Identifying the Complexity of Bipolar Disorder: A Focused Ethnography

Participant \_\_\_\_\_\_HSC Approval Number \_\_\_\_\_

Principal Investigator: Brandie Stiles

PI's Phone Number: 314-791-736

## Why am I being asked to participate?

You are invited to participate in a research study about your experience with having a new diagnosis of bipolar disorder conducted by Brandie Stiles, a doctoral student at the College of Nursing, University of Missouri-St. Louis, and a psychiatric mental health nurse practitioner at Centerpointe Hospital. You have been asked to participate in the research because you have been newly diagnosed and may be eligible to participate. We ask that you read this form and ask any questions you may have before agreeing to be in the research. Your participation in this research is voluntary. Your decision whether to participate will not affect your current or future relations with the University or Centerpointe Hospital. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

## What is the purpose of this research?

To understand your experience with having bipolar disorder.

#### What procedures are involved?

If you agree to participate in this research, you can expect:

- To be asked about your experience with bipolar disorder before, during, and after diagnosis.
- The total length of the one session will be 90 minutes, which includes 15 minutes for introductions, 60 minutes for a semi-structured interview, and 15 minutes for a debriefing session. The session will be audiotaped and will take place at a Psych Care Consultants physician office in the St. Louis/St. Louis County area closest to you.

Approximately 15 participants may be involved in this research at the University of Missouri-St. Louis.

## What are the potential risks and discomforts?

There are certain risks and discomforts that may be associated with this research. They include the possibility of psychological effects and the loss of confidential information. Sometimes answering questions about one's personal experiences may be uncomfortable. You can stop answering the questions and withdraw from the study at any point without any consequences of any kind. The investigator is a psychiatric mental health nurse practitioner and her collaborating physician and clinical expert is Dr. Azfar Malik, a psychiatrist that has over 30 years of experience in mental health.

#### Are there benefits to taking part in the research?

Although there are no direct benefits to you for taking part in this research study, findings might benefit future patients with bipolar disorder.

#### Will I be told about new information that may affect my decision to participate?

During the course of the study, you will be informed of any significant new findings (either good or bad), such as changes in the risks or benefits resulting from participation in the research, or new alternatives to participation, that might cause you to change your mind about continuing in the study. If new information is provided to you, your consent to continue to participate in this study will be re-obtained.

#### What about privacy and confidentiality?

Protected Health Information (PHI) is any health information through which you can be identified. PHI is protected by federal law under HIPAA (the Health Insurance Portability and Accountability Act). A decision to participate in this research means that you agree to let the research team use and share your PHI for the study explained above. The research team will look at your name, birthday, and interview information needed for the study in your research file. The only people who will know that you are a research subject are members of the research team. No information about you, or provided by you during the research, will be disclosed to others without your written permission, except: if necessary to protect your rights or welfare (for example, if you are injured and need emergency care or when the University of Missouri-St Louis Institutional Review Board monitors the research or consent process); or if required by law.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. If audiotape recordings of you will be used for educational purposes, your identity will be protected or disguised. Any information that is obtained in connection with this study, and that can be identified with you, will remain confidential and will be disclosed only with your permission or as required by law.

The research team will use and share your information until the data are analyzed. At that point, the investigator will remove the identifiers from your information, making it impossible to link you to the study.

Do you already have contact restrictions in place with Centerpointe Hospital? [] Yes [] No (Example: no calls at home, no messages left for you, etc.) Please specify any contact restrictions you want to request for this study only.

#### What if I am injured as a result of my participation?

If you suffer an injury in the presence of the investigator, the investigator will assist you in seeking emergency services. If you suffer an injury in the absence of the investigator, you are responsible for seeking emergency services. You or your third party payer, if any, will be responsible for payment of treatment.

### What are the costs for participating in this research?

There are no costs to you.

### Will I be paid for my participation in this research?

You will be paid a \$20 Target gift card and a \$5 Quik Trip gas gift card at the completion of the 90-minute session. If you decide to withdraw or you are withdrawn by the investigator at any time before the completion of the session, you will still be compensated with a \$5 Quick Trip gas gift card.

#### **Can I withdraw or be removed from the study?**

You can choose whether to be in this study. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You also may refuse to answer any questions you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so. If you decide to end your participation in the study, please complete the withdrawal letter found at <a href="http://www.umsl.edu/services/ora/assets/WithdrawalLetter.doc">http://www.umsl.edu/services/ora/assets/WithdrawalLetter.doc</a>, or you may request that the Investigator send you a copy of the letter.

The investigator will end the session if she feels that your judgement is impaired. Examples of this include if you become too upset or tired to finish the session. If this occurs and the session is not completed, you will still be compensated with a \$5 Quik Trip gas gift card. Also if the session is not completed, the investigator may call you at 24 hours and 2 weeks after the session to see how you are doing.

#### Who should I contact if I have questions?

The researcher conducting this study is Brandie Stiles. You may ask any questions you have now. If you have questions later, you may contact the researcher at 314-791-7346.

#### What are my rights as a research subject?

If you have any questions about your rights as a research subject, you may call the Chairperson of the Institutional Review Board at (314) 516-5897.

#### What if I am a UMSL student?

You may choose not to participate, or to stop your participation in this research, at any time. This decision will not affect your class standing or grades at UM-SL. The investigator also may end your participation in the research. If this happens, your class standing will not be affected. You will not be offered or receive any special consideration if you participate in this research.

#### What if I am a UMSL employee?

Your participation in this research is, in no way, part of your university duties, and your refusal to participate will not in any way affect your employment with the university or the benefits, privileges, or opportunities associated with your employment at UM-SL. You will not be offered or receive any special consideration if you participate in this research.

**Remember:** Your participation in this research is voluntary. Your decision whether to participate will not affect your current or future relations with the University or Centerpointe Hospital. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

You will be given a copy of this form for your information and to keep for your records.

I have read the above statement and have been able to express my concerns, to which the investigator has responded satisfactorily. I believe I understand the purpose of the study, as well as the potential benefits and risks that are involved. I authorize the use of my PHI and give my permission to participate in the research described above.

#### All signature dates must match.

Participant's Signature	Date	Participant's Printed Name	
Parent or Guardian's Signature Name	Date	Parent or Guardian's Printed	
Witness' Signature	Date	Witness' Printed Name	
Researcher's Signature	Date		
The Notice of Privacy Practices (a second privacy Practices, the research team will I have been Privacy Practices.	ormation. If you ha make one available	ave not already received the Notice of	

Initial

#### Appendix M. IRB Approval Letter



#### Office of Research Administration

One University Boulevard St. Louis, Missouri 63121-4499 Telephone: 314-516-5899 Fax: 314-516-6759 E-mail: ora@umsi.edu

DATE:	May 17, 2016
TO:	Brandie Stiles, MSN
FROM:	University of Missouri-St. Louis IRB
PROJECT TITLE:	[895151-2] Identifying the Complexity of Bipolar Disorder: A Focused Ethnography and Retrospective Chart Review
REFERENCE #:	
SUBMISSION TYPE:	Amendment/Modification
ACTION:	APPROVED
APPROVAL DATE:	May 17, 2016
EXPIRATION DATE:	May 17, 2017
REVIEW TYPE:	Full Committee Review

This proposal was approved by the University of Missouri-St. Louis IRB for a period of one year starting from the date listed above. The University of Missouri-St. Louis IRB must be notified in writing prior to major changes in the approved protocol. Examples of major changes are the addition of research sites or research instruments.

An annual report must be filed with the committee. This report should indicate the starting date of the project and the number of subjects since the start of project, or since last annual report.

Any consent or assent forms must be signed in duplicate and a copy provided to the subject. The principal investigator is required to retain the other copy of the signed consent form for at least three years following the completion of the research activity and the forms must be available for inspection if there is an official review of the UM-St. Louis human subjects research proceedings by the U.S. Department of Health and Human Services Office for Protection from Research Risks.

This action is officially recorded in the minutes of the committee.

If you have any questions, please contact Carl Bassi at 314-516-6029 or bassi@umsl.edu. Please include your project title and reference number in all correspondence with this committee.

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