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Lisa M. Jaffe
The Impact of Identity
On the Experience and
Management of Bipolar Disorders

ABSTRACT

This mixed-method thesis explores the impact of Identity, operationally defined as the framework from which individuals interact with the world, and on the lived experience and symptom management of bipolar disorder. I created an online survey for participants to use as my research tool, utilizing a standardized scale, the Sense of Self Scale (SOSS), in conjunction with my own Likert scale items for the quantitative component, and open-ended questions for the qualitative component of the research. A positive correlation was found between self-identified symptom management and SOSS, showing that individuals with a higher sense-of-self score did have better management of symptoms from the disorder. I also conducted a thematic analysis of open-ended survey items in the research and explored various treatments for multiple variables for my research. Clinical implications of this research support fostering a sense of self and strengthening identity in working with individuals diagnosed with bipolar disorder.

The Impact of Identity on the Experience and Management of Bipolar Disorders

A project based upon an independent investigation,
Submitted in partial fulfillment of the requirements
For the degree of Master of Social Work

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2015

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Chapter I

Introduction

"God and the devil are raging inside me."

- Research Participant

"Everything people know of me is wrong but I can't change it because I don't even know who I am."

- Research Participant

These quotes demonstrate the seriousness and lived experience of individuals with bipolar disorder. The experience is challenging at best, and at worse, disabling. Bipolar disorder is a common mental illness that affects the lives of many individuals that have been diagnosed with it. One survey estimates that 2.6% of the adult U.S. population have some form of the diagnosis, with 82.9% (2.2% of U.S. population) classified as "severe" by the National Institute of Mental Health (Kessler, Chiu, Demler & Walters, 2005) This disorder has been shown to have a varied quality of life outcome, even in remission (Michelak, Yatham, Kolesar et al., 2014). Individuals with this disorder also can experience a great deal of stigma associated with the disorder. People with concealable stigmatized identities – socially devalued identities that can be hidden from others – show great variability in their experience of psychological distress (Quinn, Williams, and Montana, 2014). This distress comes through in a variety of ways and causes many differing effects on the lives on individuals living with a stigmatized identity. Throughout much of the existing research, identity is brought up tangentially or solely in qualitative research and few studies exist examining identity in a quantifiable way.

This research study aims to look and listen to individuals with bipolar disorder in order to better understand their lived experience of the disorder. In addition, using a standardized scale

and quantitative analysis, I will be analyzing how identity impacts the experience of having bipolar disorder. This study aims to blend the rich and narrative experience of individuals while also having quantifiable statistical data to support the rich qualitative research. For the purposes of this study, I will define identity as a framework from which individuals interact with the world (Inder, 2008). This working definition will be used throughout the paper when describing identity. I am proposing a positive correlation in which individuals with a more integrated sense of self and positive self-image will have a better experience and management of the disorder. I used a standardized survey with a high internal reliability score to measure Sense of Self. This term will be used as a measureable unit of identity throughout the paper. Using an online survey tool that I created for my research, I will be able to test my hypotheses and use statistical treatment to find correlation. In addition, I will use thematic analysis in order to code open-ended questions and then use coded answers in the statistical treatment.

Important to the core of this research paper are the individuals' voices, the qualitative component that shows the lived experience and struggles of each individual who participated. While reading about the lived experience, in the participant's own words, I was both shocked, amazed, and inspired to hear their stories and their ways of managing a stigmatized identity, and how they managed such an impact on their daily living. The social work researcher Brene Brown refers to qualitative research as "data with a soul" (Brown, 2010). This study aimed to capture the data with a soul and look for ways in which practitioners and mental health workers could better understand the lived experience of individuals with not only bipolar disorder, but any other shaming or stigmatizing identity.

Chapter II

Literature Review

In examining the literature on the impact of identity on bipolar disorder, several key areas come to light. The first is what exactly bipolar disorder is and what the typical course of the disease is. A working definition for bipolar disorder, a severe and persistent illness, can be characterized as: experiencing recurrent episodes of depression and mania/hypomania, which are associated with high levels of psychosocial impairment (Swartz et al., 2012). Mania is the defining disease state in bipolar I disorder, and consists of a marked departure from baseline behavior and functioning, often accompanied by psychosis and/or a high risk of danger to the patient (Cerimele et al., 2013). Symptoms include grandiose thinking and behavior, elevated self-esteem, rapid thoughts, high energy, reduced sleep or drastic change in sleep patterns, increased spending, and hypersexuality. Co-occurring hypomanic symptoms characteristically include irritability, distractibility, racing thoughts, and being more talkative (Swartz et al., 2012). The depressive side of the disorder includes symptoms of major depression, such as depressed mood, feelings of worthlessness or guilt, psychomotor retardation and suicidal ideation (Cerimele et al., 2013). Bipolar disorder also has periods called mixed states, which are very common. Complex mixed states, defined as subsyndromal hypomanic symptoms co-occurring during a depressive episode are very common and include irritability, distractibility, racing thoughts, and being very talkative (Swartz et al., 2012).

Historical Context

The illness has been in diagnostic contexts since the 1970s, first as Manic Depression

Illness in the DSM II before moving to Bipolar Disorder in the DSM IV. The current APA Manual of DSM 5 also refers to the disorder as bipolar disorder (Swartz et al., 2012). The idea of a relationship between melancholy and mania can be traced back to the Ancient Greeks, and particularly to Aretaeus of Cappadocia, who was a physician and philosopher in the time of Nero or Vespasian (first century AD). Aretaeus described a group of patients that who ‘laugh, play, dance night and day, and sometimes go openly to the market crowned, as if victors in some contest of skill’ only to be ‘torpid, dull, and sorrowful’ at other times (Burton, 2012). The modern psychiatric concept of bipolar disorder has its origins in the nineteenth century. In 1854, Jules Baillarger (1809–1890) and Jean-Pierre Falret (1794–1870) independently presented descriptions of the disorder to the Académie de Médecine in Paris. Baillarger called the illness *folie à double forme* (‘dual-form insanity’) whereas Falret called it *folie circulaire* (‘circular insanity’). Falret observed that the disorder clustered in families, and correctly postulated that it had a strong genetic basis. In the early 1900s the eminent German psychiatrist Emil Kraepelin studied the natural course of the untreated disorder and found it to be punctuated by relatively symptom-free intervals (Burton, 2012).

The terms ‘manic–depressive illness’ and ‘bipolar disorder’ are comparatively recent, and date back from the 1950s and 1980s respectively. The term ‘bipolar disorder’ (or ‘bipolar affective disorder’) is thought to be less stigmatizing than the older term ‘manic–depressive illness’, and so the former has largely superseded the latter. However, some psychiatrists and some people with bipolar disorder still prefer the term ‘manic–depressive illness’ because they feel that it reflects the nature of the disorder more accurately (Burton, 2012).

Contextual Background

Bipolar disorder (BD) is defined by recurrent periods of ‘highs’ (i.e. mania, hypomania)

and 'lows' (i.e. depression) of mood, thinking and activity. These highs and lows are of different severity, duration and frequency, and can be combinations of opposite polarity symptoms (i.e. manic/ hypomanic and depressive) in the same episode (the mixed states) (Benazzi, 2008).

Bipolar disorder is responsible for the loss of more disability-adjusted life years than all forms of cancer or major neurological conditions such as epilepsy and Alzheimer disease (World Health Organization, 2002). Individuals with BD become disabled at four times the rate of the general population (Morgan et al. 2005). Bipolar disorder is a very serious disease. Suicidal ideation or recurrent thoughts of death can occur during all phases of bipolar illness. The lifetime prevalence of a suicide attempt is 17 % in bipolar I disorder and 24 % in bipolar II disorder, compared to 12 % in unipolar depression and 0.6 % in the general US population (Cerimele, 2013). Bipolar disorder is responsible for the loss of more disability-adjusted life years than all forms of cancer or major neurological conditions such as epilepsy and Alzheimer disease (Thome et al., 2012).

Bipolar patients with excessive substance use report lower educational levels and lower occupational status than the general population (Ward, 2011). Bipolar disorder is a chronic condition characterized by periods of both mania/hypomania and depression, with a lifetime prevalence rate of 1.3%, and recent estimates suggest a lifetime risk of 5% (Proudfoot et al. 2009). The cost to patients and the public associated with these conditions is substantial. The United States spends \$104 billion annually to treat mental illness and substance use, or about 7.6% of the \$1.4 trillion spent on personal health care (Ward, 2011). As demonstrated, bipolar disorder is a serious illness with a variety of symptoms that impact the lives of individuals with it.

Treatment

One aspect of many treatments for the disorder is a focus on cognitive components. For

example, the Netherlands has a routine, if somewhat problematic, course of treatment for adults with bipolar disorder. A number of interventions stand central in this guideline: pharmacotherapy, providing information and psycho-education, support activities for self-management, and the option of psychotherapy (Daggenvoorde et al., 2013). Virtually all effective psychotherapies for bipolar disorder incorporate significant elements of psychoeducation, and several studies have shown advantages of structured psycho-educational programs over non-specific therapies of similar length (Milkowitz et al., 2012). The strong similarities among the multitudes of cognitive therapies for psychological disorders, alongside abundant research evidence, have led to the conclusion that certain cognitive processes that maintain symptoms are trans-diagnostic; that is, they are shared across a wide range of disorders (Mansell, 2007). Mansell demonstrated that certain cognitions, or thinking, are present in a multitude of disorders, including bipolar disorder but also could be present in major depressive disorder, various personality disorders, or anxiety disorders. This shows how cognitive processes that correspond to bipolar disorder, and many major mental illnesses, lead to the subjective experience of *having* bipolar disorder.

One quantitative study that explored and analyzed interpersonal social rhythm therapy (IPSRT) described how important the evolution and consolidation of a sense of self or identity is for development and how individuals with bipolar disorder may often have this thwarted (Crowe et al., 2009). This form of treatment focuses on interpersonal relationships and how they impact mood, behavioral strategies designed to stabilize daily routines and psycho-education to help the patient understand the disorder and their medications- as well as recognition for a *loss of healthy self* (Crowe et al., 2009). IPSRT takes into consideration the sense of self within the disorder and how behavior is changed when an individual has bipolar disorder, since great mood changes and

behavioral changes occur from the disorder. Psychological treatments provide efficacious adjunctive treatments to medication (Thome et al., 2012). However, theoretical models underpinning such treatments are primarily based on unipolar populations and therefore may not accommodate the complexity of BP disorder (Fletcher et al., 2013). Therefore, purely cognitive based treatments can fail in treating the complex array of symptoms that come along with having bipolar disorder.

For example, hypersexuality is a common symptom of mania, hypomania, and mixed episodes in adolescents with bipolar disorder (Basco & Hoyos., 2012). Bosco and Hoyos studied how this problem of hypersexuality influences the sexual education necessary for adolescents with bipolar disorder. Using a CBT framework, the researchers explored how a better understanding the Biopsychosocial factors of bipolar disorder can help inform safe sex-practices and interventions for adolescents with bipolar disorder. Because of bipolar disorder's unique impact on judgment, decision-making, emotion, sexuality, and behavior, the delivery of information in a traditional patient education program may be insufficient for this population. Due to increased risk factors, perhaps a more tailored and specific kind of sexual health curriculum needs to be taught to individuals with bipolar disorder. This is one example of the uniqueness of bipolar disorder and how it can impact even something as benign as sexual education in the teenage years, as well as the subjective experience of having the disorder.

Diagnostic Difficulties

Diagnosis of bipolar disorder is much harder in children due to the manifestation of symptoms. Within the past 15 years, researchers have suggested that mania presents differently in youths than in adults: in youths it presents not as distinct euphoric or irritable episodes but as persistent, non-episodic, severe irritability. This marks an important deviation from the classical

conceptualization of bipolar disorder and is inconsistent with the DSM-IV *criterion A* requirement of a “distinct period” of abnormally elevated, expansive, or irritable mood (Leibenluft, 2011). This creates problems for conceptualizations that currently exist on bipolar disorder since many individuals experience symptoms in a variety of ways, especially while younger. Similarly, between 1996 and 2004, the rate of children with a hospital discharge diagnosis of bipolar disorder increased from 1.3 to 7.3 per 10,000, and discharges of adolescents with bipolar disorder increased 400% (Leibenluft, 2011). With such a drastic increase in a short time span, there must be something being left out or in need of reconsideration in the diagnostic criteria for bipolar disorder in individuals under the age of 18. If children are becoming more and more likely to be diagnosed with bipolar disorder, a connection could be drawn between development and the diagnosis itself. Also, it is possible that as the genetics and pathophysiology of both bipolar disorder and severe non-episodic irritability are discovered, these two clinical phenotypes will be found to share pathogenic mechanisms and may ultimately be considered to be on a pathophysiologic spectrum with each other as well (Leibenluft, 2011). Therefore, identity and development could be crucial in the management of the disorder. Diagnosis earlier in the course of the disorder and being put on the correct medication and treatment regime often leads to more promising outcomes (Mansell, Powel, Pedley, Thomas & Jones, 2010).

Although modern technology has greatly improved the ability of researchers and clinicians to study the brain, there is no way to map out bipolar disorder. The role of functional neuroimaging in the endeavor to move away from the symptom-based criteria of the DSM toward a biologically based nosology is controversial. However, many participants in research studies expressed a desire to know if their disorder could be seen in the brain (Buchman, Borgelt, Whitely, Illes, 2012). Although imaging could potentially locate “true bipolar disorder” in the

brain, the ability to locate it obscures the fact that the diagnostic constructs that guide functional imaging studies are themselves culturally and historically specific to the individual in the culture they have been diagnosed in (Buchman et al., 2012). This means that the diagnosis is embedded in a cultural lens and, despite the human brain being nearly universal, the experience of the disorder is not, and very symptoms are specific to the person-in-environment. Locating the disorder in a functional image of the brain takes away the cultural and environmental aspect of the disorder. In addition, patients seeking validation on a medical scan are perhaps looking for some sense of validation for their bipolar disorder identity (Mansell et al., 2010).

Existing Literature

Qualitative studies of bipolar disorder exist but are sparse in academia. While there have been a number of studies examining the impact of mental disorders, there have been few studies of bipolar disorder specifically. The studies have identified that unwanted side effects of medication, coping with unpleasant symptoms, positive and negative reactions to the diagnosis, identifying early warning signs and triggers of the illness, a loss of a sense of self, uncertainty about their future and stigma as issues of major importance after diagnosis of bipolar disorder (Crowe et al., 2009). A major theme that emerges in qualitative research is that of stigma surrounding mental illness, including bipolar disorder. Crowe et al. (2009) described how for most of the participants in their study it was not only the symptoms that impacted on their lives but also the response of others to those symptoms. Another core theme that emerged in relation to the impact of bipolar disorder on the participants' lives was their feeling of being out of control. This theme was expressed as feeling overwhelmed, experiencing a loss of autonomy and feeling flawed (Crowe et al., 2009). This loss of control and stigma had a profoundly negative impact on social relationships as well as self-esteem and ability to "trust one's own thoughts".

One interesting study presented how self-acceptance of mental illness led to a much more successful course of the disease. The study found that people with less intensive treatments therapeutic treatments were more likely to have higher levels of acceptance of mental illness, and lower levels of stigma (Mizock et al., 2014). This group also had higher levels of understanding of their illness, better engagement in the community, and more acceptance of the use and importance of medication. Moreover, participants who had a higher level of self-acceptance were more likely to engage in the community through work, social, and spiritual activities (Mizock et al., 2014).

This leads to the importance of being able to have insight into the disease for symptom management and prognosis (Mansell et al., 2010). One barrier to this is the concept of Anosognosia, or lack of awareness of illness, which is a common symptom of schizophrenia and bipolar disorder with psychotic features. It is one of the most common reasons why individuals with these disorders often refuse to take medication. Neurologists have described Anosognosia for over a century. Classically, it occurs in a patient who has had a stroke in the right parietal lobe of the brain, producing left hemiplegia. The individual so affected may deny that anything is wrong despite being paralyzed on the left side. This is not simple denial, a subconscious psychological mechanism we all use occasionally (Treatment Advocacy Center, 2013). However, with individuals with severe and persistent mental illness such as bipolar disorder, this can occur and lead to an inability to notice or observe one's own mood or state of mind, particularly in episodes of mania. Like self-acceptance, awareness of symptoms has been identified as an important contributor to symptom management. In contrast to the concept of insight, acceptance includes the active management of one's illness and related experiences. Therefore, acceptance of mental illness may require a degree of self-awareness and insight to

facilitate recovery (Mizock et al., 2014). This concept is extremely important in this current research study of identity and view of one's self into how the disorder is managed and experienced.

The information existing about the disorder is crucial in pointing out the various impacts of bipolar disorder on daily life and look at further areas of research. This also demonstrates the complexity and multiplicity of factors that come along with a diagnosis of bipolar disorder. Another qualitative study aptly identified how psychological treatments can provide efficacious adjunctive treatments to medication (Fletcher et al., 2012). Theoretical models underpinning such treatment have been based primarily on treatment of unipolar depression and may not accommodate the complexity of bipolar disorder. According to Fletcher and colleagues, unipolar depression does not have the same effects on self-esteem, self-worth, and sense of self that bipolar disorder does because it does not involve major shifts in mood and the "highs" that come along with bipolar disorder. This same study examined how recovery involves acceptance and tolerance of internal state changes and associated appraisals of the changes, learning to use less extreme behaviors, and challenging beliefs about mood and its management (Fletcher et al., 2012). Relevant to this current research, the recognition of internal states is important to mood management.

Mansell (2007) also described how research has found that people who experience mood swings have as a result formed long-held beliefs about themselves and others related to changes in their internal state. Bipolar disorder is an extremely subjective experience and an under-researched disorder. Mansell's discussion clearly indicates what treatments can happen with an integrated internal state and the efficacy of treatment. However, as his research analyzes, the research lacks a definition of what it means to "accept internal states" or how to measure this

concept quantitatively.

Subjective Experience of the Disorder

The experience of individuals with bipolar disorder is particularly subjective and personalized. In one study looking specifically at bipolar I disorder, the majority of participants reported that bipolar disorder had an extremely negative impact on their quality of life, particularly in the areas of education, vocation, financial functioning, and social and intimate relationships. Nevertheless, and in clear contrast, they reported that bipolar disorder had opened new windows of opportunity for them in terms of positively changing their career paths or social networks (Mansell et al., 2010). While coming to accept that they were suffering from bipolar disorder was an important first step in the recovery process, participants struggled to avoid defining themselves or to have others define them by their illness. Many participants talked about the process of fostering their own recovery as having made them, in the words of one participant, “more robust” in character. One participant stated that bipolar disorder “gives one an insight into suffering” (p. 457) This bold statement describes how the diagnosis is more than just a label; the diagnosis becomes an integral sense of who the individual is and affects all life domains.

Going even further within the literature, a research study conducted on quality-of-life outcomes of bipolar I disorder (Michalak, Yatham, Kolesar, & Lam, 2006) described astounding findings. A recurrent theme related to how a diagnosis of bipolar disorder can affect a person’s subjective feelings about themselves, in particular in relation to self-identity or just the construct of identity. This was often the case regardless of the life stage the individual was at, although several participants noted that they thought being diagnosed during adolescence—when most teenagers are still figuring out who they are—could have particular ramifications. These feelings

of identity loss were often tied in with loss of self-esteem. For some participants, a component of restoring their sense of self-worth and identity appeared to be related to a process of accepting their diagnosis. For example, for some people, part of restoring their sense of self-worth and identity appeared to be related to a process of accepting their diagnosis:

“Like, it doesn’t all come at once, it’s not like this little, just acceptance thing that happens, it, a whole bunch of different things happen at different times like physical acceptance of it, and the spiritual and emotional, and acceptance of the past and all the fears and things that go with it; it’s quite a complex process (p. 32)”.

For others in the study, it also appeared to be important to realize that their bipolar disorder (BD) represented just one part of them: “I guess in a nutshell it’s not letting the illness overshadow and become your life.” (p. 32) The findings of this study point to how bipolar disorder influences identity and how fragile this connection can be.

As Buckley-Walker, Crowe, and Caputi (2010) wrote, sense of self and the ability to gain insight into one’s self is crucial in comprehending and accepting a stigmatized identity:

Psychodynamic, humanistic, existential, and social psychological theories share two broad themes, which are relevant to the concept of identity. The first is that of “self and not self,” involving one’s image of one’s self, who we perceive ourselves “to be” or “not to be.” This theme reflects the notion of “possible selves” that incorporates the past accounts of the self with images of future selves, including the ideal self, the self we could become, and are perhaps afraid of becoming. The second theme, that theme of “self and others,” refers to our interactions with others and the environment. It includes social communications, as well as the decision to accept or reject social standards (p. 220).

This excerpt does a wonderful job of relaying the background for the notion of the self within the

literature. In looking at the notion of the “self”, the “other” cannot be discounted and self-identity and self-image compose key elements of identity. Within bipolar disorder, the line between “self” and “not self” can get blurred through the symptomology of the disease. I am interested in exploring this line within the current study.

Identity and Bipolar Disorder

In examining identity in relation to bipolar disorder, research has shown how important an organized sense of self is (Inder et al., 2008). The self is considered to be both a cognitive and a social construction, with marked changes in its expression as a young person undergoes normative cognitive and social changes from early to late adolescence. Identity can also be seen as a framework from which individuals interact with the world. This is the working definition in which I will use in my current research study.

Inder and colleagues (2008) examined how identity can be understood: bipolar disorder, due to the symptomology of it, can disrupt the process of forming a cohesive sense of self. The researchers studied fifteen participants with bipolar disorder. Their results demonstrated that mood state was a central defining factor which led to the development of multiple, and at times contradictory, selves, depending on the mood or illness state. Additionally, participants had difficulty differentiating between self and the illness, with resultant confusion over what was their “real self”. The study’s finding explains how having the disorder can lead to confusion in identity as well as boundaries between the disorder and identity occurring. Within this blurring, the disorder can take “control” and self-efficacy can be lost.

Singer and colleagues conducted a thematic analysis of the memories of patients with bipolar disorder, which revealed they had difficulties in constructing coherent meanings from experiences as well as a sense of discontinuity and fragmentation, based on narrative theory

research (Singer, Blagov, Berry, and Oost, 2012). Healthy narrative identity entails a capacity to narrate and draw meaning from emotionally evocative memories, while gaining freedom from narrative scripts that lead one in self-damaging directions. Accompanying cognitive-behavioral changes produce revisions in the internalized life story, enhancing agency and redemptive possibilities. In regards to bipolar disorder and identity, a healthy positive narrative demonstrates the ability to learn how to struggle and make meaning of the diagnosis. An integrated sense of identity is more likely to create a stronger personal narrative. A less integrated sense of identity is more likely to create a weaker personal narrative and thus, a more negative experience of having the disorder.

A study comparing the experience of psychosis amongst individuals with bipolar disorder who experience psychosis and individuals with schizophrenia showed that participants with each illness had very different conceptions of identity. Importantly, bipolar disorder has an extremely different course of illness than any other mental illness. The psychosis is different than for those with schizophrenia, typically (Hansen, 2009), and the experience is different than for those with unipolar depression. Although the research was neurologically oriented and focused more on the study of schizophrenia than bipolar disorder, it still identified certain qualitative alterations of subjective experience, which seem to antedate the emergence of psychotic symptoms in schizophrenia, and it appears that this evolution may follow characteristic, i.e., non-random phenomenal patterns (Hansen, 2009). Although this seems heady, the overall finding is that these experiences appear to be non-random and consequential to the course of psychosis in major, chronic, mental illnesses, including bipolar disorder.

Another study conducted by surveys looked at how stigmatizing some diagnoses can be to an individual, depending on the type of diagnosis. The study discovered that diagnoses that

were perceived to be less stigmatizing, based on their participants' responses, were less difficult to live with and had fewer negative effects on quality of life. The researchers connected this stigmatized identity with the identity of the individual (Raskin, J. D. and Harasym, M. T., Mercuri, M. A., & Widrick, R. M, 2008). The researchers found that schizophrenia and bipolar disorder were thought to be more stigmatizing than other mental illnesses, such as depression or PTSD. This study demonstrated that because bipolar disorder has a greater stigma than other diagnoses, the impact on identity could potentially be greater due to the correlation in the study, although causality was never proven.

Current Study

Both the Hansen and Raskin studies are useful in demonstrating that living with bipolar disorder is a stigmatizing—even traumatic at times—experience, but that stigma and shift in identity is *part of the disorder* and non-random. Once an individual is diagnosed, their life is changed forever. Little is known about the concerns patients face after receiving a diagnosis of bipolar disorder and how these issues impact on their ability and willingness to work with health professionals to find an optimal treatment regimen and to set up effective self-management strategies to control the condition. What is known is that poor treatment adherence and inadequate self-management are common in bipolar disorder, with 40% of patients relapsing within one year, 60% over two years and 73% over five years (Proudfoot et al., 2009). In my current study, I will be looking at the age of diagnosis in addition to the age when individuals first reported symptoms to examine the trend and reported management of symptoms. I also want to find out if individuals feel if the diagnosis fits their symptoms and how. This can be a crucial key into whether or not an individual has adapted and incorporated the disorder into their identity, or, “learned how to struggle”, with having bipolar disorder.

In searching for a scale to measure sense of self, I had to ask what does it mean to have a weak sense of self versus a strong sense of self? Individuals with a weak sense of self have been characterized as feeling as if they do not know who they are, what they think, what their own opinions are, or what religion they should adopt (Flury & Ickes, 2007). Along with the fragility and reactivity that is presumed to characterize a weak sense of self, there is also corresponding instability. People with a weak sense of self appear to experience sudden and dramatic shifts in opinion, career plans, values, preferences, and choice of friends. This behavior would not be expected from individuals who have a strong sense of self (Flury & Ickes, 2007). Flury and Ickes developed the Sense of Self Scale (SOSS). In the course of its development they identified four facets of a “weak self”. These facets are: *lack of understanding oneself, sudden shifts in feelings, opinions, and values, tendency to confuse one’s feelings, thoughts, and perspectives with those of others, and feeling that one’s very own existence is tenuous*. The SOSS 12-point scale addresses each of these facets using a likert rating of one through four, and then, through factor analysis, identifies strength of sense of self. I will be using this scale within my research because it has already been standardized and tested against many similar scales with a high r-score, alpha score, and construct validity and predictability. Using this scale is important in order to have some standardized results. I received permission from William Ickes in order to use this scale in my research.

An examination of gaps in the research reveals that the current literature describes the experience of bipolar disorder on an individual and cognitive-based treatments are the “gold standard” for therapeutic interventions outside of medication. There is a lack of quantitative studies on bipolar disorder and identity, with many of the studies being qualitative or theoretical. In addition, there is a lack of operationally defined terms in the current research, perhaps in part

due to the lack of empirical quantitative studies. Without terms that can be operationally defined, such as identity, research can be hard to conduct. In addition, because the experience of having bipolar disorder is so unique and subjective to the individual, measuring such an experience would be extremely challenging. Because there are various sub-types of bipolar disorder diagnoses, generalization might be difficult, since Type II is different than rapid cycling and so forth. A person's experience of one type might be extremely different than another's experience with a different sub-type but still fall within the realm of bipolar disorder. One fact that remains constant throughout this research is how the experience of having bipolar disorder is synthesized within the individual, and that this has important implications for the identity of an individual who receives the diagnosis of bipolar disorder.

My current study aims to look at this process of synthesization and attempt to explore the connection between identity—previously defined as a framework from which individuals interact with the world—and bipolar disorder. I will take into consideration the stigma associated with the disorder, the issues that arise as a result of diagnosis, and have quantitative data to use in order to find statistical significance. Due to the complexity in childhood or adolescent onset of bipolar disorder, this current study has been limited to adult participants to avoid the issues that arise from the potentiality of misdiagnosis or different symptom presentation in adolescents and children than adults. This study aims to prove how stronger and better-integrated identity can lead to an individual's more positive experience of the disease. This study hopes to show that individuals with a more integrated sense of self will be more likely to have a higher sense of self score, greater symptom management, and respond more positively about their quality of life than those who have a lower sense of self score.

Chapter III

Methodology

Overview of the experiment

The research question most relevant after looking at the existing literature is: How does a sense of identity impact an individual's experience and management of bipolar disorder? Based on existing research, I created the hypothesis:

There will be a positive relationship between a stable sense of self and more effective management of the disorder.

In this experiment I examined individuals' sense of self; how they perceive themselves in the world compared to how well managed they perceive their disorder to be. I studied participants' perceptions of their identity, their illness and, using open-ended questions, their subjective experiences living with bipolar disorder. This was done through an online survey created by me incorporating the standardized Sense of Self Scale (SOSS), developed by William Ickes. In addition, by asking questions regarding specific demographics, I was also able to include age as a variable to determine if there is a correlation between earlier diagnosis and better management of the disorder; length of time living with the disorder and better management; or a correlation between less time since diagnosis of the disorder and perceived less control over the disorder.

I also sought, through use of open-ended questions, to identify how identity forms a connection with the experience of having bipolar disorder and to explain that connection. A codebook was created in order to code open-ended items within the participant's responses.

Statistical analysis was performed to look for correlation, statistical significance, and validity.

Research Design

The use of a mixed-methods research design was used. This method combined qualitative and quantitative research designs to obtain a broader picture of bipolar disorder. The sampling method used was availability sampling through placing the online survey link on various Internet forums (Facebook groups, an online Bipolar Disorder support group, an online community called Reddit under the subscription about Bipolar Disorder, and personal Facebook pages) and giving people who saw the link the opportunity to take the survey. In addition, clients from a New England regional community mental health agency, ServiceNet, were able to take the survey through a list generated of all clients who met the inclusion criteria who are being seen at an outpatient-counseling clinic in five different locations in Western Massachusetts.

Before making the online survey link active, I obtained permission from the Human Subjects Review Board at Smith College's School for Social Work. I created the survey using SurveyMonkey, an online survey tool.

Participants

There were 170 participants who completed the survey. A total of 253 people started the survey but only 170 gave informed consent and checked "yes", indicating that they met all of the inclusion criteria. Those who either didn't meet all criteria or who declined to agree to conditions outlined in the consent were exited from the survey and thanked for their interest. Age range of participants was 18-63 years old with a mean of 30.41.

Almost two-thirds of participants (64.7%, $n = 110$) were female, 30.6% were male ($n = 52$), 1.75% identified as trans* ($n = 3$), 1.2% identified as being genderqueer ($n = 2$), and 1.75% did not disclose their gender ($n = 3$).

Participants also had a diverse diagnostic background with 33.1% ($n = 51$) being diagnosed as having Bipolar I disorder, and 44.1% ($n = 75$) being diagnosed as having Bipolar II. Both categories Bipolar Disorder, NOS and Bipolar Disorder-Rapid cycling comprised 7.8% of the total, respectively ($n = 12$). “Other” bipolar disorder was checked off for 2.6% ($n = 4$) of the respondents, and 9.4% ($n = 16$) did not respond to this question. Regarding geographic setting, participants responded with 45.5% ($n = 76$) living in an urban area, 7.6% ($n = 13$) in a rural area, 28.2% ($n = 48$) living in a small town or city, 17.6% ($n = 30$) in a suburban area and 0.6% ($n = 1$) on a college campus (marked ‘other’). Only 1.8% ($n = 3$) declined to respond to this question.

Race identification was extremely diverse, including participants from various countries including Canada, Samoa, the UK and Australia. Of the participants, 77.1% ($n = 131$) described themselves as White or Caucasian, with 2.4% identifying as Black or African American ($n = 4$), 4.1% as Latino or Hispanic ($n = 7$), 1.8% claiming Native American heritage ($n = 3$), and 2.4% identifying as Asian ($n = 4$). Because this question was a write in, there were several other answers including the aforementioned countries, multiracial (without saying what races) and “world citizen” totaling 12.4% ($n = 21$). Education levels of participants had a range of completed 8th grade education to completed graduate school (Table 1).

Table 1

Education Level

	Grade	Frequency	Percent	Valid %	Cum. %
	8 th grade	2	1.2	1.2	1.2
	9 th grade	1	.6	.6	1.8
	10 th grade	3	1.8	1.8	3.6
	11 th grade	1	.6	.6	4.1
	HS grad	12	7.1	7.1	11.2
	1 year college	15	8.8	8.8	20.0
	2 year college	20	11.8	11.8	31.8
	3 year college	25	14.7	14.7	46.5
	Graduated from college	48	28.2	28.2	74.7
	Some grad school	20	11.8	11.8	86.5
	Completed grad school	22	12.9	12.9	99.4
	Blank	1	.6	.6	100.0
	Total	170	100.0	100.0	

Data Collection

Once the survey was created and permission granted I utilized online communities such as Facebook, Reddit, and Support Groups to post the link for the survey. In addition, I collaborated with a local human services agency, ServiceNet, in order to reach out to a participant pool in collaboration with Jennifer Geertsma, who is in charge of research through the agency. Due to the same SurveyMonkey link being used, I was unable to tell which

participants responded via ServiceNet and which responded via the web forums.

Before participants could take the survey, they had to self-screen based on whether or not they had been diagnosed with bipolar disorder by a mental health professional and had attempted at least one treatment for the disorder. If they did not meet these criteria the survey software navigated them to a consolation page and they were unable to participate. After the screening question page, participants were required to read the informed consent and click a box agreeing to those conditions in order to take part in my research project. Once again, those who did not give informed consent (by clicking the “I agree” box) were taken to the end of the survey and did not participate. All other items on the survey were optional and participants could choose to end the survey at any time. As a result, not every participant answered every question on the survey instrument. Participants were asked basic demographic information in order to demonstrate the external validity and diversity of the sample. No other personal information was collected from participants therefore participation was anonymous. No monetary award was granted for participation. (Please see the Appendix for a copy of the survey tool.)

Materials

In addition to the survey that I had created specifically for my research question, I utilized a standardized scale because in searching for a scale to measure sense of self, I sought to compare weak versus a strong sense of self. Individuals with a weak sense of self have been characterized as feeling as if they do not know who they are, what they think, what their own opinions are, or what religion they should adopt (Flury & Ickes, 2007). Along with the fragility and reactivity that is presumed to characterize a weak sense of self, there is also corresponding instability. People with a weak sense of self appear to experience sudden and dramatic shifts in opinions, career plans, values, preferences, and choice of friends. This behavior would not be

expected from individuals who have a strong sense of self (Flury & Ickes, 2007). Flury and Ickes developed the Sense of Self Scale (SOSS). In the course of its development they identified four facets of a “weak self”. These facets are: lack of understanding oneself, sudden shifts in feelings, opinions, and values, tendency to confuse one’s feelings, thoughts, and perspectives with those of others, and feeling that one’s very own existence is tenuous.

The SOSS 12-point scale addresses each of these facets using a likert rating of one through four, and then through factor analysis identifies strength of sense of self. I used this scale within my research because it has already been standardized and tested against many similar scales with a high *r*-score, alpha score, and construct validity and predictability. Using this scale is important in order to have some standardized results and I received permission from William Ickes in order to use this scale in my research.

Statistical Treatment

The survey web site was active for approximately two months and so I was able to obtain participation from a wide range of participants. Once the survey link closed, I extrapolated the data from the SurveyMonkey website in order to code using thematic analysis for the qualitative open-ended questions, and to quantitatively analyze the SOSS scale, likert scales, and interval data information within the survey. I looked for correlation between factors, factor analysis, their SOSS scale, and comparisons based on age of the participant, age of diagnosis, and age of symptoms. I also obtained an alpha value for validity and a p-value for significance.

In addition, I utilized the assistance of Marjorie Postal at Smith College and Dr. Andrew Jaffe, a researcher at the Lieber Institute for Brain Development for statistical analysis of quantitative factors. Initially Ms. Postal analyzed data using SPSS, and Dr. Jaffe was able to help run *R-package* to analyze my results and provide feedback on which statistical treatments to run.

I created a codebook for the analysis and treatment for qualitative responses. Therefore, there were two statistical treatments run for this survey, one using SPSS and the other using *R-package*.

Chapter IV

Results

SPSS Statistics

The first treatment of statistical analysis came from using SPSS by Marjorie Postal at Smith College's School for Social Work. The descriptive statistics were given for 133 participants who completed all 12 questions of the Sense of Self Scale (SOSS) (Table 2). Some participants ($n=33$) did not fill out all items on the SOSS so were excluded from the analysis. The range of scores was 12-48 for the scale with a higher score indicating a more stable sense of self. Interestingly enough, the mode (26.00) was lower than the median and mean, which were very close (29.31 and 29.00 respectively). The standard deviation was 5.89, indicating most participants fell in a close range. The lowest scorer was 16.00, which was only slightly above the lowest possible score whilst the highest participant scored a 42.00, which was slightly below the highest possible score.

I tested the internal reliability of the SOSS scale by running a Cronbach's alpha and the internal reliability was strong with $\alpha = .85$ ($n = 137$, n of items = 12). This compared to the original validity testing of the scale which had a Cronbach's $\alpha = .86$ (Flury & Ickes, 2009).

To determine relationships between SOSS and symptom management—both at time of diagnosis and currently—Pearson correlations were run. There was a significant positive moderate correlation between SOSS and S2 (symptoms currently experienced), which assessed symptom management on my survey using a likert scale, ($r = 0.364$, $p = 0.000$, two tailed)

meaning better current symptom management was associated with a higher SOSS score. Results are in the table below.

Table 2

Pearson Correlations – SOSS and Symptoms of Bipolar Disorder

Symptoms at Dx	Pearson Correlation	-0.57	.196*
	Sig. (2-tailed)	.524	.91
	<i>N</i>	128	125
Symptoms Now	Pearson Correlation	0.79	.364**
	Sig. (2-tailed)	.382	.000
	<i>N</i>	125	128

In order to determine if there was a relationship between ages asked about in my survey (current age, age when participant first experienced symptoms or age at diagnosis) and SOSS Pearson correlations were run. There was a significant but weak positive correlation between SOSS and current age ($r = .188, p = .028$), meaning older participants scored higher on SOSS (and vice versa). There was no significant correlation between SOSS and either age when participant first experienced symptoms or age at diagnosis, which were variables given for the age of diagnosis and age of when participants first noticed symptoms. There were no statistically significant differences between types of bipolar disorder diagnoses. Of the 135 participants who answered the question about their specific diagnosis, Bipolar Type II was the most common followed by Bipolar Type I. These two comprised the large majority of my participants. Their SOSS scores were recorded and analyzed using SPSS. The descriptive statistics of the different diagnoses are below (Table 3).

Table 3

Descriptive Statistics – Participant Current Age

	<i>n</i>	<i>M</i>	<i>SD</i>	Std. Error	95% Confidence Interval for Mean		Min.	Max.
					Lower Bound	Upper Bound		
Bipolar Type 1	45	31.07	5.74	.856	29.34	32.79	19	42
Bipolar Type 2	67	28.48	5.79	0.71	27.07	29.88	16	42
Bipolar Rapid Cycling	9	26.78	5.26	1.75	22.73	30.82	20	36
Bipolar NOS	10	27.30	4.37	1.38	24.17	30.42	18	32
Bipolar other	4	34.75	3.30	1.65	29.49	40.00	31	38
Total	135	29.33	5.78	0.49	28.34	30.31	16	42

In order to examine if there was a relationship between the number of selected treatments that worked for the individual (item tx2 on my survey) and SOSS, *t*-test analysis was run (tx2: ≤ 2 or > 2). No significant difference was found between those who had more treatments that worked for them or fewer. I conducted the same analysis for treatment 1 (I created two categories: ≤ 2 tried versus more than 2 tried) and ran *t*-test analysis to determine if there was a difference in SOSS by tx1 in two categories. No significant difference was found. In order to determine if there was a difference in Sense of Self Score and the diagnosis of a participant, meaning, does having a Type I diagnosis influence the SOSS score differently than a Type II and so on, a one-way ANOVA was run and a significant difference was found between diagnoses ($F(4,130)=3.192, p = .015$). Results are shown below (Table 4)

Table 4

One-Way Analysis of Variance of difference in SOSS by diagnosis

Source	<i>df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>
Between Groups	4	401.73	100.43	3.19	0.02
Within Groups	130	4089.92	31.46		
Total	134	4491.65			

There was a significant difference between several of the groups regarding the diagnosis of the individual ($f(3,127)=2.926, p = .036$). LSD post hoc testing showed the significant differences were between:

Type 1 (SOSS $m=31.07$) and Type 2 (SOSS $m=28.47$)

Type 1 (SOSS $m=31.07$) and rapid cycling (SOSS $m=26.78$)

This shows that individuals who had Bipolar Type I had a different sense of self score overall than individuals with Type 2 and Rapid Cycling. The highest score of SOSS were in individuals with Type 1, followed by Type 2, and with the lowest score, Rapid Cycling. A Pearson correlation was run in order to determine if there was an association between the age of participant and symptom management (1 or 2). There was no significant correlation between age and symptom management at time of diagnosis. There was a significant correlation between age and current symptom management ($r = .196, p = .027$, two-tailed). Levene's Test was run in order to assess the equality of variances for a variable calculated for two or more groups, to test for internal validity of SOSS. Results showed that SOSS had a high internal validity score ($n=642$), which strengthened the validity of my results. The results are below (Table 5).

Table 5

Levene's Test

F	Sig.	t	df	Sig. (2- tailed)	Mean Diff.	SD	95% Confidence Interval of the Difference	
							Lower	Upper
.217	.642	.244	135	.808	.497	2.037	-3.533	4.526
		.271	9.496	.792	.497	1.831	-3.613	4.606

R-Package Analysis

A second round of statistical treatment was run using R-package. The median total SOSS score – summing all of the responses after flipping the 3 reverse coded questions – was 31 (with the interquartile range: 25-35). Principal component analysis (PCA) on the SOSS scores identified that the first Principle Component (PC1) explained 39.7% of the variability in SOSS scores. The principle component test produces an un-rotated principal component analysis of multiple values and cleans up the data, reduces redundancy in the data, and checks for linear correlation. Most questions on the scale contributed equally to the overall scoring of the scale, based on PCA. All further analyses were therefore conducted on both the total SOSS score (“SOSS Total”) and this first PC (“SOSS PC1”). The second and third Principle Components (PC2 and PC3) were the results of further stripping down the data to see how much each extra component accounted for the results within the data set (Table 6).

Table 6

SOSS and PCA

SOSS Q#	PC1	PC2	PC3
SOSSQ1	0.184	0.073	-0.042
SOSSQ2	0.404	0.083	-0.361
SOSSQ3	0.118	-0.468	0.030
SOSSQ4	0.213	0.438	0.657
SOSSQ5	0.210	-0.565	0.333
SOSSQ6	0.253	-0.196	0.482
SOSSQ7	0.374	0.305	0.066
SOSSQ8	0.373	-0.082	-0.125
SOSSQ9	0.268	-0.098	-0.136
SOSSQ10	0.346	-0.182	-0.172
SOSSQ11	0.307	0.056	-0.122
SOSSQ12	0.266	0.271	-0.097
VarExplain	39.70%	9.90%	8.70%

I identified a significant association between SOSS Total and the age of the study participant – older participants were more likely to have a lower score and therefore a higher sense of self ($p = 0.0169$). Each decade of life reduced the total SOSS score by 1.48 units. Two plots have been created, displaying total score of the SOSS and age, and displaying the principle component score and age. The principle component accounts for reducing background “noise” in the data and produces a purer, more linear “cleaned-up” data set. The results are in the figures below (Figures 1 and 2).

Figure 1

SOSS Plot and Age

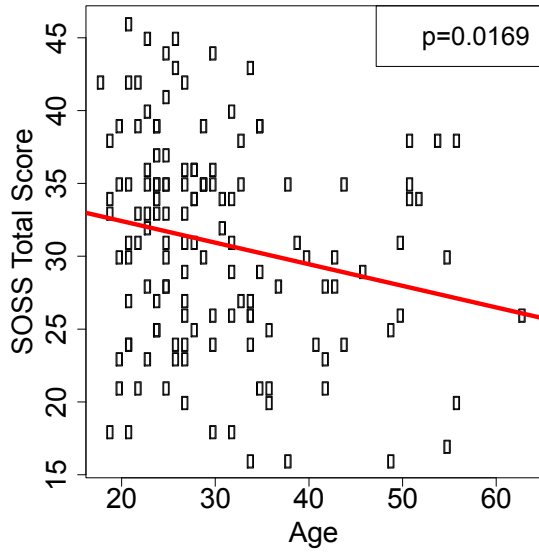
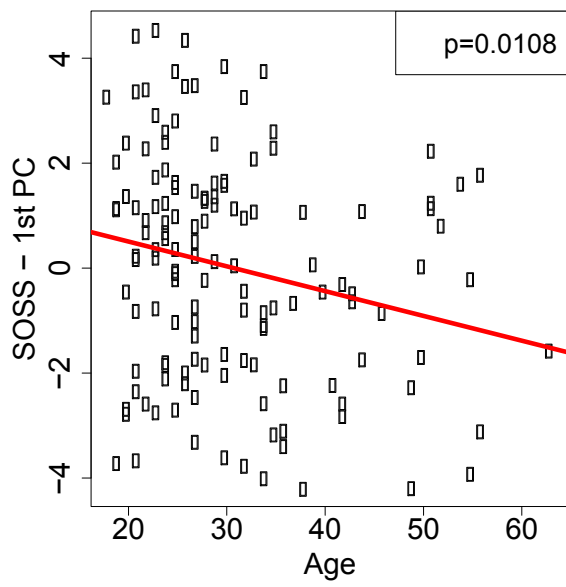


Figure 2

SOSS Plot and PC1



This association was also directionally consistent and statistically significant using SOSS PC1 ($p = 0.0108$). I found no univariate association between the age at bipolar symptom onset or diagnosis and SOSS PC1 ($p = 0.46$ and $p = 0.30$, respectively) or SOSS Total ($p = 0.47$ and $p = 0.59$, respectively). These associations were even less significant when adjusted for the age of the participant ($p = 0.63$, $p = 0.34$, $p = 0.67$, and $p = 0.32$ respectively). There was no significant association in time since diagnosis or onset of symptoms (e.g. current age minus symptom onset or diagnosis). This meant that there was no significant correlation in length of time between symptom onset and diagnosis and SOSS score. Or in other words, there was no significant difference between participants who were diagnosed with a shorter time interval between symptom onset and diagnosis and a longer time interval between symptom onset and diagnosis.

I found significant associations between *attempting peer* (3.78 point decrease, $p = 0.012$) and mood scale (2.77 point decrease, $p = 0.028$) *therapies* and marginal association with *attempting residential therapy* (4.02 point decrease, $p = 0.063$) using total SOSS score. Attempting each of those three treatments improved sense of self. There were no significant associations between SOSS Total and other treatments. Interestingly, the most commonly selected treatment of *Medication*, checked by 72 participants ($n = 72$) had no significance on SOSS score.

I found a significant increase in sense of self (decreasing total SOSS score) by my question labeled *OPEN7*, which queried if individuals felt that having the disorder affected who they have become (7.6 point decrease of “nothing” versus “negative”, $p = 0.022$, and 5.0 point decrease of “positive” versus “negative”, $p = 0.003$) and what I labeled *OPEN*”, which queried if they felt they experienced any positive effects from being diagnosed with bipolar disorder (3.9 point decrease, $p = 0.03$). There were no significant associations between SOSS Total and the other open-ended survey items.

Upon examination of the open-ended answers, results were varied and interesting to consider. The open-ended questions provided subjective data that allowed individuals to write in their answers in, using whatever format they chose, provided it fit within the text box. Major themes that came across were *stigma*, *empathy*, and *self-awareness*. Some comments that illustrated stigma:

“The social stigma that comes with telling people about my diagnosis. Many ‘normal’ people believe I am faking the illness and believe I am just lazy and stupid.”

“The stigma that comes with being bipolar was and still is the most difficult part of being bipolar.”

“Not being ‘normal’, being treated as not human and just a symptom by medical professionals.”

These comments show the everyday battle that individuals with bipolar disorder face and have taken in and believed since receiving the diagnosis.

However, positivity could be found throughout the responses. Many individuals reported that their lives changed in a positive way and dealing with the disorder has made them stronger, evidenced by various open-ended questions. The most common response ($n= 47$) to how their lives changed was that they have become more empathetic. Here are some examples of such comments:

My greatest personal strength is my compassion for other people.

I am able to empathize with others, and help them with their problems.

My greatest strength is my ability to care for others and my loyalty to them.

In addition, many participants reported gaining insight and self-awareness into how to manage the disorder and what having the diagnosis meant for their lives. Here are some examples of comments by participants:

I now force myself to maintain regularity in sleeping and eating patterns as best I can. I'm also very mindful of the way I think, and the way I interact with others. I'm constantly on the lookout for warning signs of a coming episode.

I try to be more aware of my emotions and mental state, especially in new scenarios.

I own my mood-swings and I do everything that I can to eat healthy, exercise, talk-therapy, and nutrition therapy as well.

It gives me incredible insight into the human experience. It gives me high highs, which bring euphoria and joy and low lows, which bring introspection and ultimately, empathy. It makes me a more empathetic person. It enhances my political lens. I have a heightened human experience. I write better, I create better. I love harder. Everything is enhanced, which is difficult but beautiful.

These experiences cannot be summed up in a numerical way but paint the picture of a group of individuals making sense of themselves in position to the world with self-care, self-awareness, and a sense of “ownership” over their diagnosis. When asked to describe what living with the mental illness was like in one sentence, over 60% ($n= 88$) of participants used a statement that I coded as a “self” statement because it used the word “I” or “We” showing that many individuals do connect this disorder with self and their identity.

Chapter V

Discussion

The results from this study do show a positive significant correlation between sense of self and how symptoms of bipolar disorder are managed. Also, having a high internal test reliability helps strengthen the validity of the scale used to measure sense of self. This result was an expected finding based on Flury and Ickles' (2008) scale development. The correlation between symptom management and view of self is important for understanding bipolar disorder in context of treatment. A study by Inder and Crowe (2008) indicated:

Key findings are that having bipolar illness affected the participants' construction of a sense of self and identity in a number of ways.... Additionally, there was difficulty differentiating between self and the illness, with resultant confusion over who was their "real self." (p. 130).

By strengthening one's sense of "real self", better symptom management can be achieved. In addition, gaining self-awareness is important in the clinical world. As Russell and Moss (2013) posited, this may also suggest that positive psychology interventions that pertain to acceptance and peacefulness and meaningful social connection to community could offer alternative narratives for guiding individuals with the diagnosis of bipolar disorder in their pursuit of 'happiness' and alleviating distress (442). This would lead to a higher quality of life and less distress in an individual struggling with controlling symptoms of the disorder.

Another interesting result that may prove useful in the context of understanding bipolar disorder was the connection between age and sense of self. With the knowledge that

one's sense of identity increases as age increases, a better understanding of how individuals interact in the world can be found. Although this study did not look for causality between the two factors, a common theory can be that as an individual ages and gains more life experience and has more interactions, their idea of who they are in the world is strengthened.

Interestingly enough, one statistical analysis that showed no significant changes in sense of self was related to treatments participants had attempted, while another method of analysis did show statistically significant results. In the significant results method, peer therapy, mood therapy, and residential treatment were all associated with higher sense of self-scale scores. This also supports my hypothesis because, although most individuals cited medication as the most helpful treatment, no significance was found between medication and sense of self. However, therapy and intensive treatment, in which individuals lived among other individuals with mental illness, did impact their view of self and one's own identity. Again, no causality can be demonstrated from the results but there are proposed ideas as to why this might occur. Other studies have proposed that stigma decreases when someone receives community and peer support (Thompson 2012, Fossey et al. 2002, Crowe & Inder 2008), so perhaps the participants who utilized peer support, community support from residential treatment, and mood therapy to gain insight, were able to decrease their sense of stigma. As shown within the literature, decreasing stigma and decreasing the negative quality of life indicators, individuals have a more positive quality of life. A positive quality of life measurement is indicated in a stronger and more positive sense of overall well-being (Crowe & Inder, 2008). Therefore, it is not too surprising that individuals who attempted these treatments had an impact on their sense of self.

Clinical Implications

My research study aimed to look for a connection between identity and how individuals with bipolar disorder live and function in the world. This study showed a correlation between sense of self and symptom management, a connection between peer and mood therapies and sense of self, and that sense of self improved with age, therefore connecting age and symptom management as well. In addition, this study looked at individuals' lived experiences through their narratives and how they have incorporated, or not incorporated the diagnosis into how they make sense of themselves. This is important in treating individuals with bipolar dipolar disorder at the clinical level. This study showed there is a connection between how an individual views themselves and symptom management, therefore further research and treatment for the illness could be aimed at strengthening sense of self and fostering self-efficacy for better symptom management. In addition, this study showed that decreasing stigma and integrating the disorder into the identity more positively had an effect on the experience of individuals with bipolar disorder.

The clinical implications of this study are far-reaching. Importantly, clinicians can have a better sense of how to treat and engage with individuals who have bipolar disorder; knowing that sense of self is important to symptom management can lead to meaningful ways to explore identity and sense of self in treatment. In addition, fostering a sense of self-awareness in individual therapy may increase sense of self, based on the mood scale significant correlation to the SOSS. Clinically, this is useful because treatments can be focused, using various lenses to foster insight and personal growth as a way to treat the disorder. For example, setting up more services for peer support for individuals with bipolar disorder could greatly improve the outcome of the illness for individuals, based on a positive correlation in my research. Or as another

example, individuals could use narrative therapy as a way to make sense of how they view themselves and talk about what the diagnosis means to them in a way to achieve catharsis and empathy, a trait so many of my participants self-described as possessing as their most positive attribute.

One final clinical implication that came to light within my study is that so many individuals reported noticing symptoms at an early age, many under the age of 12. However, most participants did not receive a diagnosis until their 20's. This posits the question of what does it mean, developmentally, to notice "symptoms" of a disorder at such a young age but not get the context, in this sense, the label of a diagnosis, until a much later age. I did not ask questions to explore this within my survey, but this concept could be extremely useful for clinicians working with children and adolescents diagnosed with bipolar disorder and assisting the patient in making sense of their world.

Limitations

Limitations in this study were that due to the self-report method, I was not able to verify with certainty that individuals have the diagnosis that they reported nor what treatments they had tried. In addition, I only looked at adults with access to the Internet and who could read and understand the survey, which prevented participation for individuals with severe disabilities and potentially oppressed populations without means to the Internet. In addition, I limited participation to adults only because of the difficulties of diagnosis in children and adolescents as well as the complications in obtaining informed consent for minors. For future study perhaps extending this research to include adolescents to look for trends in emerging adults and how they can better focus on sense of self and symptom management. In addition, perhaps exploring the relationship and possible causality between age and sense of self through a more controlled experiment

would be useful to the practices of social work, psychology, or social psychology. Finally, although I inquired about age and my study showed that SOSS scores increase as age increases, I did not ask questions pertaining to what it meant to experience symptoms at a young age and what it meant to the participants to “notice” symptoms. Future research could be more precise and operationally define this and also expand upon early symptom development of mental illnesses in children.

Conclusion

I believe the most important takeaway from this survey was that the participants were so willing to share and engage in talking about their experiences and spent time taking the survey and answering the questions. Finding ways to listen to people experiencing symptoms of bipolar disorder and asking questions may help increase protective factors for the illness and decrease shame and stigma associated with bipolar disorder (Crowe, 2009). This is a population that can be overlooked by mainstream society and “fall through the cracks”. Giving individuals with the diagnosis of bipolar disorder a platform in which to speak is crucial because so many of these individuals had valuable insight into how they made sense of the disorder and how they learned to struggle and live with the diagnosis. This insight is valuable in the clinical field and since 2.6% of the adult population has a bipolar diagnosis (NIMH, 2005), this is a disorder that is prevalent in our society and often misunderstood.

I received several emails from participants thanking me for doing this and saying that I “asked questions [they] had wanted to answer for awhile,” which shows that so many individuals out there have so much to say but very little platform to do so. In doing this research, I was able to give 170 people a voice in sharing such a personal and interesting part of their lives where they may not otherwise have had the chance. I hope research of this nature continues so that

more individuals have a chance to share their stories in a meaningful way and continue to find ways to make sense of who they are in the world and what those connections and implications mean for treatment. To circle back, qualitative research is just “data with a soul”, and this research study aimed to give that soul a quantitative solid footing in order to validate the lived experience of individuals with bipolar disorder.

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APPENDIX A: HSR APPROVAL LETTER

School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

December 2, 2014

Lisa Jaffe

Dear Lisa,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

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

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

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

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

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

Congratulations and our best wishes on your interesting study.

Sincerely,

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

APPENDIX B: INFORMED CONSENT

RESEARCHER:  SMITH COLLEGE Lisa M. Jaffe

DATE:

November 6, 2014
Updated 8-6-14

**Consent to Participate in a Research Study
Smith College School for Social Work • Northampton, MA**

.....
Title of Study: The Impact of Identity on the Experience and Management of Bipolar Disorder

Investigator: Lisa M. Jaffe, Graduate Student, Smith College School for Social Work, XXXXXXXXXXXX

.....
Introduction

- You are being asked to be in a research study of identity, how you view your sense of self in the world, and how identity connects to bipolar disorder.
- You were selected as a possible participant because you have clicked the link to take the survey regarding identity and bipolar disorder. You have also agreed that a mental health practitioner has made the diagnosis that you have a bipolar disorder (Either Type I, Type II, Rapid Cycling, or NOS) and are over the age of 18. You have also agreed to not be currently in a manic phase or actively psychotic, to the best of your knowledge.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

- The purpose of this study is to look at the connection between identity and how one’s sense of self impacts on the experience of living with bipolar disorder to try to determine if there is any connection between sense of self and management of the disorder.
- This study is being conducted as a research requirement for my master’s degree in social work.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

- If you agree to be in this study, you will be asked to do the following things:
 - Take the online survey that will take approximately 15-30 minutes of your time to answer the survey questions.
 - The survey questions will ask about your experience with the disorder, treatments that you have tried, how you view yourself in the world, and basic anonymous demographic information.

Risks/Discomforts of Being in this Study

- The study has the following risk: You may leave any questions blank or exit the survey at any time. If you experience emotional stress from taking this survey, you are encouraged to utilize your support system in place (such as therapist, mental health counselor, family, friends, etc.)
- Here are some National Numbers: National Suicide Prevention Hotline (800) 273-8255, NAMI Helpline (800) 950-NAMI, and online at www.crisistextline.org

Benefits of Being in the Study

- The benefits of participation are gaining insight into your disorder and your identity, learning more about what treatments have worked for you, and offering a place to share your lived experience.
- The benefits to social work/society are: Better treatment for individuals with bipolar disorder, better incorporation of identity into work with clients with bipolar disorder, and a greater understanding of how identity is formed or shaped by having the disorder.

Confidentiality

- This study is anonymous, which means I will not know your name, email address, and will not be collecting any information about your identity, and the survey website will not send me any information about you other than the answers you provide to my questions.
- Your participation will be kept confidential. None of your private information will be distributed anywhere other than what this consent has stated. The information you provide will be used solely for the purpose of this study,.
- All research materials including recordings, transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period

Payments/gift

- You will not receive any financial payment for your participation.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time-without affecting your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. You have the right not to answer any single question, as well as to withdraw completely up to the point you click on the “submit” button on the last page of the survey. If you choose to withdraw before clicking on the “submit” button, no information you’ve entered will be saved. Unfortunately there is no way to withdraw once you click on the “submit” button; since there will be no identifying information attached to your answers, I won’t be able to tell which answers are yours

Right to Ask Questions and Report Concerns

- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about

the study, at any time feel free to contact me, Lisa Jaffe, at lmjaffe@smith.edu, or by telephone at XXX-XXXX-XXXX. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

- By clicking on the “I agree” button at the end of this form you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. Please print a copy of this form to keep.

Identity and Bipolar Disorder

Identity and Bipolar Disorder

Thank you for choosing to participate in my survey. This survey aims to look at Identity and Bipolar Disorder and what the connection between the two look like. This survey will ask you questions to explore your sense of self and how that relates to the diagnosis. I am conducting this survey for my master's thesis from Smith College's School for Social Work.

In order to participate in the survey, you must be over the age of 18 years old and have received a Bipolar Disorder Diagnosis from a mental health professional (either Type 1, Type 2, NOS, or Rapid Cycling). Also, you must be in treatment, or have received treatment, or have attempted to participate in treatment at least one time in order to participate. You have also agree that you are not currently in a manic phase or are actively psychotic, to the best of your knowledge.

*

1. Do you meet these criteria and wish to participate?

Informed Consent

Consent to Participate in a Research Study
Smith College School for Social Work • Northampton, MA

.....
Title of Study: The Impact of Identity on the Experience and Management of Bipolar Disorder

Investigator: Lisa M. Jaffe

Introduction

- You are being asked to be in a research study of identity, how you view your sense of self in the world, and how identity connects to bipolar disorder.
- You were selected as a possible participant because you have clicked the link to take the survey regarding identity and bipolar disorder. You have also agreed that a mental health practitioner has made the diagnosis that you have

a bipolar disorder (Either Type I, Type II, Rapid Cycling, or NOS) and are over the age of 18. You have also agreed that you are not currently in a manic phase or are actively psychotic, to the best of your knowledge

- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

- The purpose of this study is to look at the connection between identity and how one's sense of self impacts on the experience of living with bipolar disorder. We are trying to determine if there is any connection between sense of self and management of bipolar disorder.
- This study is being conducted as a research requirement for my master's degree in social work.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

- If you agree to be in this study, you will be asked to do the following things:
 - Take the online survey that will take approximately 15-30 minutes of your time to answer the survey questions.
 - The survey questions will ask about your experience with the disorder, treatments that you have tried, how you view yourself in the world, and basic anonymous demographic information.

Risks/Discomforts of Being in this Study

- The study has the following risk:
 - You may leave any questions blank or exit the survey at any time. If you experience emotional stress from taking this survey, you are encouraged to utilize your support system in place (such as therapist, mental health counselor, family, friends, etc.)
 - Here are some National Numbers: National Suicide Prevention Hotline (800) 273-8255, NAMI Helpline (800) 950-NAMI, and online at www.crisistextline.org

Benefits of Being in the Study

- The benefits of participation are gaining insight into your disorder and your identity, learning more about what treatments have worked for you, and offering a place to share your lived experience.
- The benefits to social work/society are: Better treatment for individuals with bipolar disorder, better incorporation of identity into work with clients with

bipolar disorder, and a greater understanding of how identity is formed or shaped by having the disorder.

CONTINUED ON NEXT PAGE

Identity and Bipolar Disorder

Informed Consent - Continued

Confidentiality

- This study is anonymous, which means I will not know your name, email address, and will not be collecting any information about your identity, and the survey website will not send me any information about you other than the answers you provide to my questions.
- Your participation will be kept confidential. None of your private information will be distributed anywhere other than what this consent has stated. The information you provide will be used solely for the purpose of this study.
- All research materials including recordings, transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period

Payments/gift

- You will not receive any financial payment for your participation.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time without affecting your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. You have the right not to answer any single question, as well as to withdraw completely up to the point you click on the “submit” button on the last page of the survey. If you choose to withdraw before clicking on the “submit” button, no information you’ve entered will be saved. Unfortunately there is no way to withdraw once you click on the “submit” button; since there will be no identifying information attached to your answers, I won’t be able to tell which answers are yours

Right to Ask Questions and Report Concerns

• You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Lisa Jaffe, at lmjaffe@smith.edu, or by telephone at XXX-XXX-XXXX. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

• By clicking on the “I agree” button at the end of this form you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. Please print a copy of this form to keep.

★

2. Do you give consent to participate in this survey?

Do you give consent to participate in this survey? Yes.

No.

All of these questions are optional.

If you become triggered by any questions or are feeling under emotional distress, please stop the survey and call either your mental health provider or the National Suicide Prevention Line number to speak to someone at (800) 273-8255

3. What is your age?

What is your age?

4. What is your gender?

What is your gender?

5. What race or ethnicity do you identify as?

What race or ethnicity do you identify as?

6. At what age did you first notice symptoms of bipolar disorder?

At what age did you first notice symptoms of bipolar disorder?

7. What is the highest level of education you have completed?

What is the highest level of education you have completed?

8. Where do you live...

Where do you live... In an urban area

In a rural area

In a small town or city

In a suburban area

Other (please specify)

Identity and Bipolar Disorder

Information

9. How old were you when you were diagnosed?

How old were you when you were diagnosed?

10. What type of Bipolar Diagnosis did you receive?

What type of Bipolar Diagnosis did you receive? Type One (Manic episodes only and both manic and depressive episodes—called Manic Depression)

Type Two (Primarily depressive episodes but with some periods of mild mania—"hypomania")

Rapid Cycling

NOS ("Not Otherwise Specified")

Other (please specify)

11. Do you feel that this diagnosis fits your symptoms and/or life experiences?

Do you feel that this diagnosis fits your symptoms and/or life experiences?

12. Which treatments have you tried at least once? Check all that apply.

Which treatments have you tried at least once? Check all that apply. Outpatient Counseling

Medication
Peer Counseling
In-Home Services
Group Therapy
Dialectical Behavioral Therapy (DBT)
Pet Therapy
Cognitive Behavioral Therapy (CBT)
Mood Scales
Interpersonal and Social Rhythm Therapy (IPSRT)
Exercise
Inpatient Hospitalization
Partial Hospitalization
Outreach Support/Supported Housing
Group Home
Meditation
Residential Treatment Center
Other (please specify)

13. Which treatments were the most helpful? Check all that apply.

Which treatments were the most helpful? Check all that apply. Outpatient Counseling

Medication
Peer Counseling
In-Home Services
Group Therapy
Dialectical Behavioral Therapy (DBT)
Pet Therapy
Cognitive Behavioral Therapy (CBT)
Mood Scales
Interpersonal and Social Rhythm Therapy (IPSRT)
Exercise
Inpatient Hospitalization
Partial Hospitalization
Outreach Support/Supported Housing
Group Home
Meditation
Residential Treatment Center

Other (please specify)

14. Which was the most helpful treatment you've participated in and why?

Which was the most helpful treatment you've participated in and why?

15. How often do you drink alcohol?

How often do you drink alcohol? Daily

2-4 times a week

Once a week

2-4 times a month

Once a month

3-6 times per year

Never

I used to but I quit

All of these questions are optional.

If you become triggered by any questions or are feeling under emotional distress, please stop the survey and call either your mental health provider or the National Suicide Prevention Line number to speak to someone at (800) 273-8255

Powered by **SurveyMonkey**
Check out our [sample surveys](#) and create your own now!

Identity and Bipolar Disorder

Information

16. Which category of symptoms do you experience most?

Which category of symptoms do you experience most? Depressive Symptoms

Manic Symptoms

Hypomanic Symptoms

Mixed-States
Other (please specify)

17. Which category of symptoms do you find most disruptive to your day-to-day life?

Which category of symptoms do you find most disruptive to your day-to-day life? Depressive Sym
Manic Symptoms
Hypomanic Symptoms
Mixed-States
Other (please specify)

18. What was the hardest part about receiving a diagnosis of bipolar disorder?

What was the hardest part about receiving a diagnosis of bipolar disorder?

19. How has your lifestyle changed since receiving this diagnosis?

How has your lifestyle changed since receiving this diagnosis?

Powered by **SurveyMonkey**
Check out our [sample surveys](#) and create your own now!

Identity and Bipolar Disorder

Sense of Self Scale

This is a 12 Question Inventory to measure your sense of self, or how you perceive yourself and your own personality. This test was created in 2006 by J. M. Flury & W. Ickes.

20. Evaluate the following statements.

	Very Uncharacteristic of Me	Uncharacteristic of Me	Chara
I wish I were more consistent in my feelings.			

Very Uncharacteristic of Me

Uncharacteristic of Me

Chara

It's hard for me to figure out my own personality,

interests, and opinions.

I often think how fragile my existence is.

I have a pretty good sense of what my long-term goals

are in life.

I sometimes wonder if people can actually see me.

Other people's thoughts and feelings seem to carry

greater weight than my own.

I have a clear and definite sense of who I am and

what I'm all about.

It bothers me that my personality doesn't seem to be

well-defined.

I'm not sure that I can understand or put much trust

in my thoughts and feelings.

Who am I? is a question that I ask myself a lot.

I need other people to help me understand what

I think or how I feel.

I tend to be very sure of myself and stick to my own

preferences even when the group I am with

expresses different preferences.

Identity and Bipolar Disorder

Looking at Identity

21. Do you feel that your identity has been shaped or changed from having bipolar disorder? If so, how?

Do you feel that your identity has been shaped or changed from having bipolar disorder? If so, how?

22. What do you view as your greatest personal strength?

What do you view as your greatest personal strength?

23. How has bipolar disorder affected who you have become?

How has bipolar disorder affected who you have become?

24. Have you experienced any positive impacts in your life from having bipolar disorder?

Have you experienced any positive impacts in your life from having bipolar disorder?

25. If you could describe what living with bipolar disorder is like in one sentence, what would that sentence be?

If you could describe what living with bipolar disorder is like in one sentence, what would that sentence be?

Check out our [sample surveys](#) and create your own now!

Scales

26. On a scale of 1 (the lowest and applies the least) to 5 (the highest and applies the most), please rank your perceptions of each question.

1 2 3

How under control did your symptoms feel at the time of your diagnosis?

How under control do your symptoms feel now?

How well do you feel like you know yourself?

How much has your life changed since your diagnosis?

Compared to other people you know, do you feel like you know yourself more or less than they know themselves?

Identity and Bipolar Disorder

THANK YOU!

Thank you so much. You have completed the survey.

For any questions, comments, or concerns that you might have regarding this survey or the results, please contact the researcher, Lisa Jaffe, at XXXXXXXXXXXX or XXX-XXX-XXXX

Attention: Adults living with Bipolar Disorder

A research study is being conducted on identity, or your view of yourself, and how this connects to living with the disorder.

This is your chance to be heard! I am looking for individuals to take part in an **Anonymous and Confidential** survey on their lived experience of having bipolar disorder

Share your experience and help others learn from you!

You can take part if...

You are over 18 years old and have received a bipolar diagnosis (Type 1, Type 2, Rapid Cycling, NOS) by a mental health professional, have attempted at least one treatment for the disorder, and are not psychotic to the best of your knowledge.

Take the survey at: _____ or call me at XXX-XXX-XXXX to send you a printed version and a stamped, self-addressed envelope. Note: You do not have to give your name.

Take the information below to fill out the survey and thank you for your participation!

Survey Link

Survey Link

Survey Link

Survey Link

Survey Link

Survey Link

Survey Link

Survey Link

Survey Link

Survey Link

APPENDIX E: RECRUITMENT EMAIL

Hello,

My name is Lisa M. Jaffe and I am a graduate student at Smith College School for Social Work. I am writing to you on behalf of my master's thesis. I am currently conducting research on the connection between identity and bipolar disorder to learn more about the lived experience and how this connection influences the management of the disorder.

I am using an online survey in which adult participants with a bipolar diagnosis answer questions on an on-line survey. The survey consists of both open and closed ended questions, basic demographic information, and several scales. All of the information is anonymous and held to the standards of the Institutional Review Board and Human Subjects Review at Smith College's School for Social Work. The survey website will not record participants' identifying information, computer address.

Before completing the survey, all participants must agree to the informed consent before proceeding with the survey and participants may choose to withdraw from participation at any time before they finish the survey.

The benefits of this research are to better understand bipolar disorder and identity, to help with treatments for the disorder, and to get first-hand knowledge from individuals living with this disorder.

The link to the survey is: <https://www.surveymonkey.com/s/bipolaridentity>

If you [or your agency] could circulate this link or post this link in your community, it would be incredibly beneficial to my research. Thank you for your assistance.

If you have any questions or comments, please do not hesitate to contact me at (XXX) XXX-XXXX or by email at XXXXXX@XXXXXX.

Sincerely,
Lisa M. Jaffe