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Understanding the Experience of Early-Onset Bipolar Disorder: A Phenomenological Study of Emerging Adults

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Understanding the Experience of Early-Onset Bipolar Disorder:

A Phenomenological Study of Emerging Adults

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
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When a person realizes he has been deeply heard, his eyes moisten.

I think in some sense he is weeping for joy. It is as though he were saying

“Thank God somebody heard me.

Someone knows what it’s like to be me”

~Carl Rogers

I do have to say this is one of the first times anyone in a medical setting has asked me my perception of the disorder I have, which is one of the things I had a really hard time understanding. Especially whenever I would tell the doctor my understanding of my disorder and they would tell me that I was wrong and not want to listen. So I think that’s already extremely important, and I’m very happy someone even bothered to ask.

-Participant D

Because if people find out they look at you differently. They look at you like they’re waiting for something to happen, like a crazy person. They look at you like you’re just weird. And it’s totally different. And it sucks. Honestly, it’s deplorable. I’m kind of glad you’re doing this research study because maybe it’ll go viral and a whole bunch of people will read it, and think differently about the things that they say...

-Participant E

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Abstract

While early-onset bipolar disorder (EOBD) has increased in prevalence, much remains to be understood about its phenomenology. Research and treatment models remain rooted in neurobiological conceptualizations of the illness that borrow heavily from models for the traditional adult-onset form of bipolar disorder. This study utilized a transcendental phenomenological design as a first step in obtaining an understanding of the lived experience of EOBD. A purposive sample of eight participants ages 18-25 participated in semi-structured interviews that elicited information on experiences of EOBD symptomatology and course of illness, stigma, experience with healthcare and treatment, and impact on identity, interpersonal relationships, and coping responses. Transcendental phenomenological analysis was used to construct individual and composite descriptions of participants' experience of EOBD between ages 13 and 17. Implications of findings are presented for research and treatment of EOBD, as well as social work education and policy reform.

Chapter One: Introduction

Bipolar disorder is a significant, pervasive mental disorder comprised of a spectrum of manic and depressive symptoms manifested during episodic mood states (American Psychiatric Association, 2013; Price & Marzani-Nissen, 2012). While symptoms may remit partially or in full between episodes, bipolar disorder has an unremitting longitudinal course. Bipolar disorder is associated with significant and pervasive impairments in occupational, educational, interpersonal, and daily functioning that persist across the lifespan.

Bipolar disorder has historically been conceptualized and operationalized across research and clinical settings as an adult disorder, with the onset and course of symptoms diagnosed and treated after 18 years of age (Garnham et al., 2007). However, bipolar symptoms often begin in adolescence. Twenty-eight percent of adults with bipolar disorder report experiencing manic and depressive symptoms prior to age 13, and 66% of adults with bipolar disorder report experiencing symptoms prior to age 18 (Perlis et al., 2004). Early-onset bipolar disorder (EOBD), in which the illness manifests in full prior to age 18, is regarded as potentially difficult to diagnose accurately and treat effectively; this is largely due to dispute regarding diagnostic criteria, nosology, and treatment interventions for the juvenile population (Ghaemi & Martin, 2007).

The impact of bipolar disorder extends beyond its symptoms and affects the individual's sense of self, identity, and self-esteem. The stigma of bipolar disorder is reflected through the individuals' sense of loss of control over their lives due to persistent symptoms, self-blame for

symptoms, and believing a healthy sense of self is contingent upon successful symptom management (Crowe et al., 2012).

Bipolar disorder influences psychosocial development extending through adolescence and into emerging adulthood. The presence of patterns of conflict, communication, and support within the family system and peer relationships during adolescence impact not only psychosocial functioning during adolescence but identity development, relationships, and goal attainment during the period of emerging adulthood (Aquilino, 2006; Arnett, 2006a; Collins & van Dulmen, 2006; Miklowitz, 2008). Protective factors in peer and family relationships, including reappraisal support, validation, and increased capacity to build intimacy facilitate adjustment and acceptance of bipolar disorder and counteract the inception of associated stigma and self-stigma (Dahl, 2004; Doherty & MacGeorge, 2012).

Theoretical Underpinnings

To achieve a more accurate and thorough understanding of the phenomenology of EOBD, the incorporation of multiple theoretical frameworks is needed. A greater understanding of the individual course of illness and treatment response, family history and functioning, and biological markers can improve diagnosis and treatment of EOBD (Ghaemi and Martin, 2007). Theories of neurology and biology, stigma, and interpersonal functioning provide both explanatory and predictive properties to better understand the etiology, nosology, prognosis, course of illness, and associated psychological and developmental changes in functioning incurred by EOBD.

Neurological and biological theories have largely dominated the study of bipolar disorder. Neurobiological theories propose a bipolar disorder etiology consisting of biological vulnerabilities such as smaller amygdala volumes (Bitter et al., 2011), enlarged portions of the

basal ganglia (Ahn et al., 2007), variances in limbic volumes (Frazier et al., 2008), and different psychophysiological responses to stimuli for frustration and reward (Alloy et al., 2012b; Rich et al., 2007). Much of the cumulative literature has been devoted to identifying biological or genetic risk factors for bipolar disorder, including patterns of heredity and factors associated with onset of symptoms (Alloy et al., 2012a; Berk et al., 2009; Daban, Colom, Sanchez-Moreno, García-Amador, & Vieta, 2006; Goldstein, 2012).

While neurobiological theories address the etiology of bipolar disorder, they offer limited contributions toward other facets of the phenomenology of bipolar disorder. Individuals with bipolar disorder are subject to critical and judgmental messages from both external and internal sources, affecting developmental processes such as development of identity and self-esteem (Moses, 2009). Indeed, modified labeling theory describes stigma as the byproduct of the social exchange between the individuals with bipolar disorder and larger society. Furthermore, higher levels of stigma and self-stigma correlate with poorer prognosis, management of the illness, recovery between episodes, and overall functioning in individuals with bipolar disorder (Alreja, Mishra, Sengar, & Singh, 2009; Cerit, Filizer, Tural, & Tufan, 2012; Moses, 2009).

The theory of emerging adulthood offers explanatory properties for the experience of early-onset bipolar disorder in the present study's sample. Theory of emerging adulthood identifies a unique and distinct period between adolescence and adulthood (between ages 18-25), characterized by increased opportunity and independence, as well as a lack of stability regarding attainment of adult goals. This conflict includes struggles in building relationships and intimacy, identity development, and goal attainment (Arnett, 2006a; Bynner, 2005).

Gaps in Cumulative and Existing Research

The literature on EOBD is characterized by efforts to conceptualize bipolar disorder and prescribe appropriate interventions for the juvenile population. This movement, however, has occurred largely without the inclusion of the qualitative perspectives of the individuals with an EOBD diagnosis. This may be due in part to the domination of clinical research by the medical sciences; however, even within the medical sciences, various authors (Parry & Levin, 2012; Sullivan & Miklowitz, 2010) have stated the need for qualitative research to explore the full phenomenon of bipolar disorder. Current literature includes quantitative inquiries into epidemiology (e.g., Goldstein, 2012; Harris, 2005), differential diagnosis (e.g., Carlson, 2012; Galanter et al., 2012), psychopharmacology (e.g., Dusetzina et al., 2011; Raven & Parry, 2012) and prognosis of EOBD (e.g., Axelson et al., 2011; Berk et al., 2009; Daban et al., 2006; Perlis et al., 2004), but does not incorporate the perspectives of the individuals with the disorder. One exception is a study by Moses (2009) that combined both qualitative and quantitative data from 54 adolescents with various mental illnesses. While the interviews and standardized measures created a more thorough understanding of the adolescents' experiences with stigma and self-labeling through interviews and standardized measures, the study was not specific to EOBD. These limitations notwithstanding, the literature to date has not incorporated such qualitative approaches to better understand adolescents' experiences of mental health.

Moreover, while the literature on bipolar disorder references the importance of interventions to address families and stigma (Heflinger & Hinshaw, 2010; Perlick et al., 2007; Perlick et al., 2008), these studies focus on adult-onset bipolar disorder and incorporate quantitative approaches to evaluate the effectiveness of interventions (e.g., Brown, Rempfer, & Hamera, 2008; Struening et al., 2001) rather than eliciting the first-person experience of bipolar

disorder. Aquilino (2006) highlights the absence of qualitative inquiries in research on emerging adulthood incorporating both clinical and community samples.

Purpose of the Study

The purpose of the present qualitative study is to explore the experience of EOBD through semi-structured interviews of emerging adults with a history of EOBD diagnosis. Semi-structured interviews will elicit a deeper knowledge of EOBD through participants' descriptive accounts. First-person qualitative reports are perhaps the most important and overlooked resource in the search to conceptualize and treat EOBD. This study will address aspects of EOBD such as onset, diagnosis, and experience of symptoms; psychosocial and identity development; stigma; treatment interventions; and developmental changes occurring through emerging adulthood.

Research questions

This qualitative study will address the following research questions:

- 1) How do emerging adults (ages 18-25) describe the experience of EOBD during adolescence (ages 13-17) in terms of experience of symptoms; changes in individual, social, and family functioning caused by course of illness; and the experience and perception of stigma and self-stigma?
- 2) How do emerging adults (ages 18-25) characterize the cumulative influence of interactions with healthcare systems and treatment interventions on their experience of EOBD?
- 3) What are the characteristics of the relationship between EOBD, social and family relationships and the developmental transition to adulthood according to emerging adults?

- 4) How have stigma and self-stigma associated with EOBD affected the social, emotional, and cognitive development of emerging adults ages 18-25?

Relevance and Significance of Study

Within the last 20 years, the prevalence of bipolar disorder diagnoses prior to age 18 has increased at a rate disproportionate to our understanding of its phenomenology (Carlson, 2012; Ghaemi & Martin, 2007; Harris, 2005; Moreno et al., 2007). The cumulative literature illustrates efforts not only to establish the etiology and nosology of EOBD, but also to develop treatment interventions for the juvenile population.

Social workers are present throughout the healthcare system in hospital, outpatient, and intensive treatment settings as an integral part of treatment approaches for individuals with bipolar disorder and their families. Interventions incorporating the multitheoretical framework of neurobiological, modified labeling, and developmental theories specific to the unique phenomenology of EOBD are needed to improve treatment outcomes (Brown et al. 2008; Corrigan, Powell & Rüsch, 2012). Limitations in the development and delivery of psychosocial rehabilitation interventions targeted to issues of stigma, individual and family functioning, and symptom management are emphasized throughout the literature (Camp, Finlay, & Lyons, 2002; Cerit et al., 2012; Crowe et al., 2012; Davis, Kurzban, & Brekke, 2012; Heflinger & Hinshaw, 2010). Several researchers have identified the need to improve understanding of the phenomenology of EOBD through qualitative research with adolescents and their families (Moses, 2009; Sullivan & Miklowitz, 2010).

This study constitutes an important first step in improving conceptualization and treatment of EOBD by providing a more accurate and thorough phenomenology of EOBD from the perspective of emerging adults with history of EOBD diagnosis. The integration of multiple

theoretical frameworks will create a comprehensive perspective from which to understand EOBD. Study conclusions and implications will address gaps in existing research and better inform the development of theory and therapeutic interventions for EOBD.

Definitions

Bipolar disorder. Bipolar disorder is a mental illness comprised of a longitudinal pattern of depressive and manic or hypomanic episodes (APA, 2013). Bipolar I disorder consists of a cyclical progression of manic and depressive episodes, while bipolar II disorder consists of a similar progression of hypomanic and depressive episodes in the absence of manic symptoms (APA, 2013).

A manic episode is defined by the presence of “abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity or energy” (APA, 2013, p. 124). Manic episodes last a minimum of one week in duration and include behavior changes such as grandiosity, decreased need for sleep, pressured speech, racing thoughts and flight of ideas, distractibility, increase in psychomotor activity and agitation, and excessive involvement in reckless activities with high potential for adverse consequences. Symptoms must be severe enough to cause impairment of the individual’s normal functioning and cannot be attributed solely to a medical condition or substance (APA, 2013).

A hypomanic episode is defined by the presence of manic symptoms at a lesser severity, such that the individual’s ability to function is not as fully impaired as in a manic episode. Additionally, the minimum duration of a hypomanic episode is 4 days, compared with the one week minimum duration for a manic episode. Hypomanic episodes occur in both bipolar I and II disorders and often are preceded or followed by depressive episodes (APA, 2013).

A depressive episode lasts for a minimum of two weeks and includes the following symptoms: depressed mood (sadness, hopelessness, tearfulness), diminished interest or pleasure in almost all activities, unintended weight gain or loss (5% or more of body weight within a one-month period), insomnia or hypersomnia, psychomotor agitation or retardation, fatigue, feelings of worthlessness or inappropriate guilt, diminished ability to think or concentrate, and recurrent thoughts of death or suicidal ideation. Depressive episodes cause significant distress and impairment in the individual's ability to function and similarly cannot be solely caused by a medical condition or substance. Bipolar disorder may additionally include atypical features such as episodes with concurrent ("mixed") manic and depressive features, rapid cycling, psychosis, catatonia, and a seasonal presentation of symptoms (APA, 2013).

Early-onset bipolar disorder. Early-onset bipolar disorder (EOBD) is defined as the presence of bipolar disorder symptomatology (depressive and manic or hypomanic episodes) manifested in full prior to age 18 (APA, 2013). While each individual's presentation of bipolar symptoms and course of illness may vary (i.e., increased incidence of rapid cycling, episodes with mixed manic-hypomanic and depressive symptoms, and increased risk of suicide in the juvenile population), the diagnostic criteria for bipolar disorder, regardless of age of onset, persists across the lifespan (Perlis et al., 2004). In the fifth edition of its Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2013), the APA further emphasized the longitudinal congruence of bipolar disorder with the introduction of Disruptive Mood Dysregulation Disorder (DMDD, discussed below) to categorize disturbances in affect occurring in childhood and adolescence that do not meet criteria for full bipolar symptomatology.

Stigma. Stigma is defined as stereotypes, discrimination, and devaluation associated with a condition or trait perceived as negative (Corrigan, 2005). While stigma originates from external

sources such as stereotypes and beliefs of the general population, self-stigma occurs when the individual internalizes stigmatizing beliefs as self-directed criticism (Corrigan et al., 2012).

Through stigma, individuals are devalued due to their membership in an undesirable or defective group with low social power. Stigma has been shown to increase the subjective burden of mental illness while negatively affecting the help-seeking behaviors and functioning of both individuals and families (Heflinger & Hinshaw, 2010; Perlick et al., 2008; Struening et al., 2001).

Emerging adulthood. Emerging adulthood is defined as a distinct developmental stage occurring between ages 18-25 that spans the gap between adolescence and adulthood (Arnett, 1999). Emerging adulthood is a time of exploration of identity, interpersonal relationships, and goal attainment occurring alongside increased independence and agency in decision-making responsibilities (Arnett, 2006a, 2006b). As emerging adults, the participants' experience of bipolar disorder during adolescence will be recent; therefore, participants will be able to accurately recall the adolescent experience of EOBD while providing the insight and cognitive depth associated with emerging adulthood. The resulting phenomenological data will significantly enrich and expand upon current understanding of the phenomenology of EOBD.

Delimitations

This study seeks to better understand the phenomenology of EOBD as defined above. Several issues therefore fall outside the scope of this study. These issues are present across the debate within the literature regarding nosology, differential diagnosis, and etiology of EOBD.

Phenotype controversy. Much of the literature on EOBD has reflected the nosological debate between the narrow phenotype and broad phenotype definitions of bipolar disorder. The narrow phenotype, preserved by the APA (2013) in DSM-5, specifies an episodic course of illness comprised of distinct manic and depressive symptoms that differ significantly from the

individual's baseline functioning. The broad phenotype incorporates a more inclusive presentation of a continuous, non-episodic course of persistent irritability and affective instability that may be difficult to distinguish from the individual's personality and functioning (Ghaemi & Martin, 2007). This study adheres to the DSM-5 definition of bipolar disorder and does not incorporate the more inclusive broad phenotype conceptualization of EOBD.

Disruptive mood dysregulation disorder. In the DSM-5, the APA (2013) introduced a new diagnosis, Disruptive Mood Dysregulation Disorder (DMDD), as an alternative to a broad phenotype diagnosis of EOBD. DMDD is included in DSM-5 solely as an alternative diagnosis for the severe, non-episodic irritability and affective instability that has frequently been misdiagnosed as EOBD. Whereas an adolescent with EOBD experiences manic and depressive episodic mood states, an adolescent with DMDD experiences anger outbursts and continuous irritability in the absence of the episodic bipolar mood states. The APA states a prevalence of DMDD in 2-5% of children and adolescents, compared with EOBD prevalence of less than 1% prior to age 18 (p. 157).

DMDD and EOBD are defined as mutually exclusively occurring disorders, and as such cannot be diagnosed in the same individual (APA, 2013). This study explores the phenomenology of EOBD; and as such, selected only participants with an EOBD diagnosis during adolescence.

Heritability and genetic risk factors. The family system has been extensively incorporated into bipolar disorder research. Much of this research, however, has focused on heritability and genetic predisposition to bipolar disorder. This study does not address or explore the presence or heritability of psychiatric symptomatology in family members.

Chapter Two: Literature Review

This literature review will address two main areas related to the phenomenology of EOBD. First, theoretical frameworks will be reviewed as they relate to EOBD among adolescents and their caregivers. Second, pertinent domains such as the identity development and perception of self, interactions with the healthcare system, and stigma will be examined. Gaps in the literature will be discussed and research questions will be presented.

Theoretical Framework

This section reviews the neurobiological, modified labeling, and emerging adulthood theoretical frameworks that guide and inform this study's design.

Neurobiological theories. Neurobiological theories offer causal explanations for the presence and development of bipolar disorder symptomatology. Neurobiological theories address physical abnormalities of the brain, dysregulation of neurotransmitters, and dysfunction of brain activity.

Structural brain irregularities. Research utilizing neurobiological testing indicates several brain structural abnormalities are associated with bipolar disorder. Ahn et al. (2007) reported an association between increased volume of nucleus accumbens (NA), a basal ganglia (BG) structure, and EOBD diagnosis in participants age 6-16. Ahn et al. reported psychotropic medications were negatively correlated with decreased structural abnormality, possibly illustrating the effect of pharmacological interventions on bipolar disorder. Frazier et al. (2008) reported findings indicating not only larger NA volumes in participants ages 6-17 with EOBD, but also smaller left and right cerebral volumes. Bitter et al. (2011) reported abnormal

development of the amygdala in participants age 12-17 following onset of EOBD symptomatology. While amygdala volume was within normal limits at onset of EOBD symptomatology, volume did not increase as expected during the first year with active symptomatology. These findings are consistent with structural abnormalities of the prefrontal cortex, BG, hippocampus, anterior cingulate, and amygdala associated with adult-onset bipolar disorder (Miklowitz & Johnson, 2006).

Brain activity dysfunction. In addition to structural abnormalities, abnormal functioning of brain activity is associated with bipolar disorder. Rich et al. (2007) reported significant differences in the response to frustration in participants with EOBD that indicate executive attention deficits and inability to modulate attention in the presence of increased emotional demands.

Behavioral approach system (BAS) sensitivity, a type of brain activity dysfunction, is highly correlated with EOBD and may predict the onset of symptomatology (Alloy et al., 2012b). The BAS model is a biobehavioral system activated by goal- or reward-relevant stimuli. Behavioral approach system (BAS) activation includes increased motor behavior, incentive-reward motivation, and positive goal-striving emotions. Individuals with EOBD are likely to have a BAS with greater sensitivity and response to environmental cues. Behavioral Approach System (BAS) hyperactivation is associated with manic symptoms of bipolar disorder; increased reward responsiveness and increased goal-striving may be predictors of onset of bipolar symptoms. BAS hypoactivation is associated with depressive symptoms of bipolar disorder. Adolescents with greater BAS hyperactivation and hypoactivation had greater incidence of development of bipolar disorder. Alloy et al. (2012b) reported 42.1% of adolescent participants with high to moderate BAS activity had first-episode onset of bipolar II disorder, while 10.5%

experienced first-episode onset of bipolar I disorder within the 4.5 year follow-up period. BAS hypersensitivity is therefore associated with vulnerability to onset of EOBD as well as course of illness and may offer predictive properties regarding onset of illness.

Neurotransmitter dysregulation. Neurotransmitter dysregulation is a primary contributing factor to bipolar disorder symptomatology. While manic and depressive symptoms of bipolar disorder have been attributed to imbalances in transmission of the chemicals dopamine, serotonin, and norepinephrine within the brain, current neurobiological theories focus on the functioning of larger neurotransmitter systems. Miklowitz and Johnson (2006) point to the interaction of dopamine and serotonin systems with other neurotransmitter systems (such as gamma-Aminobutyric acid (GABA)) as causes of manic and depressive symptoms.

Manic symptoms such as hyperverbality, heightened mood, increased energy, and sleep deprivation are associated with dopamine dysregulation (Miklowitz & Johnson, 2006). Dopamine dysregulation is linked to brain functioning associated with reward motivation (i.e., BAS) and regions such as the NA (Ahn et al., 2007; Alloy et al., 2012; Frazier et al., 2008), indicating an association between the increased sensitivity of dopaminergic pathways and the subsequent onset of bipolar disorder symptomatology. While decreased sensitivity of serotonin receptors has been associated with mood disorder symptomatology, including bipolar disorder, the exact nature of serotonergic system dysregulation remains undefined (Miklowitz & Johnson).

Neurobiological theories offer an explanation for EOBD symptomatology and course of illness comprised of a complex, interwoven pattern of dysfunction in the brain involving neurotransmitters, structural irregularities, and activity disturbances within the brain's interactive systems. Neurobiological theories continue to strongly influence research and treatment of EOBD and bipolar disorder.

Modified labeling theory. Modified labeling theory asserts that individuals with and without mental illnesses internalize role behaviors associated with mental illness. While individuals with mental illnesses internalize ‘sick’ behaviors, individuals without mental illnesses internalize the devaluation and discrimination of those with mental illness. Modified labeling theory states that stigma is manifested through devaluation, in which the presence of mental illness decreases the perceived value of the individual, and discrimination, in which the individual is distanced and ostracized from larger society (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989).

Modified labeling theory can be used to explain the inception of stigma within the healthcare system as well as society. Psychiatric diagnoses assigned by the healthcare profession carry labels not only for the behaviors associated with mental illnesses, but also the expectations and limitations regarding individual functioning and prognosis. Individuals with mental illnesses internalize healthcare providers’ conceptualizations of mental illness. The provision of treatment interventions that decrease symptomatology often incorporates labeling practices by healthcare professionals that facilitate the inception and perpetuation of stigma. Labeling within the healthcare system also produces devaluation and discrimination; the individual with mental illness comes to expect rejection from others and subsequently adopts avoidance coping, in which potential sources of stigma are avoided (Kroska & Harkness, 2006).

Longitudinal effects of stigma and labeling include negative connotation toward mental illness, self-blame, social withdrawal, and secrecy that occur independently of the type of mental disorder and length of treatment history. Furthermore, stigma may increase risk of relapse of mental illness and failure of symptoms to remit, thus contributing to the identity as well as mental health of the individual (Link et al., 1989).

Labeling in adolescence. Stigma and labeling associated with mental illness occur with adolescents as well as adults. In a study of adolescents with mental illness, Moses (2009) found that 37% did not self-label or view themselves as mentally ill. These adolescents described psychiatric symptoms and associated behaviors in terms of situational contexts and manifestations of identity rather than symptomatic of mental illness. Approximately 42% of adolescents reported ambivalence regarding labeling and self-labeling through the healthcare system. These ambivalent adolescents identified psychiatric symptoms, yet expressed both uncertainty and limited understanding of diagnostic issues and labels from healthcare professionals. Ambivalent adolescents displayed a tendency to attribute symptoms and psychiatric hospitalizations to identity and personal choices rather than the label of a mental disorder. Approximately 20% of adolescents strongly endorsed diagnostic labels. The self-labeling group displayed a tendency to attach the possessive pronoun “my” to a diagnosis (i.e., “my bipolar disorder”), thereby fusing the disorder to their identity. The self-labeling adolescents additionally displayed higher levels of self-awareness and insight regarding symptomatic behaviors (Moses, 2009).

Moses (2009) concluded that adolescents vary regarding their endorsement and application of labeling. Self-labeling adolescents reported experiencing more rejection, more difficulties in social functioning, and more avoidance coping. Moses hypothesized that adolescents’ ambivalence regarding self-labeling may be related to continuing psychological and cognitive development, social context, or limited understanding of the phenomenology of mental illness. Self-labeling among adolescents was correlated with higher self-stigma and depression. Moses asserted that self-labeling in adolescents with mental illness may be demoralizing, stigmatizing, and disempowering. While higher levels of public stigma, social rejection,

devaluation, discrimination, and depression correlated with self-labeling, it is unknown whether self-labeling is the causal factor or by-product of these processes. Depressive symptoms may be symptomatic of mental illness as well as an outcome of social rejection and stigma. Furthermore, Moses reported that younger age at onset of symptoms was associated with increased self-labeling; this could be due to increased experience with labeling of the healthcare system, public stigma, devaluation, discrimination, or social rejection. While the nature of the relationship between labeling and self-labeling in adolescents remains largely undefined, the process of labeling and self-labeling is an integral part of the phenomenology of adolescent mental illness.

Theory of emerging adulthood. Theory of emerging adulthood asserts that the period between ages 18 and 25 is a distinct stage occurring between adolescence and adulthood in which increased independence and exploration facilitate growth and development across multiple domains. Emerging adulthood encompasses five main features: 1) identity exploration, 2) instability regarding life circumstances and decisions; 3) focus on self; 4) feeling ‘in between’ adolescence and adulthood; and 5) possibility and optimism of the emerging adults in response to increased ability to effect change on their lives (Arnett, 1999; Arnett, 2006a). Factors influencing identity development and exploration include life events such as moving out of the family home, the formation of new relationships, and choice of occupation; as well as environmental influences, the individual’s collective social support, and belief system. (Bynner, 2005; Schwartz, Côté, & Arnett, 2005). Emerging adulthood inherently incorporates a perceived sense of uncertainty regarding adult tasks such as marriage, beginning a family, and creating a career path; and the associated decision-making to attain these goals that requires an established sense of identity (Arnett, 2006a). Emerging identity varies culturally and is subjectively defined.

Emerging adulthood is considered complete once the individual feels adult goals have been attained, thereby completing the transition to adulthood (Arnett, 1999).

Emerging adulthood and psychosocial development. Psychosocial development in emerging adulthood is characterized by a sense of opportunity and possibilities that include changes and developments in family, social, and romantic relationships. During emerging adulthood, the relationship between the emerging adult and the parent changes toward a relationship comprised of two adults, rather than a parent and dependent child. This change in the parental relationship requires the parent's acknowledgement of their child as an emerging adult in terms of status, independence, and agency. While patterns of parent-child interaction and family dynamic during childhood and adolescence influence the parent-child relationship during adulthood, this influence weakens as the emerging adult moves further into adulthood. Affection, open communication, and mutual respect in family relationships influence identity development and exploration in emerging adulthood (Aquilino, 2006). Increased independence in emerging adulthood allows emerging adults to detach from unhealthy family relationships and establish strong bonds in both peer and romantic relationships (Arnett, 2006b; Aquilino, 2006; Collins & van Dulmen, 2006).

Emerging adulthood and stigma. Emerging adults remain susceptible to stigma and self-stigma, particularly regarding identity development. Components of stigma such as viewing oneself self as "less than" others without mental illness, avoidance, and coping methods present in adolescence continue through emerging adulthood and present as a challenge to identity development. Moreover, emerging adults with mental illness reported difficulty disclosing the mental illness, which carries significant implications for relationship building during emerging adulthood (Elkington et al. 2012).

Support from relationships in emerging adulthood may be the greatest protective factor against stigma and self-stigma. Appraisal support, which encourages the individual to reframe situations in a more positive light, is particularly associated with decreased stigma among emerging adults with mental illness (Dahl, 2004; Doherty & MacGeorge, 2012).

Emerging adulthood and EOBD. Emerging adults with a diagnosis of bipolar disorder are more likely to have received the diagnosis in recent years; the majority of cases have onset of symptoms and diagnosis between ages 18-25 (Dahl, 2004; McGorry, Purcell, Goldstone, & Amminger, 2011). Furthermore, emerging adults' family and social support, relationship building, and efforts to cope with stigma are processes that began during adolescence (Aquilino, 2006; Elkington et al., 2012).

Paradoxically, a positive correlation occurs between mental illness and wellness during emerging adulthood; while psychopathology of mental illness increases during emerging adulthood, well-being and self-esteem increase as well (Arnett, 2006b; Galambos, Barker, & Krahn, 2006; Schulenberg & Zarrett, 2006). Processes that occur in emerging adulthood such as increase in social support, commitment to education and goal attainment, and greater sense of meaning are associated with increased well-being (Galambos et al., 2006; Schulenberg & Zarrett, 2006; Steger, Oishi, & Kashdan, 2009). Thus, while emerging adults may encounter the difficulties associated with experiencing symptomatology of mental illness, the developmental processes occurring during emerging adulthood may provide protective properties and facilitate development of healthy identity and relationships (Arnett, 1994; Elkington et al., 2012; Schulenberg & Zarrett, 2006). This study's sample is comprised of emerging adults who offer both the recent experience of EOB

Interpersonal functioning and social support. Social support in bipolar disorder is an important component toward maintaining wellness, as it is associated with decreased vulnerability to bipolar depressive episodes and a shorter recovery time following symptomatic episodes (Johnson et al., 1999). Individuals with bipolar disorder report increased difficulty in social activities and interpersonal relationships, including social and family interactions (Calabrese et al., 2003). During symptomatic episodes, deficits in interpersonal functioning increase; while during periods of symptomatic recovery interpersonal functioning has been shown to improve (Weinstock, Keitner, Ryan, Solomon, & Miller, 2006). Furthermore, deficits in social cognition and functioning in adults with bipolar disorder are also present in EOB and believed to persist across the lifespan throughout the course of illness (McClure et al., 2005). Social functioning and relationships therefore have significant implications for the course of bipolar disorder.

Interpersonal social rhythm therapy. Social functioning is a core concept in interpersonal social rhythm therapy (IPSRT), a therapeutic intervention for bipolar disorder that seeks to stabilize symptomatic episodes through achieving lifestyle balance. IPSRT integrates behavioral, interpersonal, and psychoeducational models to alleviate severity and frequency of symptomatic episodes of bipolar disorder. IPSRT focuses on stabilizing circadian rhythms and sleep-wake patterns, as well as the social cues that affect these patterns. Personal relationships and their social demands are viewed as mediators between biological and psychological vulnerabilities for symptomatic episodes of bipolar disorder (Frank, Swartz, & Kupfer, 2000).

Family-focused treatment. For families affected by bipolar disorder, impairment in family functioning is associated with course of illness and persists even in the absence of symptomatic episodes (Weinstock et al., 2006). Therefore, it is important that therapeutic

approaches to bipolar disorder also focus on interpersonal functioning within the family. Family-Focused Treatment (FFT) is a therapeutic approach that focuses on the balancing patterns of interpersonal communication and expressed emotion (EE) within the family system. Greater levels of EE within the family are associated with high levels of criticism, hostility, and emotional over-involvement as well as risk of symptomatic relapse for the individual with bipolar disorder (Miklowitz, 2008; Morris, Miklowitz, & Waxmonsky, 2007). FFT aims to stabilize bipolar disorder by balancing protective and risk factors in family and social environments. FFT interventions address interpersonal functioning within the family through psychoeducation, relapse prevention, communication enhancement, and problem-solving with family members (Miklowitz, 2008). When used with EOBD, FFT addresses age-appropriate developmental tasks, the family experience of EOBD, and works to reduce negative high EE family behaviors such as criticism and hostility (Morris et al., 2007).

Extant Knowledge on EOBD

The phenomenology of EOBD is explored across five domains within the literature: a) scope of the illness; b) the adolescent perception of self; c) interactions with the healthcare system; d) the family system; e) stigma. When viewed collectively, the research across these domains provides a comprehensive understanding of existing knowledge of EOBD.

Scope of EOBD. Prevalence data and course of bipolar disorder illness are discussed across the lifespan, with consideration and implications for EOBD. Information presented for bipolar disorder is inclusive to both early- and adult-onset presentations in accordance with the DSM-5 conceptualization of bipolar disorder (APA, 2013).

Prevalence. Bipolar disorder occurs in 1-2% of the adult population. While EOBD prevalence is consistent with adult-onset prevalence at 0 – 2% of adolescents in community

samples and 6.0 - 6.9% of adolescents in clinical samples, it has been diagnosed in up to 13% of the adolescent and child population across community and clinical samples (APA, 2013; Harris, 2005; Miklowitz & Johnson, 2006). The discrepancy between EOBBD prevalence and diagnostic rates is not rooted in whether bipolar disorder symptomatology can manifest prior to age 18, but in whether EOBBD is conceptualized and operationalized consistently with adult-onset bipolar disorder (Miklowitz & Johnson, 2006). The trending conceptualization of EOBBD as a chronic and continuous state of irritability, tearfulness, and psychomotor agitation with prolonged temper outbursts, rather than as an episodic illness with distinct manic and depressive states has impacted treatment interventions, prognosis, course of EOBBD illness, and the psychological development of adolescents with EOBBD (Biederman, 1995; Biederman et al., 1995; Faedda et al., 1995; Wozniak et al., 1995).

Bipolar disorder is the sixth cause of disability worldwide, and its functional impairment occurs even in the absence of full symptomatic episodes (Cerit et al., 2012; Judd et al., 2002). Psychotropic medications may decrease the severity and frequency of both subthreshold and full symptomatic episodes, but management of bipolar disorder remains challenging. In a study of five guideline-concordant psychotropic medications, only 58-63% of participants' symptoms responded partially or in full to the prescribed medications (Garnham et al., 2007). Furthermore, up to 30% of individuals with bipolar I disorder and 15% of those with bipolar II disorder experience impairment in functioning in the absence of symptomatic episodes. As many as 20% of individuals with bipolar disorder transition between symptomatic episodes without periods of symptom-free recovery (APA, 2013).

Course of illness. The average age of onset of bipolar I disorder is 18 years and for bipolar II disorder occurs in the mid-20s (APA, 2013). However, the literature indicates onset of

symptoms occurs an average of ten years prior to a diagnosis (Berk et al., 2009; Torrey & Knable, 2002). Within the literature, varying estimates indicate a significant portion of individuals with bipolar disorder report onset of symptoms in their youth. Torrey and Knable stated 20-40% of individuals with bipolar disorder report onset of symptoms in childhood, while Perlis et al. (2004) reported onset of symptoms prior to age 13 in 28% of individuals with bipolar disorder and onset of symptoms prior to age 18 in 66% of individuals.

The onset of bipolar disorder often occurs over with symptomatology progressively increasing to its full diagnostic presentation over the course of several years. In a clinical sample, 45% of participants age 7-17 progressed from subthreshold symptoms to bipolar I or II disorders over a period of 5 years. Twenty-three percent of participants developed bipolar I disorder, 9 of which first progressed to bipolar II disorder within the sample timeframe. Twenty-two participants met criteria for bipolar II disorder (not including the 9 participants who eventually met criteria for bipolar I disorder) by conclusion of the study. Furthermore, hypomanic symptoms were present in 85% of participants within one month prior to onset of bipolar I or II symptomatology (Axelson et al., 2011).

The polarity (i.e., manic or depressive) of the first episode at onset of bipolar disorder may contain important clues for the prognosis and course of illness. Approximately two-thirds of adults with bipolar disorder (67%) reported first episode was depressive in nature, and 75% of these adults with depressive onset reported a course of illness dominated by depressive episodes. In comparison, only 27.9% of participants with manic episode at onset of illness experienced course of illness dominated by depressive episodes. Improved identification of episode polarity at onset of bipolar disorder may facilitate improved intervention and course of illness (Daban et

al., 2006). Additionally, successful treatment early in the course of illness is associated with an improved prognosis (McGorry, 2010).

Determining first episode polarity in adolescents with emerging mood symptomatology can be challenging for the clinician due to factors such as differential diagnosis between bipolar disorder subtypes (i.e., type I, II, or unspecified; APA, 2013). Furthermore, clinicians face the often-nuanced nosological diagnostic challenges of distinguishing between mood swings and mood episodes, continuous irritability and episodic course of illness, and rage outbursts in contrast to true manic symptoms in order to make an accurate EOBD diagnosis. Co-occurring conditions such as psychotic features, substance abuse, atypical depression, and ADHD further complicate the clinician's ability to accurately diagnose EOBD. Additional factors include consideration of the adolescent's age and cognitive and normative development, the clinician's adherence to either broad or narrow conceptualization of EOBD, the reliability of child and parent report of symptoms, and utility of family history in making a diagnosis (Carlson, 2012).

EOBD and adolescent perception of self. Neuroplasticity and neurobiological changes are a critical component in the onset of EOBD and have significant implications for emotional and social development, including normative processes of cognitive and psychosocial development, achieving symptomatic and syndromic recovery, and identity development that begin during adolescence and continue through emerging adulthood (Dahl, 2004).

Adolescent cognitive development. Adolescence is a developmental period frequently defined as occurring between ages 11 – 22 in which significant changes occur in biological, cognitive, emotional, and social functioning (Gutsegell & Payne, 2004). Cognitive, emotional, and social development each occur at differing rates as influenced by biological pubertal changes, rather than as a uniform process occurring consistently throughout adolescence

(Steinberg, 2005). Cognitive improvements in reasoning, information processing, self-regulation, self-evaluation, and coordination of affect and cognition occur alongside growth in the prefrontal cortex region in the brain (Steinberg, 2005). Adolescents progress from operating based on conceptualizations of concrete rules and ideals to independent reasoning based on deductive hypotheses and logic (Piaget, 1964). Adolescents may begin to use reasoning and logic in early adolescence but continue to refine this process of *formal operations* (Piaget, 1964; Steinberg, 2005). Cognitive development is influenced by social context and emotion, and in turn influences social and emotional development. Self-regulation, comprised of the coordination of emotional, intellectual, and behavioral processes, is the desired outcome of adolescent cognitive development (Steinberg, 2005).

Adolescent moral and psychosocial development. While an EOBD diagnosis can affect the adolescent's self-concept and psychosocial development, the symptomatic course of EOBD illness can impact normal, emotional, cognitive, and social development (Birmaher et al., 2006; Parry & Levin, 2012). During adolescence, a process of moralization occurs alongside cognitive development, in which the interaction between the adolescent and social environment transforms both the adolescent's attitudes and conceptualizations of their environment (Kohlberg, 1963). Between ages 10-16, adolescents typically progress from conventional morality to post-conventional morality according to Kohlberg's stages of moral development; obedience to authority is replaced with abstract conceptualizations of justice and the value of individual rights may override adherence to rules. Moral development during adolescence reflects patterns of interaction between the adolescent, social environment, and peer groups (Kohlberg, 1963).

Peer relationships and social functioning in adolescence have significant implications for the course of EOBD illness and identity development. Peer rejection and subsequent loneliness

are associated with a trajectory of illness that consists of more depressive symptoms (Pederson, Vitaro, Barker, & Borge, 2007). Challenges to social functioning such as romantic interests, increased self-consciousness, and social anxiety occur concurrent to biological and behavioral changes associated with adolescence (Forbes & Dahl, 2010). Peer relationships may influence self-regulatory skills both negatively and positively, while self-regulatory skills can influence the quality and quantity of peer relationships (Farley & Kim-Spoon, 2014). The development of a personal identity is an essential task during adolescence. Social relationships serve as a mediating factor through which a strong sense of self can be developed, as opposed to persistent role confusion and identity diffusion (Erikson, 1997).

Early-onset bipolar disorder (EOBD) symptomatology can negatively affect adolescent progress toward developmental tasks pertaining to identity, relationships, academic functioning, and psychological autonomy (Miklowitz & Johnson, 2006). While psychiatric and therapeutic treatment interventions can potentially decrease the symptomatic effect on adolescent development, adolescents remain vulnerable to stigmatizing messages through healthcare systems and society that impact normative processes of identity development (Alreja et al., 2009; Miklowitz & Johnson, 2006).

Effect on psychosocial development. The diagnosis and treatment of EOBD are influential to the adolescent's physical and psychosocial development. As a result of an overreliance on neurobiological theories, comprehensive and multidisciplinary treatment approaches have frequently been reduced solely to pharmacotherapy; and the significance of contributing factors such as the family system and impact of environmental triggers has been minimized. Pharmacological interventions carry the potential for both positive and negative outcomes in child and adolescent populations. While psychotropic medications have

demonstrated similar benefits in the adult and juvenile population bipolar populations, these medications carry significant health risks for the juvenile population, such as health complications (i.e., weight gain; metabolic syndrome; tardive dyskinesia; polycystic ovarian syndrome; thyroid and parathyroid function; and hyperprolactinemia associated with changes in estrogen levels) and documented fatalities (Correll & Carlson, 2006; Parry & Levin, 2012). The long-term effects of pharmacotherapy on the adolescent's physical health remain largely unknown; and impact on self-concept, psychological development, and family communication have been questioned as well (Parry & Levin, 2012).

Defining recovery. While treatment interventions for bipolar disorder have primarily focused on the reduction and management of bipolar symptomatology, research is increasingly exploring the concept of recovery. Conus et al. (2006) identified three types of recovery: syndromic, symptomatic, and functional. Syndromic recovery consists of a clinically significant reduction ($> 50\%$) in severity of bipolar symptomatology to the extent that diagnostic criteria are no longer met; however, mild residual manic or depressive symptoms may persist (McMurrich et al., 2012; Sachs & Rush, 2003; Stotland, Mattson, & Bergeson, 2008). Symptomatic recovery refers to an improvement in the magnitude of symptoms while diagnostic criteria remain significant (McMurrich et al., 2012; Stotland, Mattson, & Bergeson, 2008). Functional recovery incorporates a return to previous level of functioning and psychosocial activity (McMurrich et al., 2012; Zarate, Tohen, Land, & Cavanagh, 2000). Functional recovery consists of improvements in social functioning, occupational functioning, and independent living, and therefore addresses impairments and life stressors associated with bipolar symptomatology, medication side effects, and societal stigma (Stotland et al., 2008).

Within the literature, complete syndromic and symptomatic recovery from bipolar disorder are viewed as potentially unattainable. Bipolar disorder has a chronic course of illness that worsens over time without proper treatment, and is characterized by high recurrence of symptomatic episodes as well as chronic and unremitting residual symptoms that occur between symptomatic episodes (Angst & Sellaro, 2000; Frank et al., 2000; McMurrich et al., 2012). A permanent cure, or complete remission of bipolar disorder symptomatology, is considered to be nonexistent due to the course of illness—as many as 90% of individuals who have experience one manic episode will experience another throughout their lifetime (Sachs & Rush, 2003). Furthermore, subsyndromal and residual symptoms persist even in the absence of full symptomatic episodes and are associated with profound psychosocial impairments (Zaretsky, 2003). Bipolar disorder is considered in to be partial remission if symptomatic recovery was achieved for a two-month period, and in full remission if syndromic recovery was achieved for a two-month period (APA, 2013; Perlis et al., 2009; Sachs & Rush, 2003).

Inquiries across the interdisciplinary literature regarding longitudinal aspects of EOBD recovery are limited. As compared to adult-onset bipolar disorder, EOBD course of illness is associated with poorer treatment outcomes and course of illness; includes higher incidence of rapid cycling without asymptomatic periods of recovery between symptomatic episodes; and is associated with greater stressful live events, poorer quality of life, and increased risk of impairment in social functioning (Elgie & Morselli, 2007; Findling et al., 2001; Paykal, 2001; Perlis et al., 2009). Other aspects of recovery such as the developmental impact of EOBD, resilience factors, functional impairment, and maturation effects on episode recovery, recurrence, subsyndromal and residual symptoms also remain under researched (Strober et al., 2006).

EOBD course of illness is affected by both risk and protective factors that influence treatment outcomes. Identified risk factors include lower perceived social support, stressful life events, disruption in social and circadian rhythms, and medication noncompliance (Cohen, Hammen, Henry, & Daley, 2004; Frank et al., 2000). Protective factors include high levels of social support, psychotherapy and psychosocial interventions, higher level of education, being married, and short duration of illness (Johnson et al., 1999; Sachs, 2008; Wingo, Baldessarini, Holtzheimer, & Harvey, 2010).

Identity development and stigma. Individuals with bipolar disorder report concern regarding not only the effects and experience with psychotropic medication, but also the effect of bipolar disorder itself on their identity. In a phenomenological study of adult patients after receiving a diagnosis of bipolar disorder, participants reported ambivalence and hesitation regarding psychotropic medications specifically due to concern regarding side effects such as decreased cognitive functioning, weight gain, decreased energy, and decreased creativity. The trial-and-error approach of trying multiple medications was reported as frustrating, but some participants reported willingness to tolerate side effects if symptom reduction was deemed beneficial (Proudfoot et al., 2009).

Participants identified symptom management as one of their greater concerns associated with receiving a diagnosis of bipolar disorder. Some participants reported “terrifying” fear of symptomatic episodes due to perceived loss of control over their lives. While some participants reported feeling relief after receiving the diagnosis of bipolar disorder following years of experiencing symptoms, some participants reported denial, anger, disbelief, and shock. Participants discussed attempts to come to terms with their ‘new’ identity and merge ‘old’ and ‘new’ identities. Participants reported difficulty regarding trusting their thoughts, emotions,

impulses, and reality-testing ability. Additionally, participants reported questioning course of illness, ability to function, and ability to have a ‘normal life’ regarding social, family, and work relationships (Proudfoot et al., 2009).

Proudfoot et al. (2009) reported individuals with bipolar disorder may experience a loss of self following a diagnosis of bipolar disorder, and reported stigma was also of significant concern. Participants reported fearing they would lose relationships if people found out about the bipolar disorder diagnosis and worried about how to disclose the diagnosis to others. Participants reported that stigma increased the isolation of bipolar disorder, specifically when support people were unsure how to help. Proudfoot et al. identified the need for psychoeducation for friends, family, and the larger community, to increase support for individuals with bipolar disorder.

EOBD and interaction with the healthcare system. Treatment for EOBD occurs within the healthcare system and includes psychiatric, pharmacological, and therapeutic interventions designed to alleviate bipolar disorder symptomatology and improve both individual and family functioning. This section reviews stigma and treatment as experienced through the healthcare system. Inception of stigma, loss of autonomy, and psychiatric, pharmacological, and therapeutic interventions are discussed.

Inception of stigma. Labeling and stigma associated with mental illness often originate within the healthcare system. Stigmatizing practices such as labeling and referring to the youth by their diagnosis (i.e., “that bipolar boy” or “that boy is bipolar”), focusing treatment and assessment on deficits indicated by the medical model, and treatment planning without the youth or family present commonly occur within the healthcare system. Treatment models often focus exclusively on symptomatology rather than a holistic and strengths-based approach incorporating protective family and environmental factors. Individuals and families often experience a

dichotomous relationship between the ‘expert’ healthcare professional and ‘ignorant’ patient, rather than a collaborative relationship in which the youth and family are experts as well.

Stigmatizing practices within the healthcare system may negatively affect the recovery of individuals with bipolar disorder and influence families to avoid contact with the healthcare system (Browne, Hemsley, & St. John, 2008; Heflinger & Hinshaw, 2010). Families, as well as individuals, are subject to stigma through the healthcare system, which may lead to reduced contact with the healthcare system to avoid stigmatizing services (Heflinger & Hinshaw, 2010). Recovery-oriented interventions that enhance functional recovery and minimize stigma are more successful in facilitating the individual’s recovery (Stotland, Mattson, & Bergeson, 2008).

Loss of autonomy. Stigmatization and labeling experienced through the healthcare system negatively affect individuals’ self-esteem, and result in loss of identity and loss of confidence (Browne et al., 2008). In a qualitative study of adults with bipolar disorder the core theme from participants was feeling out of control regarding the illness and over their lives (Crowe et al., 2012). Participants reported difficulty managing symptoms, and stated the onset of symptoms created a significant change in their lives. Participants reported their self-identity was affected by their experience of bipolar symptoms as well as the responses of others to their symptoms. Participants reported feeling flawed, powerless, and incapacitated by symptomatic episodes. Psychotropic medications were associated with loss of autonomy, defectiveness, and identity; in turn, loss of autonomy was associated with interaction with healthcare professionals. Participants reported the need to take medication indicated they were not normal and were not who they wanted to be. Participants reported believing they were different in negative ways, even in the absence of these beliefs from others; this indicated the internalization and endorsement of stigmatizing beliefs (Crowe et al., 2012).

Therapeutic interventions. Therapeutic interventions have significant implications for the long-term course of bipolar illness. Therapeutic interventions for EOBD include individual, group, and family modalities. While data on EOBD remains limited, the literature on adult-onset bipolar disorder indicates the combination of psychotherapy, and pharmacotherapy is effective in reducing rates of symptomatic relapse by 30 – 40% over a 12 to 30 month period. Benefits such as symptom reduction, improved interpersonal and daily functioning, and medication adherence were present for one or more years following termination of therapy services (Miklowitz, 2008).

Informal support. Community-based peer supports provide recovery-oriented, complimentary approaches to clinical interventions for bipolar disorder and EOBD. Perceived social support can be both a risk and protective factor for individuals with bipolar disorder. DeVylder and Gearing (2013) identified declining social support occurring in adolescents prior to psychiatric hospitalization, and advocated for social interventions to indirectly improve symptomatology. Peer support is associated with enhancing individual's sense of empowerment, reducing stigma, improving self-esteem, decrease symptomatology, and decrease risk of symptomatic relapse (Corrigan, Powell, & Rusch, 2012; Davis et al., 2012). Perlick et al. (2004) reported a correlation between stigma and intentional reduction in social functioning, and advocated for recovery-based peer support to inoculate against the effects of stigma. While peer supports do not directly address symptomatology as clinical interventions do, participants in peer support groups report a simultaneous decrease in symptomatology and increase in hope and empowerment (Brown et al., 2008; Fukui, Davidson, Holter, & Rapp, 2010).

EOBD and the Family. The family system is an important mediating variable in the comprehensive management and course of illness of bipolar disorder. This section discusses

family burden and stigma, family functioning, and the family's experience of bipolar disorder symptomatology.

Family functioning. Family functioning and cohesion are each affected by bipolar disorder. During both symptomatic and symptom-free episodes families appear to operate in a more cohesive, adaptive manner, while during prodromal and recovery periods, families experience less cohesion, ability to adapt, and more conflict. Family functioning may also be affected by relationship stress and conflict common during symptomatic episodes of bipolar disorder (Sullivan & Miklowitz, 2010).

Conversely, family functioning may influence the severity of bipolar disorder symptomatology. Living with an intact biological family and enhancing family relationships are protective factors toward alleviating symptomatic episodes and improving course of illness, while family hostility, stigma, misunderstanding, and low maternal warmth are risk factors associated with increased symptomatic episodes (Elgie & Morselli, 2007; Geller et al., 2002). Adolescents with EOBD in families with greater conflict experienced more severe manic symptoms over a two-year period, while adolescents in families with greater cohesion experienced decreased severity of depressive symptoms (Sullivan, Judd, Axelson, & Miklowitz, 2012). While family functioning has important implications for the treatment and course of bipolar disorder, the cumulative literature has not explored the possibility of positive family outcomes due to EOBD. Family cohesion has been identified as a protective factor to reduce bipolar symptomatology and incorporated into Family Focused Treatment (FFT) intervention (Miklowitz, 2008; Sullivan & Miklowitz, 2010; Sullivan et al., 2012); however, family cohesion has not been studied as a positive outcome of EOBD.

EOBD and Stigma. Stigma has been discussed in the context of the perception of self, the healthcare system, and the family. In this section, stigma is reviewed in more detail regarding its relationship to symptomatology, social and occupational functioning and predictive ability of functioning.

Symptomatology and stigma. As explained by modified labeling theory, societal views contribute to the stigma associated with mental illness. In bipolar disorder, societal stigma and labeling may differ according to each symptomatic episode. In a sample of college students, 40% described manic symptoms as voluntarily aggressive, dangerous, and unpredictable with a lack of self-control, and expressed irritability, lack of understanding, and the desire to withdraw from the individual. In contrast, participants reacted to depressive symptoms with pity and desire to help the individual (Wolkenstein & Meyer, 2008). While stigma research specific to the fluctuations in bipolar mood states is limited, this study suggests varying societal attitudes relative to manic and depressive symptoms.

While symptomatology may influence societal stigma, stigma appears to affect bipolar symptomatology as well. Cerit et al. (2012) identified three predictors of functioning in individuals with bipolar disorder: severity of depression, perceived social support, and internalized stigmatization. Severity of depression emerged as the strongest predictor of poor functioning; recurrent mild depressive symptoms in particular were negatively associated with functional recovery in bipolar disorder. Stigma directly predicted functioning as well as predicted pathways for other predictors of functioning. Cerit et al. (2012) suggested a bidirectional relationship exists between bipolar disorder and stigma, in which stigma can exacerbate bipolar symptomatology; and in turn, symptoms perpetuate stigma beliefs. Therefore,

treatment interventions for bipolar disorder that address stigma may have important implications for symptom reduction.

Social functioning and stigma. Sensitivity and concern regarding stigma may impair social functioning. In a clinical sample of adults with bipolar disorder and their caregivers, participants that reported greater concern regarding stigma displayed greater impairment in social functioning. Stigma was associated with increased avoidance coping, including increased psychosocial isolation, but not with decrease in family functioning. Participants who reported concern regarding stigmatization experienced poorer social adjustment at the seven-month follow up (Perlick et al, 2004). Stigma appears to negatively affect social functioning and recovery in individuals with bipolar disorder.

Limitations of Previous Studies

At present there are no published studies investigating the experience of EOBD by adolescents or emerging adults with a history of EOBD diagnosis. The cumulative literature predominantly adheres to the medical model, with a quantitative focus on establishing neurobiological markers for EOBD and effectiveness of pharmacological interventions used to treat adult bipolar disorder. With a few exceptions (i.e., Moses, 2009), there is an overwhelming absence of qualitative inquiries into the experience of adolescent mental illness. Research and treatment for EOBD have largely been conducted in the absence of the self-report of the adolescents affected by bipolar illness as a primary data source (Heflinger & Hinshaw, 2010). Emerging adulthood has been similarly overlooked as a source of information and reflection of past experience of EOBD in adolescence.

Various authors have recognized these limitations within the literature and addressed the need for qualitative, family- and adolescent-focused research to better understand the

phenomenology of EOBD. Sullivan and Miklowitz (2010) stated the need for qualitative research to better understand family experience and functioning during symptomatic episodes of bipolar disorder. Miklowitz (2008) identified the need for increased research to improve pharmacological and therapeutic interventions for EOBD, including greater inquiry into the adolescent experience of EOBD. Miklowitz, Biuckians, and Richards (2006) called for research to investigate EOBD adolescent physiological and symptomatic responses to family conflict. Heflinger and Hinshaw (2010) questioned the application of theoretical frameworks from the adult to the juvenile population as well as the absence of theory specific to the juvenile population. In summary, the first-person experience of adolescents with EOBD has been largely peripheral in research, despite the acknowledgement within existing research of the need for the phenomenological data.

Aims of Present Study

To address limitations of previous studies, the present study will explore EOBD in a sample of emerging adults ages 18-25 with a history of EOBD diagnosis. Many existing studies have utilized quantitative methodologies, relying on the scoring of standardized measures to approximate an understanding of the phenomenology of EOBD. While past inquiries have included quantitative investigations into neurobiological malfunctioning, pharmacological approaches, and family functioning, the present study will utilize qualitative methodology to explore the full phenomenology of EOBD.

While the literature on bipolar disorder has incorporated self-report from adults with bipolar disorder, adolescents and emerging adults have been underutilized as primary informants and sources of data in EOBD research. The present study utilizes the reflection of emerging

adults to reconstruct their experience of EOBD in adolescence to increase understanding of the phenomenology of EOBD with implications for current functioning.

Previous studies have explored EOBD through various theoretical perspectives; however, our understanding of the phenomenology of EOBD remains limited. The present study proposes the integration of neurobiological, modified labeling theories with the theory of emerging adulthood as the foundation for a more complete and multidimensional understanding of the phenomenology of EOBD.

Summary of the Study

This qualitative study will explore the phenomenology of EOBD among emerging adults by addressing the following research questions:

- 1) How do emerging adults (ages 18-25) describe the experience of EOBD during adolescence (ages 13-17) in terms of experience of symptoms; changes in individual, social, and family functioning caused by course of illness; and the experience and perception of stigma and self-stigma?
- 2) How do emerging adults (ages 18-25) characterize the cumulative influence of interactions with healthcare systems and treatment interventions on their experience of EOBD?
- 3) What are the characteristics of the relationship between EOBD, social and family relationships and the developmental transition to adulthood according to emerging adults?
- 4) How have stigma and self-stigma associated with EOBD affected the social, emotional, and cognitive development of emerging adults ages 18-25?

Chapter 3: Methodology

To obtain an understanding of the lived experience of EOBD and best address research questions, this study incorporated a transcendental phenomenological design. This chapter reviews transcendental phenomenology and its application to study design, including sampling, data collection, and data analysis.

Transcendental Phenomenology

Phenomenology is the philosophy and study of pure phenomena through human consciousness (Husserl, 1965, 2012; Moustakas, 1994). Derived from the Greek word *phaenesthai*, ‘phenomenon’ means ‘to bring to light’ or ‘show itself completely’ (Moustakas, 1994). A phenomenon is a reality contained within the human experience. Phenomenological data is obtained through the individual’s subjective report of the experience (Groenewald, 2004). In transcendental phenomenology, the researcher sets aside all previous habits of thought and breaks down the barriers or biases generated by these habits in order to uncover the pure essence of the phenomenon (Groenewald, 2004; Husserl, 2012). The goal of phenomenology is a return to things as they truly are, rather than how they are perceived and judged (Groenewald, 1994; Moustakas, 1994).

Transcendental phenomenology seeks to uncover the essence of human experience through a transcendental, or pure, ego free of prejudgment and presupposition. To accomplish this, transcendental phenomenology asks two questions: a) what is the essence of the experience of the phenomenon; and b) in what context(s) did the experience occur (Moustakas, 1994)? Through transcendental phenomenology, an accurate description of the phenomenon is obtained

through explication and synthesis of the subjective experiences of the phenomenon (Groenewald, 2004; Moerer-Urdahl & Creswell, 2004).

Transcendental phenomenology utilizes qualitative methods to obtain the lived experiences of the phenomenon of study through the individuals' self-report. The philosophical assumptions of transcendental phenomenology uniquely focus on eliciting the experience of the phenomenon, as opposed to similar methodologies such as ethnography, in which the phenomenon is observed by the clinician, and narrative approaches such as oral history, in which the focus is on narration. Qualitative interviews are interactive and semi-structured, relying on the two core transcendental phenomenological questions as stated in the previous paragraph to guide the interview while incorporating flexibility, allowing for the full revelation of the experience as directed by the individual rather than the researcher (Moustakas, 1994).

Phenomenological interviews are iterative in nature, as the researcher continuously reflects on the relationship between the individual's self-report and core research questions, often diverging from intended questions to allow the individual to guide the interview and capture the essence of the phenomenon as he or she experienced it. The goal of the phenomenological interview is for the individual to share as much of the experience as authentically and unselfconsciously as possible in his or her own words (DiDicco-Bloom & Crabtree, 2006).

Epoche, intentionality, noema, and noesis. Several concepts are central to the design and implementation of transcendental phenomenology. Here, these concepts are discussed here in brief, with further application in data analysis.

Epoche. In transcendental phenomenology, a transcendental state incorporates “a readiness to see in an unfettered way, not threatened by the customs, beliefs, and prejudices of normal science, by the habits of the natural world or by knowledge based on unreflected

everyday experience” (Moustakas, 1994, p. 41). The absence of bias is accomplished through a process called epoche (from the Greek *ἐποχή*) in which all judgment is suspended in order to view the phenomenon as it is.

Epoche is regarded both as a philosophical concept and a component of data analysis. Epoche is the first step in the phenomenological reduction process, in which the experience is conceptualized according to recurrent themes and textural descriptions present in interview data; phenomenological reduction is discussed further in discussion of data analysis. While pure epoche is difficult to achieve, even its approximation reduces researcher bias and maximizes the credibility of the study (Moerer-Urdahl & Creswell, 2004; Moustakas, 1994). Through epoche, the researcher gains the ability to collect, describe, and analyze the phenomenon of study as accurately as possible without the influence of his or her own experiences.

Intentionality. Intentionality is the awareness, or perception, of the phenomenon. Intentionality is not the phenomenon itself, but rather the subjective lived experience of the phenomenon and includes judgment, interpretation, and value of the phenomenon (Moustakas, 1994). Intentional experiences contain the essence of the experience of the phenomenon, and are therefore sought out through phenomenological interviews as representative of the phenomenon of study (Husserl, 2012). The essence of the phenomenon is constructed through a compilation of multiple intentional experiences.

Noema and noesis. Each intentionality is comprised of a noema and noesis. In its most simple definition, noema refers to the phenomenon itself, the object of the experience, and noesis is how the phenomenon is experienced. Noema represents the sensory experience of the phenomenon, while noesis contains the meaning of the experience through perception, emotion, memory, and judgment. Through reflecting on the noema the noesis is uncovered, and with it the

essence of the phenomenon. Transcendental phenomenology seeks to discover both noema and noesis of each intentional experience of the phenomenon, and it is through this process that the phenomenon can be truly understood (Moustakas, 1994).

Participants

Transcendental phenomenology utilizes a homogenous sample of individuals who have experienced the phenomenon of study. This study utilized purposive sampling to recruit emerging adults ages 18-25 with history of diagnosis of EOBDD between the ages 13-17 per self-report. Participant eligibility and recruitment are discussed below.

Participant eligibility. Participants were eligible to take part in this study if they met the following inclusion criteria: a) between 18 and 25 years of age; b) diagnosed with bipolar disorder between the ages of 13 and 18; c) spoke English fluently; d) did not have an active substance abuse or substance dependence disorder, drug-induced mood disorder, pervasive or intellectual developmental disorder, unremitting psychosis or psychotic disorder, posttraumatic stress disorder, or a life-threatening eating disorder (adapted from Sullivan & Miklowitz, 2010); e) did not display imminent danger to self or others.

Recruitment of sample. The researcher coordinated with clinical sites and community support groups in Tampa, Florida and Orlando, Florida areas and also recruited participants via online advertising, summarized in Table 1. Sample sites were provided with study flyers and were asked to display and/or distribute flyers to potential eligible participants. A study flyer is included in Appendix A.

Table 1. Study Recruitment Sources

	Tampa	Orlando	Internet
Clinical sites	USF Counseling Center USF Psychological Services Center USF Student Health Services USF Psychiatry Clinic	UCF Counseling and Psychological Services UCF Student Health Services Aspire Health Partners 18 Clinicians in private practice	WeSearchTogether.org DBSA.org online listing DBSA.org online support group listing Facebook page and advertisement
Community support	DBSA Tampa Bay MHA Tampa Bay NAMI Hillsborough	Greater Orlando Bipolar Support MHA Orlando NAMI Greater Orlando	

Response and enrollment. The researcher was contacted by 26 potential participants. Five were excluded due to not meeting study criteria for current age or age of EOBD diagnosis. Eleven potential participants reported meeting study criteria but did not follow through or maintain communication with the researcher. Two potential participants were scheduled for interviews but “no-showed” (confirmed interview but never responded to phone or email contact attempts at scheduled time).

Eight participants consented and were enrolled in the study between May and December 2016. The sample consisted of 7 females and 1 male between ages 18 – 25 ($M = 21.75$; $SD = 2.31$); participants reported receiving EOBD diagnosis between ages 13 and 17 ($M = 15.56$; $SD = 1.50$). Table 2 summarizes the sample recruitment.

As part of the iterative process of phenomenological research, the researcher reviewed interview recordings and transcripts in October 2016. The researcher observed then that content and description was similar across participant interviews, creating a consistent and detailed portrait of participants’ experience of EOBD. As a result, the researcher noted that the study sample was approaching saturation in terms of data as well as size for a phenomenological

design (Creswell, 2007; Dukes, 1984; Edward, 2005; Smith, 2004). By the end of December 2016, eight participants were enrolled and recruitment concluded.

Table 2. Sample Recruitment

Category	<i>N</i>
Excluded (Criteria)	5
Never scheduled	11
No-Show	2
Drop-Out	0
Enrolled	8
Total	26

Obtaining informed consent. Data collection was facilitated through telephone interviews. Following initial phone or email contact, the researcher emailed the USF Institutional Review Board (IRB) Verbal Consent form (see Appendix B) to participants for review. At the beginning of the scheduled interview telephone call, the researcher reviewed and obtained verbal informed consent. Participants additionally were asked for permission to audio record interviews; all participants consented to have their interviews recorded by the researcher.

Ethical Considerations

DiCicco-Bloom and Crabtree (2006) propose four ethical issues pertaining to participant involvement in qualitative research: a) reducing the risk of unanticipated harm; b) protecting the participant's information; c) effectively informing participants about the nature of the study; and d) reducing the risk of exploitation. These considerations are addressed in the IRB protocol and are discussed here in brief.

Risk of unanticipated harm to participants. The first ethical issue addresses the risk of unanticipated harm to participants. The qualitative interviews address the phenomenon of EOBD as experienced by emerging adults ages 18-25. The phenomenon of EOBD may be a sensitive

issue to participants, and while the researcher is a licensed clinician and therapist, it is not appropriate for the researcher to provide clinical services to study participants. To address this possibility, participants were provided with information for follow-up care if needed. As part of obtaining verbal informed consent, the researcher advised each participant that the interview could be stopped, paused, or discontinued at any time at the participants' discretion (i.e., due to emotional distress or discomfort). Per IRB, if any participant displayed indications of significant emotional distress during or following the interview that necessitate immediate intervention, the researcher would contact emergency medical services with the physical address provided by the participant at time of interview. This did not occur, but was designed to address care and safety of participants throughout data collection.

Protection of participant data and identifying information. The second ethical issue involves the protection of participant data and identifying information. Audio recordings, transcripts, and identifying information of participants were stored by the researcher in two locations: a locked cabinet and a secure storage drive in the researcher's office. Participants were informed that referral sites would not be informed of their participation in the study and no identifying information or data would be released to referral sources.

Nature of the study. The third ethical issue addresses informing participants of the nature of the study

The researcher obtained verbal informed consent via telephone per IRB policy. Informed consent addressed the extent and nature of the study. Participants were informed that the purpose of the study was solely to collect data and that no treatment interventions would be provided. Per IRB, participants were additionally informed that while the study was considered minimal risk, the content of interview questions could potentially result in emotional distress. The researcher

provided participants with information on follow-up mental health care and informed participants they had the right to withdraw from the study at any time.

To facilitate participants' understanding of the nature of the study, the researcher sent the verbal informed consent form, interview questions, a detailed overview of the study, and follow-up care information to participants via email prior to the telephone interview for their review. The researcher reviewed each of these documents prior to obtaining informed consent and proceeding with the research interview.

Participant exploitation. The fourth ethical issue addresses the risk of participant exploitation. Participants were not exploited for personal gain or for the sake of the study. Participants were each compensated for their time and participation with a \$20 gift card following completion of the interview.

Data Collection

Qualitative interviews. Phenomenological studies utilize qualitative, semi-structured interviews to collect data from participants (DiDicco-Bloom & Crabtree, 2006). Phenomenological interviews contain pre-determined, open-ended questions generated by the study's research questions; yet during the interview these questions may be modified in whole or in part, omitted, or expanded upon according to the participants' self-report of the experience of the phenomenon of study (DiCicco-Bloom & Crabtree, 2006; Moustakas, 1994).

The researcher's flexibility and reflexivity throughout the interview establishes rapport with the participant and facilitated obtaining the full essence of the participant's experience. Table 3 displays the semi-structured interview questions organized by research question and theory. Appendix C contains the semi-structured interview schedule as delivered during participant interviews.

Participant interviews were conducted via telephone, audio recorded, and transcribed by the researcher. Interviews were 45 – 75 minutes in length. While participants agreed to participate in a second interview for clarification or expansion of qualitative data if needed, no second interviews were conducted. No clarification or expansion of data was needed during data analysis, as participant accounts provided rich description that led to achievement of thematic saturation. Additionally, participants reported during member checking (discussed further below) that their individual and composite descriptions were accurate with no missing or incorrect information, and stated that no additional interviews were needed. Using the steps in phenomenological data analysis described below, interview transcripts were then analyzed to construct individual and composite descriptions of the phenomenology of EOBD.

Data Analysis

Analysis of phenomenological data includes the processes of epoche, phenomenological reduction, and imaginative variation. In contrast to quantitative data analysis, the goal of phenomenological reduction is the explication of data, rather than explanation of data—the phenomenon is exposed and described using the participants’ own words, rather than explained and interpreted by the researcher (Van Kaam, 1969). This study used Moustakas’ (1994) transcendental modification of the Van Kaam anthropological method of analysis of phenomenological data (Van Kaam, 1969). Moustakas adapts Van Kaam’s method to transcendental phenomenology, thus altering the data source from observed behavior to participant self-report via semi-structured interviews. Table 4 summarizes Moustakas’ modification of Van Kaam’s phenomenological data analysis as applied in this study.

Table 3. Interview Questions Arranged by Research Question

Variable	Theory	Question
Q1. How do emerging adults (ages 18-25) describe the experience of EOBD during adolescence (ages 13-17) in terms of experience of symptoms; changes in individual, social, and family functioning caused by course of illness; and the experience and perception of stigma and self-stigma?		
EOBD	Neurobiological	<p>How old were you when you were diagnosed with bipolar disorder? How old are you now?</p> <p>What was it like to receive the diagnosis of bipolar disorder?</p> <p>What did the illness mean to you at that time?</p> <p>How would you describe your experience of bipolar symptoms during your teenage years? What were your manic episodes like?</p> <p>Your depressive episodes?</p> <p>Did you feel that other people (friends, family, healthcare providers) understood your experience of bipolar disorder?</p>
Q2. How do emerging adults (ages 18-25) characterize the cumulative influence of interactions with healthcare systems and treatment interventions on their experience of EOBD?		
EOBD	Neurobiological; Modified labeling theory	<p>Who diagnosed you with bipolar disorder? In what treatment setting (inpatient, outpatient)?</p> <p>What events led up to the diagnosis?</p> <p>Did you have a psychiatrist? A therapist? What was your experience with them?</p> <p>Have you ever been hospitalized due to bipolar disorder? If so, what was that like?</p> <p>Were you prescribed medication for bipolar disorder during this time? How would you describe your experience with medication?</p> <p>Did you feel that the treatment you received was helpful?</p> <p>[Whether yes or no:] In what way?</p> <p>Did your experience of bipolar disorder change during or after receiving treatment? If so, in what way?</p>
Q3. What are the characteristics of the relationship between EOBD, social and family relationships and the developmental transition to adulthood according to emerging adults?		
Interpersonal Support and Relationships; Transition to Adulthood	Emerging Adulthood; Modified Labeling	<p>After the onset of bipolar symptoms but prior to diagnosis, do you remember whether any changes occurred in relationships with your family or with friends during this time?</p> <p>After receiving the diagnosis of bipolar disorder, do you remember any changes occurring in relationships with your family or friends during this time?</p> <p>What were your greatest supports during this time? What were your greatest challenges?</p> <p>How did these changes affect you as you moved from adolescence into young adulthood?</p>

Table 3 (Continued)

Variable	Theory	Question
Q4. How have stigma and self-stigma associated with EOBD affected the social, emotional, and cognitive development of emerging adults ages 18-25?		
Stigma; Social, emotional, cognitive development/identity	Modified labeling;	Did you experience self-stigma, in which you label or judge yourself, during this time? If so, what was that like?
	Emerging	Do you feel that any of the changes you experienced in your support system or related to stigma or sense of self had an effect on your bipolar disorder and mental health during this time?
	Adulthood	Do you feel that your sense of self (sense of identity) changed due to your experience of bipolar disorder during this time? If so, in what way?
		Did you feel that you understood the changes in your life that were occurring due to bipolar disorder?

Epoche. Establishing and maintaining epoche allowed the researcher to analyze findings in terms of participants' experiences of the phenomenon, rather than the researcher's interpretation through preexisting bias. To facilitate epoche, the researcher maintained a reflexive journal throughout the study; this is discussed further under implementation of strategies for rigor, below.

Phenomenological reduction. Phenomenological reduction includes the processes of horizontalization, reduction and elimination, clustering, and validation of themes. These processes are reviewed in terms of application in this study.

Horizontalization. Horizontalization consists of identifying and listing every relevant expression of the experience; these expressions or moments of the experience are also referred to as intentionalities. Intentionalities include both sensory components of the experience (noema) and the perceptions, emotions, and meaning attached to the experience (noesis).

The researcher read each interview transcript three times to obtain not only an overall understanding of participants' experiences, but also to identify and compile written descriptions

of units of meaning of participants' descriptions. After reviewing all interviews three times, the researcher had a compilation of intentionalities, or units of the essences of participants' experiences.

Table 4. Modification of Van Kaam's Phenomenological Method of Data Analysis

Step	Process
1) Listing and Preliminary Grouping (Horizontalization)	List every expression relevant to the experience.
2) Reduction and Elimination	Review descriptions and keep only those that describe a unit of the essence of the experience (invariant constituents). Merge and eliminate descriptions as needed to remove overlapping, vague, and repetitive descriptions.
3) Clustering and Thematizing the Invariant Constituents	Organize related invariant constituents (codes) into themes and sub-themes.
4) Final Identification of the Invariant Constituents and Themes by Application: Validation	Review codes, sub-themes, and themes to verify they accurately represent participants' collective experiences. Discard any themes that are not compatible or relevant.
5) Individual Textural Description	Using codes, sub-themes, and themes, create a description for each participants' experience of the phenomenon.
6) Individual Structural Description	Using codes, sub-themes, and themes, create a description for each participants' description of the meaning and associated thoughts and emotions experienced as part of the phenomenon.
7) Textual-Structural Description	Combine the textural and structural descriptions for each participant to create complete individual descriptions of participants' full experience of the phenomenon.
8) Composite Description	From the individual textual-structural descriptions, develop a composite description of the meanings and essences of the experience, representing the group as a whole

Note: Adapted from *Phenomenological Research Methods* by C. Moustakas, 1994 and *Existential Foundations of Psychology* by A. Van Kaam, 1969.

Reduction and elimination. The researcher then reviewed the compiled list of intentionalities according to two criteria:

- 1) Does it contain an essential moment of the experience?
- 2) If yes, can this intentionality be described abstractly and labeled?

Expressions that did not meet both criteria, that overlapped, were repetitive, or non-descriptive were discarded. The labeled intentionalities that remained represented the invariant constituents (codes), or elements of the participants' experiences.

Clustering and thematizing the invariant constituents. The researcher next organized the invariant constituents into visual clusters according to participants' descriptions. The researcher re-read interview transcripts and reviewed the clusters both separately and comparatively to ensure the notes were grouped in a way that accurately represented the participants' experiences. The researcher then created a label for each cluster.

The resulting product was a visual series of seven clusters of invariant constituents: family, experience of illness, identity, impact of illness, peer relationships, stigma, and management of illness. The researcher compiled the visual code-mapping into a preliminary codebook that contained the seven clusters (families) and a total of 115 codes.

Final identification of invariant constituents and validation of themes by application. The researcher then reviewed transcribed interviews from participants A, E, and H, and coded each interview with the preliminary codebook. Each code was then reviewed three times against the following criteria:

- 1) Is the code expressed equally throughout each individual transcription, as well as among transcriptions A, E, and H?
- 2) Are codes explicitly stated and compatible?

Through this process, the invariant constituents (codes) were validated, or confirmed, through application to interviews A, E, and H. Codes that were not consistently present throughout the data, or were not explicitly stated or compatible were removed from the codebook. The final codebook includes 54 codes and is included as Appendix D.

Imaginative Variation. Through imaginative variation, the data is explicated to expose the essential structures of the phenomenon and establish the participants' experience. Imaginative variation answers the two core phenomenological questions: a) what is the essence of the experience of the phenomenon; and b) in what context(s) did the experience occur (Moustakas, 1994)?

The completed output from imaginative variation includes four components: an individual textural description; an individual structural description; an individual combined textural-structural description; and a composite description for all participants.

Use of qualitative software in data analysis. The researcher utilized ATLAS.ti software during steps 4 through 8 illustrated in the phenomenological data analysis process presented in Table 4. While the initial identification of invariant constituents and codes were developed by hand, the researcher used ATLAS.ti was used validate codes, code each interview, and incorporate code reports in synthesis of themes and sub-themes used to create the individual and composite descriptions. The codebook was revised and finalized through consensus coding and review of each interview. Following verification of codes, the researcher entered the final codebook into ATLAS.ti. Using ATLAS.ti, each interview transcript was analyzed and coded with the final study codebook. Once interviews were coded, the researcher created code reports that guided the grouping and consolidation of codes into themes and sub-themes. Code reports were created for individual interviews as well as for the project (Hermeneutic Unit, or HU).

Individual descriptions. Imaginative variation begins with analysis of the individual participant's experiences. Using ATLAS.ti software, the researcher coded participant interviews and created an individual code report linking each code with the participant's quotations. From the code report, the researcher created the individual textural and structural descriptions incorporating participants' wording to capture the full essence of participants' descriptions

Textural description (noema). A textural description was completed for each participant to describe their experience of EOBD, including onset of symptoms, diagnosis, and course of illness. In analysis, this emerged as the code family for the experience of the illness itself (i.e., symptomatology).

Structural description (noesis). A structural description was completed for each participant to describe their experience of the impact of EOBD, including perception, thought, emotion, and coping reactions. Participants described their experience of identity, the healthcare system, interpersonal relationships, labeling, and mediating factors associated with EOBD during adolescence.

Textural-structural description. The researcher constructed a merged description for each participant that included their experience of EOBD, the illness itself, as well as their experience with the impact and effects of EOBD on their sense of self, relationships, and coping behaviors during adolescence. The individual textural-descriptions are included in a companion volume to this manuscript.

Emerging adulthood. While the interviews elicited retrospective data, throughout the course of the interviews the participants discussed related components of their experience with bipolar disorder during emerging adulthood. Participants' accounts of emerging adulthood yielded distinct and separate invariant constituents and themes as compared to participants'

accounts of adolescence. As this study's purpose and research questions address participants' experiences of EOBD between ages 13 -17, the presentation of findings include only the themes encompassed by the study research questions that pertain to adolescence. Additionally, participants' experiences of bipolar disorder after the age of 17 no longer fit within the scope of the study, as EOBD is defined as occurring with the ages of 13 – 17. The data on emerging adulthood is therefore not included in the composite description and phenomenology of EOBD; however, this data is included in the audit trail and within the individual descriptions for each participant.

Composite textural-structural description. In the final step of phenomenological analysis, the researcher creates a combined textural-structural description that incorporates the invariant constituents and themes of participants' combined experiences into a composite description, or explication, of the phenomenon of study. This final step embodies the essence of the experience of the phenomenon.

Following completion of the individual textural-structural descriptions, the researcher constructed the composite textural-structural description. Using the process outlined above, the researcher used ATLAS.ti to synthesize codes into sub-themes and themes that represented participants' complete experience of EOBD. The composite textural-structural description is presented in Chapter 4.

Strategies to Maximize Rigor

This section reviews strategies to maximize trustworthiness and enhance the rigor and validity of the study. Reflexivity of the researcher, member checking, peer examination, audit trail, and thick description are discussed with applications for this study.

Reflexivity of the researcher. Strategies for enhancing rigor must be built into the study design, rather than solely during post-hoc evaluation (Morse et al., 2002). Similar to construct validity in quantitative research, reflexivity refers to the researcher's attitude and mindfulness regarding how his or her preconceptions affect the research (Thomas & Magilvy, 2011). Reflexivity of the researcher affects the methodological coherence of a study. Considerations of sampling strategies and composition, data collection and saturation, and data analysis must be congruent to the research questions and methodology. These considerations are established during study design but are confirmed and modified throughout the execution of the study through the reflexivity of the researcher (Morse et al., 2002).

In this study, reflexivity of the researcher was employed through continuous iteration—implementation, reflection, and evaluation of the phenomenological research design—throughout data collection and analysis. The researcher's reflexivity facilitated maintaining mindfulness and adherence with study measures designed to maximize trustworthiness, such as reflexive journal, audit trail, consensus coding, and member checking.

Reflexive Journal. Through the study, the researcher used a reflexive journal to record, express, and ventilate not only preexisting bias but also the researcher's reactions and responses to participant data during data collection and analysis. The journal was used in a raw and honest matter; entries chronicle the researcher's reflexivity and iteration in designing and implementing the study, responses to planned and unanticipated events, and the researcher's candid and sometimes emotional reactions to participant data; as a result, the researcher maintained the ability to remain 'in the moment' with minimal bias.

Peer review and reliability. To ensure dependability and reliability, the researcher utilized two qualitative approaches: consensus coding (interrater reliability) and stability reliability. Table 5 summarizes reliability in coding of participant interviews.

Table 5. Summary of Reliability in Interview Coding

Interview	Agreements	Disagreements	Consensus
Participant A	76	5	.938
Participant B	60	11	.845
Participant C	98	16	.860
Participant D	40	8	.833
Participant E	68	15	.819
Participant F	50	10	.833
Participant G	49	6	.907
Participant H	68	9	.883
Total Consensus	509	80	.864

Stability reliability consensus (A, B, C, E) = .865

Interrater reliability consensus (D, F, G, H) = .8625

Consensus coding. Four of the eight transcribed interviews (D, F, G, H) were coded and compared through consensus coding with a peer reviewer. Two peer reviewers assisted in this study: a classmate provided consensus coding for the first interview with the initial codebook, which included identification and validation of codes by application. The second peer reviewer was the researcher's major professor, who also provided consensus coding and validation of codes by application for four interviews.

Reliability coefficient. To establish dependability and reliability of data analysis, an interrater reliability ratio of .70 was used for each of the four interviews in consensus coding (Hays & Singh, 2012).

Stability reliability. To maximize dependability of individual coding, the researcher independently coded interviews A, B, C, and E; and recoded the interviews two days later. As

with comparison coding, the researcher compared both codings for each interview and created a merged consensus coding using the same interrater reliability ratio of .70. The same codebook was used to code all eight interviews.

Peer examination. An external review can enhance the study's credibility (Creswell & Miller, 2000). Collaboration between the external reviewer and the researcher occurring throughout the study can produce an exchange of feedback, criticism, and examination of study method and processes. To maximize credibility, the researcher maintained communication and collaboration with her major professor throughout design, implementation, and review of the study. The major professor provided feedback on implementation of study methods, with suggestions for improvement and review.

Audit trail. The researcher maintained an audit trail throughout the study, beginning with the dissertation proposal defense in 2014. The audit trail is presented as a companion volume to this manuscript and includes the following components: a) an explicit statement of purpose; b) rationale for sampling strategy and selection; c) detailed descriptions of the process of data collection and length of time required; d) thorough explanation of data analysis, including thematic reduction; e) discussion of the interpretation and presentation of findings; and f) verification strategies to establish credibility of study conclusions (Thomas & Magilvy, 2011). The audit trail allows for external review and feedback to confirm that study findings are grounded in data, inferences are logical, methodology is justifiable and appropriate, extent of researcher bias, and use of verification strategies were used to enhance rigor and credibility (Creswell & Miller, 2000).

Thick description. Rich descriptions of the setting, participants, and themes further establish the credibility of the study (Creswell & Miller, 2000). Thick descriptions allow the

reader to feel the experience of the phenomenon being investigated. In contrast with descriptions simply reporting facts or conclusions, thick descriptions employ a constructivist perspective and provide as much detail as possible regarding interaction with participants, participants' language and perhaps body language, and examples of interaction and experience with the participants. In this study, thick description consisted of direct quotations and wording of participants to describe their experiences of living with EOBD.

Member checking. Member checking is the most crucial technique for establishing credibility (Lincoln & Guba, 1985). Study participants present as a lens through which to establish study validity (Creswell & Miller, 2000). From the constructivist perspective, participants' self-report is reality. Therefore, verifying the accuracy of the study's representation of participant data is essential to establishing the rigor of the study. Through member checking, participants review both data and interpretation (data analysis) for confirmation and verification.

After completing participants' individual textural-structural descriptions, the researcher contacted the eight participants to request engagement in member checking. Four participants replied that they would participate, while one participant replied that she did not wish to participate and entrusted the researcher with the analysis. Three participants did not reply to multiple series of communication from the researcher.

The four participants who agreed (A, B, F and H) to participate in member checking were sent their individual textural-structural descriptions and a summary of themes from the composite description. Participants were asked to address a) if themes and study conclusions in both their individual and composite descriptions were accurate; b) whether any elements of their missing were inaccurate or needed adjustment; c) whether any elements of their experience were missing and needed to be included; and d) to provide any additional information or feedback on

their descriptions. Participants A, B, F and H each replied that they found the individual and composite descriptions to be accurate, but did not offer any additional comments or request a second interview. Appendix E includes a summary of the themes sent to participants for member checking of composite description.

In summary, four of eight participants (50%) participants responded to member checking and verified their individual description as accurate, while 4 of 8 participants (50%) responded and verified the composite description as accurate.

Chapter 4: Findings

The purpose of the present qualitative study is to explore the experience of EOBD through semi-structured interviews of emerging adults with a history of EOBD diagnosis. Data analysis yielded a construction of participants' experience of EOBD as an interconnected web of five main themes and fifteen sub-themes that characterized participants' experience of EOBD. When describing themes and sub-themes, participants consistently depicted themes as experienced in relation to or in conjunction with other themes. Figure 1 displays the interconnectivity of participant themes.

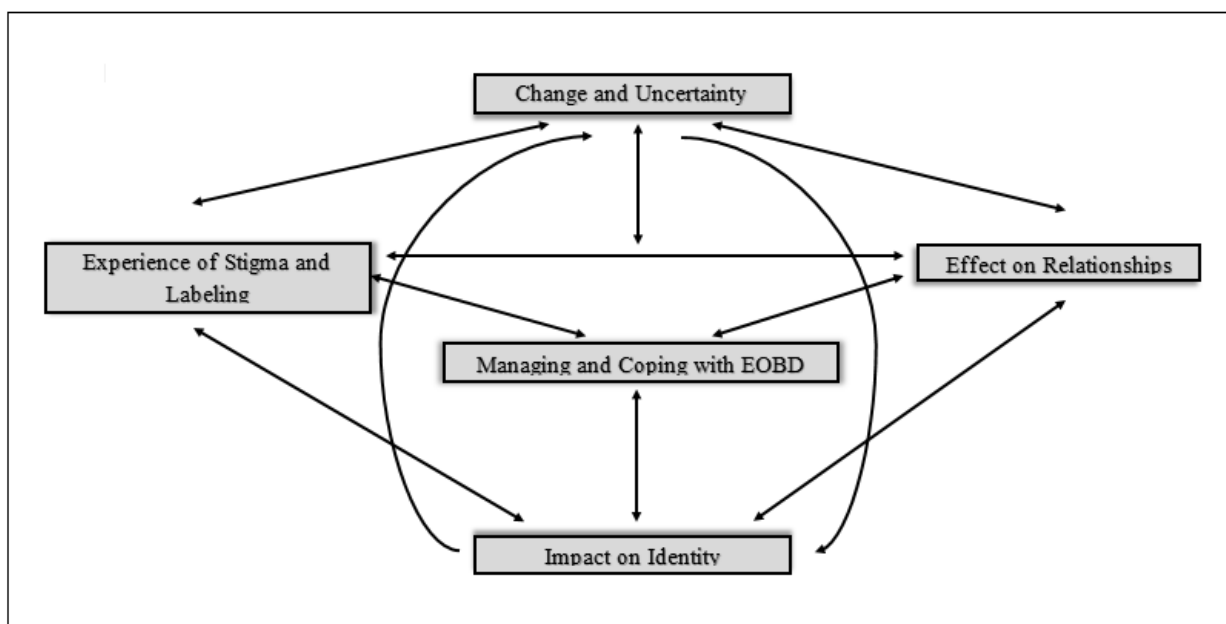


Figure 1. *Thematic Illustration of the Phenomenology of EOBD*

Study findings are therefore presented in two sections. First, the composite textural-structural description of participants' experiences is presented in relation to the purpose of the study. Table 6 presents the five themes and sub-themes that comprise the composite textural-

structural description. Second, themes and sub-themes are discussed according to study research questions. Table 7 displays the themes and sub-themes characterizing participants' experience of EOBD as organized by research question.

Composite Textural-Structural Description of the Phenomenology of EOBD

Participants described their experience of EOBD across five main themes: managing and coping with EOBD, effect on relationships, change and uncertainty, impact on identity, and experience of stigma and labeling. Each theme and its associated subthemes are presented below.

Table 6. Summary of Themes and Sub-Themes

<u>Managing & Coping with EOBD</u>	<u>Effect on Relationships</u>	<u>Change and Uncertainty</u>	<u>Impact on Identity</u>	<u>Experience of Stigma & Labeling</u>
Experience of Illness	Seeking and receiving support	Change in illness	Adaptation & integration	Labeling
Treatment and engagement with healthcare system	Difficulty maintaining social functioning	Change in identity and sense of self	Emotional adjustment	Self-labeling
Perceptions of healthcare and treatment		Change in relationships	Secrecy & selective disclosure of illness	Challenging and rejecting labeling
Knowledge and understanding of illness		Life changes		
Use of coping skills				

Managing and Coping with EOBD

Participants described their efforts to manage and cope with EOBD symptoms and course of illness. Sub-themes include participants' experience of illness, perceptions of healthcare and treatment, treatment and engagement with the healthcare system, knowledge and understanding of illness, and use of coping skills.

Experience of Illness. Participants described their experience of EOBD as characterized by manic and depressive symptoms, changes in illness, and comorbid symptoms such as anxiety and self-injury. Participants' age at the time of EOBD diagnosis varied from 13 to 17 years old ($M = 15.56$, $SD = 1.50$). Participants reported age at onset of EOBD symptoms between 7 and 17 years old ($M = 12.88$, $SD = 2.66$). Three participants reported polarity at onset of symptoms as manic, while four reported polarity at onset of symptoms as depressive. Participants' experiences of EOBD symptomatology and course of illness are explored here.

Manic and hypomanic symptoms. Three participants described the polarity of their first episode as manic, and all eight participants described experiencing manic or hypomanic symptoms during adolescence. Participants described their experience of mania in terms of increased energy and productivity, impulsivity, decrease in rational decision-making, increase in risky behavior, increased social activity, increased energy and hyperactivity, racing thoughts, decreased sleep, euphoria and elation, agitation and aggression, delusional thoughts, grandiosity, and hallucinations.

Participant H described his first manic episode:

...and I would say my manic episode probably started sometime right around when high school started, like the beginning of the year. But it was definitely a lot of classic symptoms of bipolar mania[pause] it was like delusional thoughts, hard to relate to people in social situations, grandeur thoughts, grandiosity [pause] towards the end was I was being hospitalized there were some hallucinations going on [pause] just kind of out of touch, having that out of touch feeling...feeling like you're on top of the world, you can get anything done [pause] just having really elated thoughts, elated emotions that were blown out of proportion. And just like overly emotional in situations, like no control over.

Participant D similarly described her experience with mania:

When I was younger it would kind of be like I would study nonstop, I would read everything, I would do, like, everyone's homework...I would

do so much. I would literally be running up and down my hallway, like screaming and studying, and I would get so hyper. Then, like a lot of racing thoughts that I would get just kind of made me a good student and at the time there was [sic] no depressive symptoms so everyone just told me that I was smart and hyper. And so I thought it was normal. But it wasn't really that normal. I had a bit of a hard time sleeping. I would just do a little too much than most normal people would...

Two participants reported experiencing dysphoric symptoms, including agitation and aggression. Participant G described her manic symptoms in this manner:

I would get aggressive with my parents. They would even have to call the police sometimes, and they would have me take a walk and get me to calm down because it would go on for hours at a time. Aggravation, a lot of yelling and arguing.

Depressive symptoms. Five participants described their first episode as depressive, and all eight participants described experiencing symptoms of depression during adolescence. Participants characterized depression as low mood, sadness, social isolation, decreased focus and clarity of thought, decreased motivation, decreased ability to do things, crying, and spending a great deal of time in bed.

Participant C described feeling “numb” and “defeated,” and elaborated further:

And I knew it was depression, but either way [pause] I was lack of myself. I was lack of life. I was basically black and white. Everything was just nothing.

Participant B described her experience with depression:

When I was depressed I remember laying in bed for months just watching TV, just showering was hard, anything like that. I played thoughts in my head over and over, like I wasn't good enough, like no one cared about me, and just stuff like that. I would cry a lot, so sometimes I would fall asleep crying and wake up crying.

Participant H described experiencing significant changes in cognition and social impairment:

And my depressive symptoms [pause] I've never been [pause] I've not usually been suicidal. I've never attempted suicide. But just really low motivation, low social desire, low desire to get out or do anything, low drive to accomplish anything, your thoughts are a little cloudier, and your cognitive function I think is affected slightly since you just are not interested in anything. You're not really—your brain doesn't really get going. It doesn't really get your gears going about anything...[it] renders me not wanting to do anything for anywhere of period of a few weeks to a few months.

Comorbid symptoms. Seven of the eight participants described experiencing symptoms or diagnoses of other mental health conditions, including anxiety, self-injury, eating disorders, and substance abuse. Only one participant described experiencing exclusively manic and depressive symptoms throughout adolescence.

Six participants described experiencing symptoms of anxiety, including excessive worry, panic and panic attacks, and ritualistic behavior to alleviate anxiety. Participants described anxiety as emerging from other stressors, as well as stressors associated with EOBD itself. Participants D and F described experiencing anxiety as a result of the illness and stressors associated with seeking treatment. Participant G described being treated for anxiety prior to EOBD diagnosis.

Participant C described her experience of having a panic attack:

I do get a lot of anxiety episodes, and a lot of them are really random. No reason to happen. But I could be driving to Home Depot and next thing you know I'm having a full-blown panic attack and I'm having to pull off the side of the road.

Three participants described engaging in self-injury during adolescence concurrent to bipolar symptomatology. For participants, self-injury was consistently described while

discussing anxiety, interpersonal stressors, and lack of control over situations or bipolar symptomatology. Methods of self-injury included cutting, burning, and hitting oneself.

Participant B described self-injury as a component of her experience of depressive symptoms:

I would kind of like make decisions, like just to stay in my room, and I don't know, like hit things and stuff. But then I also cut myself and would burn myself. Stuff like that. I hit myself sometimes.

Participant D described self-injury as related to depression and suicidality:

I think that I was 13 turning 14 or something like that, and I basically started cutting myself when I was 11 [pause] so it progressed over the years and when I was 13 turning 14 I was cutting a lot more and I cut very, very deeply so I had to go to [pause] I was feeling suicidal and I wanted to practice cutting myself so that I could commit suicide. I don't know what I was thinking. I was young. Um, anyways. So during this episode of cutting I had slit my wrists too deep and my brother saw it, so they took me to the hospital.

Two participants described being diagnosed with attention-deficit disorder. Participant H described ADHD as an additional challenge during adolescence:

I was getting tested because I thought I had ADHD. And I eventually got diagnosed and medicated for ADHD, and it felt like the right thing to do because I was really struggling to focus on my schoolwork, but I only stayed on medication for about 3 years [pause] just getting on the meds itself was a challenge. And dealing with a dual diagnosis, another diagnosis, ADHD, in addition to bipolar disorder...

One participant described comorbid substance use during adolescence. Participant E described marijuana and alcohol use that coincided with onset of her first manic episode.

Participant E described her substance use as a trigger that obscured the onset of symptoms.

I started smoking and drinking, and then after that it was just like... you know sometimes with drugs it makes things more uh [pause] amplified I guess. Like they really bring out the symptoms. And when I was at school,

I would smoke a lot and I would drink a lot. And I remember one night I started hallucinating, and I was like ‘yo, like I’m seein’ shit’—excuse my language. I curse a lot—‘I’m seein’ shit, like what is going on?’ And my roommates were looking at me like, ‘what? Like, are you that high?’ At first it was cool that I was smoking, that I could put everything on a drug and just be like ‘oh I was high. That’s some strong weed!’ and people obviously didn’t really know that I was like having a breakdown.

Participants B and C described having an eating disorder during adolescence. Participant C stated her eating disorder began following a significant reduction in appetite due to ADHD medication, while Participant B described her eating disorder as associated with self-esteem, self-judgment, and self-labeling.

Suicidality. Two participants reported experiencing suicidal ideation with suicide attempt.

Participant D described her suicidal thought processes:

...at the time I felt like, ‘oh well I should [commit suicide] [pause] if this is who I am, like, I should just kill myself.’ I was like, if I’m sick why am I going through this, or whatever [pause] and for some reason I didn’t [commit suicide]. I don’t know why.

Participant C described feeling defeated as a part of depression, and associated defeat with suicidal ideation:

And I always kind of knew I was kind of defeated and I wanted to defeat myself, I wanted to hurt myself, I wanted to end my life. I did several suicide attempts to try to do that. And all the suicide attempts that I have done have failed.

Two participants described suicide attempt in addition to ideation. Participant C recounted her experience with a failed suicide attempt:

And I actually attempted suicide. I had a belt that I was trying to hang myself with, but it broke. And it took a lot for me to build up to do that, and when it failed I didn’t really have—I couldn’t build myself up to do it

again. I guess I was just scared of what would happen. I wasn't scared of dying, I was just more scared of what would happen after I went. You know, what would my parents say about me?

Treatment and engagement with healthcare and treatment. As part of symptom management and treatment for EOBD, participants described their experiences with the healthcare system. All participants described accessing healthcare at varying levels of acuity ranging from psychiatric hospitalization to outpatient treatment. Participants described sub-themes that included their perceptions of healthcare, as well as ease or difficulty of access to services.

Accessibility of healthcare. All participants described utilization of healthcare services throughout adolescence. All participants described seeing a psychiatrist and taking psychotropic medication following receipt of EOBD diagnosis, while five participants described additionally seeing a therapist. Five participants reported history of psychiatric hospitalization due to bipolar disorder. Two participants were diagnosed in hospital settings, while six were diagnosed in an outpatient setting by a psychiatrist or therapist. Two participants described initially accessing healthcare and treatment involuntarily through law enforcement, while six participants described voluntarily seeking treatment. Accessing healthcare did not necessarily coincide with onset of symptoms or receipt of EOBD diagnosis. While four participants described receiving EOBD diagnosis and treatment upon first accessing healthcare, the other four participants described initially seeking and receiving treatment and non-EOBD diagnosis such as depression or anxiety.

Participant H described entering the healthcare system through hospitalization during his first manic episode after a prolonged experience of untreated symptoms:

So at 14 when I first got diagnosed, that was probably the worst manic episode I've ever had. And it was the first time I ever experienced the symptoms of my bipolar disorder. And it was probably as bad as it was

because I was unmedicated. My parents never thought about treating me for a mental illness or going to see a psychiatrist for any of my issues that I had...and I would say my manic episode probably started sometime right around when high school started, like the beginning of the year. And it only took me 6 to 8 weeks into high school to have full-blown manic feelings and to have my mom realize 'okay, you need to go to the hospital.'

All participants described continuing healthcare and treatment for EOBD in some form throughout adolescence. Six participants described maintaining continuous psychiatric care and psychotropic medications, while two participants described receiving only psychiatric care, one participant described receiving only therapeutic care, and two participants described inconsistent compliance with treatment of any kind. Participants ascribed their decisions to maintain engagement in healthcare as related to their perceptions of treatment, discussed further.

Psychotropic medication. Psychotropic medication was a core component of all eight participants' treatment for EOBD, and was described as profoundly impacting their experience of EOBD throughout adolescence. All participants reported taking medication throughout adolescence. Five participants described an improvement in symptoms with medication and maintained compliance with psychiatric treatment, while two participants reported that medications at times appeared to exacerbate symptoms and reported intermittently discontinuing medication as a result. One participant described resistance to psychotropic medication throughout adolescence and stated she did not begin taking medication until age 19.

All participants described having multiple healthcare providers during adolescence and taking several medications before finding a medication that worked with tolerable side effects. Of the seven participants who were prescribed psychotropic medication during adolescence, all identified medication side effects as a significant challenge.

Participant H described experiencing significant side effects from medication that included sedation, cognitive dulling, and weight gain, and described being “like a zombie.”

Over the course of my adolescence I probably gained 75 pounds or something, and some of it might be due just to growing—I mean not growing height-wise, but just growing, everything filling in—some of it was definitely due to the medication and weight gain. And then from 18 to 23, with the different medications I’ve been on, I’ve gained an additional 100 pounds. And I’m not even that fat of a person, I’m like 6’ 3” and weigh 270 right now. But the fact that being on medications caused me to gain almost 200 pounds in the course of my lifetime is just crazy.

All seven participants who reported taking medication during adolescence described being prescribed stronger medication during and immediately following symptomatic episodes, with adjustments in medication strength occurring as symptoms stabilized.

Participants C and G described reported mixed benefit from medication and stated at times their symptoms appeared to worsen with medication. Participant G described experiencing increased agitation, suicidality, and sedation due to medication, while Participant C described experiencing cognitive changes:

I had a very terrible effect with that medication. I was driving to work and I felt like I was detached—I felt like I was a puppet on strings and it just felt like when I stood up or did anything, it just felt like the strings got cut. So it really felt like I just couldn’t move myself. Someone just took—it felt like they just took my soul away. It really just—all of me they just kind of removed. All my personality they just removed. And I only took it once, a very low dose too...Either way, I was driving and I had a bad reaction to it and I almost got into a car accident. It just wasn’t a good medication.

Participant H described medication as beneficial, but also addressed the challenge of medication for differing manic and depressive episodic states. Participant H described the desired outcome of balance and remission of symptoms as difficult to attain.

And it [EOBD] sometimes can get helped with the medication, but sometimes the medication can only help so much without them wanting to induce a manic episode. So I think that's the toughest part of bipolar disorder—you need to stay in the middle and that's not how medications work all the time.

While participants described the challenges associated with psychotropic medication, they also acknowledged its benefits. Six of the seven participants who were prescribed medication in adolescence described psychotropic medication as the catalyst for their symptomatic improvement. Participant A described medication as effective and the key factor to her stability:

I don't know if I would be able to effectively handle it if I had just had counseling. I just know that since I started taking the medication my life has improved immensely. And there has not been a point where I have gone off my medication and had issues. So I think that is—that has to be what is helping.

Participant B described both the benefit and uncertainty associated with psychotropic medication:

You know, I think medicine has helped me so much. I really do think it's helped save my life. And it's still really difficult. It's really hard when the medicine stops working and you have to try a new one. You don't know what it will do. And the side effects [pause] it's really difficult. But I want to do everything I can to help myself, so I think medicine is a good thing.

Psychoeducation. Participants described psychoeducation as helpful in understanding EOBD and their experience of symptoms during adolescence. Participants described obtaining psychoeducation from providers as well as through their own self-education. Participants described psychoeducation being provided to family members as well.

Participant G described psychoeducation she received at time of diagnosis:

They said it was a mood disorder mostly. Nothing to do with physical or real bad mental issues, but they said I would need to take medicine for it, come back for treatment, and basically get it in check to see if everything was okay.

Participant H described receiving psychoeducation from providers, but stated his own research and self-education were beneficial in understanding EOBD:

I still think that [psychoeducation from providers] got me halfway there. And the other half was me reading online about bipolar disorder and learning about it myself.

While participants described the value of psychoeducation, they did not describe a change in stigma, acceptance of denial of illness, or interpersonal relationships concurrent to psychoeducation. Additionally, knowledge and understanding of illness was described as separate and unrelated to provision or receipt of psychoeducation. Psychoeducation, therefore, emerged as the transmission of information rather than the absorption, incorporation, or understanding of the information.

Perceptions of healthcare and treatment. Participants described their perception of healthcare and treatment for EOBD as both beneficial and non-beneficial. Participants additionally described the healthcare system as potentially difficult to navigate. Participants also expressed avoidance and ambivalence toward healthcare and treatment for EOBD.

Healthcare is beneficial. All participants described healthcare and treatment for EOBD as beneficial. Psychotropic medication and psychotherapy were identified as particularly beneficial to participants.

Participants who described psychotherapy as beneficial identified validation, psychoeducation and normalization of their experience, unconditional regard from healthcare

providers, and ability for self-expression were as specific components of their experience that were beneficial.

Participant G additionally described her therapist as beneficial due to validation, self-expression, and gaining an understanding of her experience:

And my therapist, talking to them [therapist] actually helped me out a lot, being able to get stuff off my chest that I wasn't able to with my own family. But being able to talk the situation out with somebody else that actually had somewhat of an understanding of what I was feeling made the situation a lot better.

Participant B described therapy as beneficial because it “served as an escape” from stressors and symptoms. Participant B also described therapy as beneficial when it was individualized and incorporated her use of art as a coping skill.

Participants also described the combined treatment approach of psychiatric care and psychotropic medication as beneficial. Participant A described seeing several therapists during adolescence, but stated it was upon seeing a psychiatrist and beginning medication that EOBD symptoms began to improve, while Participant E described healthcare and treatment as beneficial in helping “taming” the illness and stabilizing symptoms.

Participant F described her experience with therapy and medication as an influential part of her adolescent experience:

Yeah looking back—well the therapy that I had when I was a teenager was so important. And she was a really good therapist and helped me through. But yeah, the psychiatry too, because I wouldn't have had my medication corrected with the mood stabilizer and would probably be a very different person or in a very different place if I hadn't been put on it.

Healthcare is not beneficial. Six participants described aspects of their experiences with psychotherapy, medication, and hospitalization as not beneficial. Participants identified lack of knowledge and understanding of illness as the factor that determined whether healthcare and

treatment were beneficial. Lack of knowledge and understanding of illness emerged as the most common code across all participants and is discussed further below.

Several participants described therapy as non-beneficial due to lack of rapport and therapist understanding of their experience. When asked about whether her experience with therapy was beneficial, Participant D replied:

The therapy no because...the therapy, especially no, because she would just scribble things in her notebook and ask one question, sit there ten minutes in silence. So therapy, no.

Participant H described experiencing therapists' lack of knowledge and understanding:

In understanding what I was going through and also, as a therapist it's your responsibility to help people get through what issues they need to work on, and I just don't feel like they were able to provide that especially in the context of having bipolar disorder.

Participants described psychiatric hospitalization as a negative experience with limited benefit. Overall, hospitalization was described in terms of lack of understanding by staff and providers, as well as lack of control over admission, discharge, and treatment. Participant D described her experience with psychiatric hospitalization in terms of lack of knowledge and understanding by hospital staff and providers:

So they don't know [pause] there's different levels of illness I want to say in the hospital setting, or mental health setting, medical setting...so it's like, they stick us all—these different levels. And it's like this one person might be very hostile...I mean, in the hospital this girl was throwing a chair at me, and like threatening to kill me, and they didn't know what to do about it. And I told them—before it even happened—this girl is harassing me, I know it's going to get worse; can you do something? They would just tell me that I'm being paranoid, that with my disorder making me think things that aren't true. And, so just like...I don't know. There's a lot of things. It's like the fact that they think you should just do whatever because you have a disorder and not take care of you. It's negligence. And

the setting itself is just [pause] a lot of things about it. I don't even know how to get into it, so I'm just going to leave it there.

Avoidance of healthcare. Several participants described avoidance of psychiatric treatment and psychotropic medication during adolescence. Participant F described seeing a therapist while declining medication until she noticed EOBD symptoms were not improving. Participant A described beginning therapy in eighth grade, but stated she did not see a psychiatrist or begin medication until age 17; at which point she was diagnosed with EOBD when symptoms had not improved.

Participant B stated that while she received multiple EOBD diagnoses by psychiatrists at age 16, she refused to return for psychiatric treatment and medication until age 19. Participant B described her decision in terms of avoidance to preserve autonomy and self-sufficiency:

I just wanted to be able to do it by myself instead of having something to help me. Because I didn't like taking them [medications] every day and like, I just didn't like being on meds. I don't know why I was really so against it as a teenager.

Participants C and G described self-discontinuing a medication regimen for several years due to negative experiences with medication effects and side effects. Participants D, E, and H also described efforts to prevent and avoid psychiatric hospitalization following negative experiences.

Difficulty navigating the healthcare system. Three participants described difficulty accessing healthcare due to issues with insurance or ability to afford services, finding available providers, getting medication on time, and coordinating between providers. Participant G described difficulty finding providers due to insurance, and stated she continued to see ineffective providers for years due to lack of alternate options:

At times it was hard to find a provider, be able to get different help, because a lot of the providers didn't accept the insurance that I was getting, and they wouldn't accept it for therapists and psychiatrists. So it was a lot of moments where I felt like I was not able to get help for myself, but I went back to the same provider for those 4 years because I wasn't able to get the help that I needed at the time.

Participant F described difficulty coordinating between providers, specifically between psychiatrists and pharmacies to ensure they received psychotropic medication regularly. This participant also described incidents of having to forego medication temporarily due to difficulty navigating coordination between providers:

Ambivalence toward healthcare. One participant described ambivalence and uncertainty regarding treatment interventions and providers associated with lack of trust and loss of autonomy. Participant H described his ambivalence toward healthcare providers:

Like, they're [healthcare providers] the people you're supposed to trust, and they're the people you rely on for your medication. Like if I went off my medication I would go bipolar again. And I can't have that. And so it's really hard...you're put in a really tough spot where it's like you're forced to trust them, they have no—like, you have no cards in your hand and the cards are all in their hand.

Knowledge and understanding of illness. Knowledge and understanding of EOBD, as well as lack of knowledge and understanding of EOBD also emerged as core components of participants' experiences. While six participants described knowledge and understanding of EOBD as part of their experience, lack of knowledge and understanding of illness was endorsed by all eight participants and was the most common invariant constituent throughout all interviews. Participants described not only their own lack of knowledge and understanding, but that of their families, peers, and healthcare providers.

Lack of knowledge and understanding of illness. Participants described experiencing confusion and lack of understanding of emerging symptoms. Participants described having a limited understanding of EOBD at the time of diagnosis.

Participant D described her own confusion and lack of understanding of EOBD symptoms:

It's still hard because my brain isn't even fully developed yet, nor was it when I was at that age. With my emotions and everything, it was like really hard. I didn't understand any of it. Like, when I was younger I literally didn't understand what was going on, why I couldn't focus or why I was having strange thoughts that I couldn't really explain. And it just kind of felt like [pause] I don't know. It was confusing.

Participants described their families' lack of knowledge and understanding of EOBD throughout adolescence. While some family members lacked understanding of specific components of EOBD, others viewed EOBD as an 'excuse' for unstable and symptomatic behavior. Participants A and F described their parents as understanding components of EOBD, specifically depression, without understanding the full scope and nature of EOBD and need for psychiatric treatment.

Participant F stated her parents did not fully understand bipolar disorder symptomatology:

...they just don't always seem to get what's happening because—or they see it still as depression rather than bipolar. Because they don't really understand the manic part of it, and that my mom has had bouts of depression in her life, so they don't really understand the manic part of it at all.

Participants C and G described their families' lack of understanding of EOBD and stated their families viewed the illness as attempts to justify behavior disturbances. Participant C described her mother's lack of knowledge and understanding:

My mom basically had to deal with me and all my appointments and my bipolar symptoms. She was there to, like, see it all, but yet she didn't understand. So she would come home and get upset, why didn't you do the dishes, why didn't you do this, why didn't you do that. Like, it's almost kind of like every parent says that. So this would go on for weeks. I wouldn't get out of bed. She didn't really understand it.

Participant A attributed her family's lack of understanding in part to the difficulty distinguishing between normative adolescent mood swings and EOBD symptomatology:

I think that people generally expect teenagers to be super moody and fluctuate in terms of how they feel all the time, and so I think that being a teenager with bipolar disorder is extremely hard because you have to communicate that what you're feeling is not within the normal range. When people expect that kind of depressive symptoms. And I think that was the hardest thing with my family, with trying to convince my mom that she was wrong to think that what I was experiencing was normal. So I think that's the biggest challenge. Because once you get older, I think if you have symptoms of bipolar disorder people generally tend to think that they are abnormal and you get help faster but as a teenager they're introducing so many things that people can't look into how difficult it is for you in comparison to others.

Knowledge and understanding of illness. Participants described attaining their own understanding of the illness and discussed the knowledge and understanding of illness of their support system as well as healthcare providers. All participants described knowledge as part of receiving the EOBD diagnosis and attaining an understanding of the symptoms, course of illness, and treatment implications for EOBD. Seven participants described receiving the EOBD diagnosis as a confirmation of the problematic symptoms they had been experiencing.

Participant D described her reaction to receiving the EOBD diagnosis:

...but it did also provide me some sort of feeling of understanding of what I was going through, like the sixth sense. Like there's a pattern here, you know?

Participant F described gaining an understanding of her experience:

...because I'm a really upbeat person, so depression never seemed right. Because I would have manic episodes and not really get how that fit into it, so having the diagnosis of bipolar just made so much more sense as to what was going on with me personally.

Denial of illness. While participants described knowledge and lack of knowledge and understanding of illness, six participants additionally described experiencing denial of illness, in which the knowledge and understanding of EOBD was present but simultaneously refuted. Participants described their own denial as well as that of their support systems. Participants described difficulty accepting EOBD diagnosis as influencing engagement in treatment and interpersonal relationships; as well as related to participants' sense of self.

Participant H described EOBD diagnosis as difficult to accept. Participant B described being "in denial a little bit," getting three EOBD diagnoses by multiple providers (the initial diagnosis as well as a second and third opinion), and avoiding seeing a psychiatrist or taking medication for several years.

Participant E described experiencing denial during onset of symptoms and for several years following diagnosis. Participant E described compliance with treatment out of fear of relapse, but stated she continued to hope the diagnosis was wrong:

...it's like yes, I understood it but I was in denial for I would say...I was in denial for about 4 years or so. So I knew it, like I would go to a psychiatrist and get medicine and stuff like that. But I was still kind of hoping that, in the back of my mind I was always hoping that I really wasn't bipolar and really it was just like the drugs that were doing something.

Five participants described their family's denial of illness and need for treatment.

Participants described others' denial of illness as unaffected by interactions with healthcare providers and psychoeducation.

Participant A described recognizing and accepting EOBD symptoms; however, described her mother's denial:

And my mom was also very adamant about the fact that she didn't want to have a child with mental illness, and thought that it would reflect on her as a parent if I did, and so she was also very invested in making sure that she mitigated my symptoms and basically just dismissed them.

Participant E described denial of illness within community and cultural context that shaped her experience of EOBD:

I want to say I'm African-American, first of all. A black woman. So I think mental illness especially in the black community is—how do I say this—it's something that black people, like, deny. Because black people for so long have always tried to be so strong and, you know, it's just something that...for example, one of my friends was depressed and her father was like 'only white people get depressed.' You know, get over it, toughen up and keep going.

Use of coping skills. In addition to treatment interventions, five participants described their own coping efforts and use of coping skills to alleviate symptoms and stressors.

Participant G described writing poetry, listening to music, and talking to others as helpful with agitation, anxiety, and depression. Participant B described art as both helpful and therapeutic.

Participant E described reading success stories of others with mental illness as inspiration and a source of strength.

I would read stuff about people who were bipolar. Or I would look at celebrities or other people that were famous and living their life wonderfully, that were bipolar. Like, I forgot...what's his name? Robert Downey, Jr or something? That guy, Iron Man. He has mental disorders. And I know there's some other woman that's, like, gorgeous that has bipolar disorder. So that's basically what I did, is I didn't let it get me down. Obviously I propelled my life into something else.

Effect on relationships

A second theme of participants' experience of EOBD was the changes that occurred in interpersonal relationships. Participants described their efforts navigating normative adolescent changes in peer and family relationships as well as the added element of changes prompted by the presence and course of EOBD illness, stigma, and engagement with the healthcare system.

Difficulty maintaining social functioning. Participants described difficulty maintaining peer and family relationships due to decline in social functioning, isolation, and conflict. While participants noted change as a normative part of adolescence, the difficulties noted below were attributed specifically to the impact of EOBD.

Family relationships. All participants described change and conflict in family relationships, ranging from lack of understanding to fighting and aggression. Participant G described experiencing frequent family conflict she associated with EOBD, including yelling, arguing, and fighting with family members' and identified rebuilding family relationships as her greater challenge during adolescence

Participant E described an intense argument with her sister that occurred when living with her sister following diagnosis:

I lived with her [sister] when I transferred back and went to a different school. And one time she and I had an argument. She got really pissed off. I don't remember what we'd argued about. And she told me—she's like,

*'you know what...you are so annoying. I'm just going to take all your medicine and I'm just going to flush it down the toilet so you don't have any medicine.' And she was like 'and then you'll just have an episode again.' And when she said that to me, I was like, wow. And it took me years to forgive her for saying that, because I was like, you're my f***ing sister...how dare you, in the heat of an argument, use my mental disorder and threaten the argument on throwing away my medicine so that you'll affect me.*

Peer relationships. Six participants also described experiencing difficulty and conflict in peer relationships. Participants described difficulty making and maintaining friendships due to the presence of EOBD symptoms and resulting changes in behavior.

Participant C associated difficulty maintaining friendships in high school with peers' lack of knowledge and understanding of EOBD:

I lost every single one of my friends in high school. People just saw me as a freak. They didn't like--they didn't like that I was just unstable. And I can see from their point of view. Who wants a friend, you know, who's going through a hard time? and they try to help and nothing they do helps. So basically a lot of friends would give up on me or people would just walk out immediately. They just don't want to deal with it, or they don't like it.

Following hospitalization and beginning treatment, Participant H stated his parents transferred him to a different high school. Participant H then described the difficulties associated with social functioning while receiving treatment for EOBD:

I knew I had to make friends all over again after losing all my friends, and I don't know [pause] it was really rough with relationships with friends because I was zonked out on really heavy sedating meds that hadn't gotten phased out yet since being in the hospital. So just kind of now, instead of dealing with having a manic episode while adjusting to going to a brand new high school, I was dealing with bipolar disorder diagnosis and medication while going to a brand new high school and that was just as rough in my opinion.

Isolation. Four participants described an increase in isolation associated with onset and experience of EOBD symptomatology, including withdrawal from social situations, pushing others away, and selectively leaving their ‘safe space’ (e.g., bedroom). Participants described isolation occurring in conjunction with symptoms of depression and anxiety, as well as part of efforts to cope with EOBD symptomatology.

Participant B described isolation and a disruption in relationships associated with EOBD symptomatology:

So [I] just became a lot more isolated. I guess because I was just crying all the time and I just would go by my feelings with friends. I think a lot of it was on my part, with my change in relationships just because I became more isolated. I would get attached to certain people but then detach and [pause] I would just go by my feelings and moods with people.

Participant A described an association between isolation and increase in symptomatology:

I think that feeling socially isolated just makes everyone’s symptoms worse. That was a pretty big piece. And I don’t think I’ve felt as socially isolated as I did during my senior year at any other point in my life.

Seeking and receiving support. Participants described seeking and receiving support from others as a key component of their experience of EOBD throughout adolescence. Seven participants described having a support system, while two participants described a lack of support during adolescence. Participants also described seeking help and support upon noticing EOBD symptoms and receiving support from family, peers, and healthcare providers.

Support. Seven participants described their family and peers as supportive during adolescence. Participants described support as separate from knowledge and understanding and

involvement in treatment. Support was described as listening, attempting to understand, and trying to help unconditionally.

Participants B and H described their parents' support in the process of coping with emerging symptoms, seeking help, and receiving the EOBD diagnosis.

Participant B described approaching her mother upon noticing prodromal symptoms:

I struggled a lot before that [EOBD diagnosis]. I came out to my mom and told her I had been having a lot of the mood swings, which she noticed. And I told her about all my suicidal thoughts, the trouble I'd been having. I opened up a lot. And she helped me get a therapist and stuff.

Participants also described receiving support from friends and peers. Participant A described her friends as having an active role in advocating for her to seek treatment due to emerging symptoms:

There were a couple people who I was friends with who I didn't see in person, so some long-distance friendships. People who just saw my emotional patterns and were trying to persuade me to get a diagnosis because I wasn't seeing anyone... I think that getting the bipolar diagnosis definitely confirmed what they had suspected, that there was something more significant going on than depression and they were much more vigilant in trying to help me.

Involvement of others in treatment. Six participants reported that family members provided referrals or facilitated treatment, coordinated with healthcare providers, participated in treatment sessions, and administered participants' medication. Involvement of others in treatment was described as separate from support and lack of support, and was perceived as both beneficial and not beneficial.

Participant G stated her mother would attend therapy sessions with her and would at times receive progress reports from providers. Participant B described her mother's involvement as helpful in conveying emerging symptoms to the psychiatrist. Participant A stated her mother

recommended and paid for her to see a psychiatrist at age 17 when symptoms had not improved through therapy.

For some participants, family involvement was not a positive experience. Participant C described her mother's involvement in treatment as having a negative effect on therapeutic rapport:

I was trying different medications and my mom only had to take me to therapy sessions. The therapist would eventually try to tell her what my mood disorders are and what are the actual symptoms and my mom would fight it. And eventually the therapist would get so tired of fighting with my mom they would—the therapist would say 'your mom's being right. You're being lazy, so you need to step up or you need to help out your mom.' It just felt—I changed therapists shortly after, but with that it didn't feel like I actually had a therapist.

Loss of autonomy due to healthcare. Participants C, D, E, G, and H described incidents in which they felt excluded from their treatment team and experienced a loss of autonomy. Each of these participants described incidents when healthcare providers spoke only to their parents and they were not involved in treatment sessions or decisions. Additionally, participants D and H stated they were not able to administer their own medications for significant periods of time. Participants described feeling invalidated and frustrated, and associated the lack of inclusion and autonomy with their age.

Participant H described loss of autonomy:

And so...from ages 14 to 16 I didn't administer my own meds. My dad was the one who gave them to me every night, and he kept them locked up. And I don't know if it was a lack of trust or what [pause] and my dad would frequently come to my psychiatrist appointments and there were times, especially if I was really depressed, he would just talk to the psychiatrist instead of me. And that made me feel really not included in my own treatment plan. So it definitely was less trust and more careful treatment. And it's kind of weird because I didn't cause myself to have bipolar

disorder, so why they thought that they needed to do that was [pause] I don't know, maybe it was their own m.o .

Lack of support. Participants A and C described having limited support during adolescence. Participant A described peer support as indicated above, but described an absence of family support characterized by her mother's denial of illness.

...and so I really didn't feel support sometimes. I really didn't feel support from family, and still don't really feel support from family.

Participant C described a lack of family and peer support, as well as limited support during her pregnancy at age 15. Participants A and C both described feeling alone and having 'no one there' for support.

Seeking help and support. Four participants described seeking treatment and support from others voluntarily upon noticing emerging symptoms. Each participant described reaching out to their parents for assistance accessing healthcare and for support in managing symptoms. Participant B described reaching out to her mother first for help seeking a psychiatrist, but also described seeking support from friends and church leaders in her support system. Participant B described receiving limited support and stigmatizing responses from friends and church leaders; this is discussed more fully as part of the theme of stigma.

Change and Uncertainty

Participants' overall experiences of EOBD were characterized by change and uncertainty. All eight participants described their adolescence as a period of continuous changes in symptomatic states and course of illness, identity and sense of self, and relationships. Participants also described life changes that affected their experience during adolescence.

Change in illness. While each of the participants described experiencing depressive, manic, and comorbid symptoms, each of the 8 participants characterized their overall experience of EOBD as dominated by change, uncertainty, and instability of symptoms. Duration of episodes varied from days to weeks or months; the severity and frequency of symptoms similarly varied. The severity of manic and depressive episodes was described as ranging from disruptive to debilitating. While some participants described an experience dominated by depressive episodes, others described that manic episodes were more disruptive to their lives in adolescence.

Participant G described her experience of changes in duration and type of episodic states

I experienced depression for weeks at a time. It would come and go. And then I have moments of anxiety, aggravation, and irritability. And I was really becoming passive-aggressive towards everybody around me.

Participant B described experiencing instability in the type of symptoms as well as course of illness:

I've heard of this thing called rapid cycling. I'm not sure what that is, but they [symptoms] would shift a lot. But there would be times where I'd have a long depression, like where I had it for a couple months. And there would be weeks of hypomania. But a lot of it was throughout the day, even.

All participants also described a change in the type of episodes they experienced throughout adolescence. . Participants E and H experienced manic polarity at onset of illness, and described a pattern in which manic symptoms largely subsided, while depressive episodes had become more dominant. Participants A and F described the inverse: a course of illness initially dominated by depressive episodes, and more recently characterized by manic episodes. Participant F also described experiencing more depression when younger. Participants C and G additionally described experiencing persistent symptoms of anxiety, irritability, and emotion

dysregulation. Participants described ideation for self-injury and suicide as overall decreasing throughout adolescence as well.

Change in identity and sense of self. Each of the eight participants described experiencing changes in sense of self. Six participants described experiencing a change in identity that consisted of viewing themselves as different or defective as a result of EOBD. Three participants described a change in their thoughts, beliefs about themselves, and behavior occurring as a result of EOBD.

View of self as different or defective. Six participants described experiencing a change in identity in which they came to view themselves as defective, damaged, or different from others due to EOBD—a sense of liminality and ‘otherness.’ Participants described themselves as flawed, abnormal, worthless, and weak. Participants described feeling that there was something ‘wrong’ with them, that they were an outcast, and that others would not care for them if they became symptomatic.

Participant A described her experiencing a change in identity due to the implications of an EOBD diagnosis, as opposed to her previous diagnosis of depression.

I went from thinking that I was basically experiencing something that a lot of people go through to thinking that I was just having depression and when I was older like my siblings I would be able to get out of it from having that diagnosis and having the psychiatrist tell me this [bipolar disorder] is a lifelong thing that I’m going to have to manage that really shifted my sense of self.

Participant B described feeling worthless and not ‘good enough:’

I was very judgmental. I had this self-esteem thing going on as well as the bipolar, so I did go through a lot...just thinking I’m worthless and trying to be better looking. Like I had an eating disorder as well at 18. Um. I just didn’t think I was a good person. I just thought I wasn’t worth it, I guess.

Changes in decision-making. Three participants described experiencing significant changes in their identity in the form of changes in thought patterns, perceptions, beliefs about themselves, and behavior. Participants described engaging in unhealthy behaviors, choosing not to pursue goals, and changes in coping patterns following EOBD diagnosis.

Participant E described change in social behavior and viewing herself as flawed due to emerging EOBD symptoms:

I knew there was something wrong, and because of that I thought I was flawed and I didn't want to hang out with anybody.

Participant G described changes in her thoughts, perspective, and behavior following EOBD diagnosis. Participant G described feeling that she had lost sight of her future and that her life was falling apart

I got into really bad habits. I started drinking at parties, and smoking, and getting into a lot of bad habits and getting in trouble a lot. And I felt like before the [EOBD] diagnosis I had good grades and everything, and then it all started to decline rapidly.

Changes in relationships. All eight participants described experiencing significant changes in family and peer relationships during adolescence. Participants described changes as occurring independently of EOBD as well as in response to EOBD.

Participant D described the loss of her older brother as a significant change unrelated to EOBD that impacted other interpersonal relationships throughout adolescence:

So yeah, around 11 or so, or 12 or so, my oldest brother was with my father. He took care of us at 28. He came out of the closet, and he decided to leave the house a week before telling me and my brother. So that was very depressing to me, because to me it felt like [pause] it felt like I lost him. It almost felt like a grieving session for death or something. That's what it felt like. And relationship-wise, my family did start, kind of, turning different. And so I also behaved differently. A lot of my early relationships did fall apart at that time. That's one thing that kind of triggered the

depression symptoms, but afterwards I did carry that and it kind of did ruin a lot of other relationships I had [pause] teacher-student relationships, whether friends, friend to me relationships, or mother-daughter relationship...

Participant H described experiencing a change in his relationship with his parents following hospitalization and diagnosis of EOBD:

But as far as family goes, yeah, my parents definitely treated me differently from after I got diagnosed. They were less likely to allow me to do risky things or to stay out late with friends, which kind of sucked, because—I mean, I’m just talking as an angsty teen here—but it kind of sucked because I was already trying really hard to make new friends and then they’re not letting me do things with these people who could become my friends.

All participants also described experiencing changes in peer relationships associated with EOBD. Participants attributed changes in peer relationships to symptomatic states, changes in illness, and peers’ limited ability to understand and provide support. Participants additionally acknowledged changes in their own behavior that placed strain on peer relationships; Participant E described deliberately creating conflict with others, and Participant F described her symptomatic behavior as “high maintenance” and off-putting to her friends.

Participant G described experiencing changes in peer relationships she associated with feeling ostracized, self-isolation, and lack of understanding:

... nothing was working. Nobody understood what I was going through, even before the diagnosis. And I didn’t really know what was going on, and everybody was pushing me away, it felt like, and I was pushing them away. Nobody wanted to be near me. That’s what it felt like.

Life changes. Participants described experiencing significant life changes associated with onset and experience of EOBD, such as moving and beginning a new school. Participant H

described onset of symptoms coinciding with beginning high school, while Participant A described onset of symptoms beginning with moving to attend a new school in a different state.

Participant E described onset of symptoms beginning shortly before she graduated high school, and described exacerbation and experiencing her first full manic episode at age 17 while at college in a different state.

...just from the stress of graduating and leaving the state that I was used to just triggered it [EOBD]. And all that stress and smoking was just too much for my body and it was just like [pause] it just triggered it.

Participant C stated she became a mother at age 15. Participant C described her pregnancy and motherhood as a significant life change and additional challenge in managing EOBD:

I mean, it's a lot of [pause] you've got a lot of responsibilities once a child is born and you've got to really step up your game. When the baby is awake and hungry you need to go feed the baby, otherwise you're just neglecting a child. And it was a real big struggle for me. It's not my intention to neglect my son but it was really hard for me to just fight [depression] and not get frustrated and get mad at my son and especially with his age and so I was really trying to struggle with being a mom and going through post-partum depression is the depression I've always had anyway...

Impact on Identity

A fourth theme identified by participants was the impact that EOBD had on their identity. Participants described an experience in which the process of normative adolescent cognitive, moral, and psychosocial identity development was altered due to the impact and implications of EOBD on their identity and sense of self. Participants described sub-themes of secrecy and selective disclosure of illness, difficulty trusting self, maintaining sense of self, and integration of illness into identity.

Secrecy and selective disclosure of illness. Participants described a sense of secrecy associated with ‘hiding’ not only the illness but a portion of their identity from others. Secrecy was described in conjunction with isolation and disclosure of illness, but also with self-protection and vulnerability—that with EOBD the participants now had a defective portion of their identity that needed to be hidden.

While Participant F described disclosing EOBD diagnosis to those she trusted, she described hiding the onset of symptoms from those she did not trust:

I don't think [they knew], of my high school friends. I don't think they ever had any idea because I pretty much hid it from people that I wasn't comfortable talking about it with.

Participants additionally described secrecy as related to judgment and fear of others finding out. Participant C described hiding symptoms out of fear of judgment and rejection:

A lot of people—I never tried to show the symptoms to people that I feel like they might judge me [pause] But basically I've always been afraid to be judged.

Participant E further described bipolar disorder as “very, very private” and described her efforts to prevent others from finding out:

I've always kept my mental health apart from everything else. I will seek a psychiatrist or a therapist somewhere super far away, like one I went to in [city], they were an hour and a half away where I knew nobody would see me. And I would pick up my medicine at a drugstore or a pharmacy super far away where the chances or odds of me running into somebody I know is very slim. I think that has a lot to do with the fact that I don't want anybody to know...Even now I will go somewhere that's a little bit further just for the sake of not running into anybody I know, or not having anybody know me. Seriously. It's very, very private.

Related to participants' description of secrecy was their discussion of disclosure of illness. While some participants described open disclosure of illness, those who

strongly endorsed secrecy described selectively disclosing EOBD to others. Selective disclosure was described as a means to maintain secrecy.

Participant A stated that at the time of interview, she had never disclosed EOBD diagnosis to her siblings:

I actually have never told my siblings that I have been diagnosed with bipolar disorder just because I don't really trust them to understand so they just think that I have depression.

Participant E described a very selective pattern of disclosure, stating that she told few of EOBD diagnosis:

So no, I didn't tell my friends, and 'til today I only think maybe two of my ex-boyfriends know [and] one of my other friends. Not a lot of people know. Like I haven't told that many people, actually. So no, they don't know.

Participants also described selective disclosure of illness by family members. Participant F stated she and her family have not disclosed or discussed bipolar disorder diagnosis with extended family:

Not anyone in my family besides my parents knows, just because we have a very bizarre family dynamic and it would just—it just doesn't feel like the time or the space to let them know about it.

In contrast, participants described a more open disclosure of illness with those they associated with lower risk of judgment and rejection.

Participant F described disclosing her symptoms to her parents in adolescence, and described an open disclosure with friends to her:

Probably over 20 [people know]—most of the people I'm friends with know about it. Especially because—I'm an only child, so I'm pretty good at being independent, and I don't mind being alone—but I'm really open when I'm a depressive or manic state, that I need to be around other

people. So I feel like I just let people know. Like all my roommates have always known. Pretty much everyone close to me has always known.

Participant C described open disclosure with her fiancé:

But when I comes to my fiancé now, I'll let everything shine through. He's seen everything.

Participant H described an open pattern of disclosure of illness beginning in adolescence:

I'd say ages 13 to 17, I would disclose—it was my choice to disclose it to people, if I felt I could trust you I would disclose it to you. From ages 18 to now, 23, I feel like I would tell pretty much anyone as long as they weren't malicious about it. And I don't bring it up, but if someone asks or if it's relevant I might tell them.

Adaptation and integration. Participants described the sub-theme of adaptation to EOBD as part of their identity, including preserving portions of their sense of self while integrating the illness.

Participants described maintaining or exceeding levels of functioning throughout adolescence while experiencing EOBD symptomatology. Participants primarily referred to maintaining academic functioning.

Participant F described depressive symptoms as a “really big problem” her senior year of high school, yet she performed well academically and was accepted to college. Similarly,

Participant B described maintaining her academic performance through use of coping skills:

Participant C described experiencing significant sedation from psychotropic medication during high school, but described continuing to pass her classes:

I would sleep all the time in class, but mostly due to the medications I was on. I think the biggest one that took effect was Seroquel, and basically I wasn't awake at all at any time of day. And that really kind of ticked my parents off that I was sleeping all the time, and they get calls that I'm sleeping in the class. But I was still passing my classes, but to this day I

don't even know how. I would do all the tests, I would do everything. It's almost as if I learned in my sleep.

Participants described efforts to maintain sense of self and integrate EOBD as disruptive and a struggle. Participant F described struggling with identity throughout adolescence due to EOBD:

I struggled with self-identity and self-image for a pretty long time in middle school. So when I was 12 to about 16, I feel like I kind of got the hang of who I was. And I've pretty much had the same self-identity since being 16, but it was—yeah, it definitely just disrupted my self-worth and who I thought I was for a long time.

Participant E described adaptation and integration of EOBD as her greatest challenge during adolescence:

I think my biggest challenge [during adolescence] was really just accepting this [EOBD] and honestly figuring out how to make this fit with my life, and how to still enjoy life and explore it, as well as live with it responsibly and not have another breakdown. So that was my biggest challenge, just trying to enjoy life. And that was my biggest challenge then.

While some participants described achieving a sense of self, others described a loss of self due to the presence and impact of EOBD.

Participant G described feeling as if she lost identity with the onset of symptoms:

Before I was able to be friends with everybody. I was doing good [sic] in school. I went to school every day. I was getting along with all my friends and teachers and all my siblings. But after a while depression started to set in and I didn't feel like doing anything anymore. I felt like I lost who I was before, and things started to change around me. And I started to push everybody away and was more aggravated when people tried to talk to me.

Participant C described the process of searching how to find a sense of self:

Basically I had a hard time trying to figure out who I was. I was changing myself a lot, whether it was like a physical appearance or I was changing my attitude toward a lot of things. Every single time. I didn't know basically who I was. I didn't know how to define myself because I couldn't be true [pause] I mean, I was around a bunch of people all the time—I was around my parents, I was around people at school [pause] I mean, I was afraid that when I found my true self nobody was going to like me.

Emotional adjustment. All eight participants described experiencing an internal struggle and emotional adjustment to receiving the diagnosis of EOBD and throughout course of illness. Emotional adjustment included participants' emotional reactions to the illness itself as well as fear related to what the illness meant for their lives and what it represented in terms of their identities. Participants described feeling out of control, having difficulty trusting their own thoughts and emotions, and fear of EOBD.

Emotional response to illness. All participants described experiencing strong emotional responses to the EOBD diagnosis and symptoms as well as to the implications EOBD had for their identity.

Participants A and D described EOBD as fear provoking. Participant D also described experiencing confusion and sadness:

It was confusing and kind of heartbreaking. Especially the prognosis. Being told by a psychiatrist you're going to have to take meds your whole life. And you might die. They're both kind of scary.

Participant E described feeling frustrated and blaming herself for what she perceived as a “flaw”:

It [receiving the EOBD diagnosis] kind of made me frustrated, because it was just like, damn I have a flaw now. That's what it was like. I was upset. That made me feel kind of weak, because I was upset that I could let something like that happen even though obviously you know it's genetic,

and sometimes different environments and stuff like that [pause] but I was kind of upset that it happened to me. But I was kind of like, 'well it is what it is.'

Feeling out of control. Five participants further described a sense of feeling out of control and a fear of losing control over their thoughts, emotions, behaviors, and their lives due to EOBD. Participants described feeling that EOBD was in control or worrying that the course of illness would take control over their lives, and expressed a fear of losing their identities and autonomy in the future.

Participant A described feeling out of control over her emotions:

I think that it [EOBD] meant that I was basically just emotionally unstable and that I like wasn't able to have control over any of my emotions and that I was just constantly fluctuating between extreme emotional states.

Difficulty trusting self. Participants ultimately described the result of fear and feeling out of control in terms of distinguishing normative and authentic thoughts, emotions, and perceptions from symptomatic experiences. Participants described difficulty trusting themselves and differentiating their identity from EOBD symptoms.

Participant A similarly described the inclination to merge her identity with symptoms:

Feeling like if I just started getting into a mindset that was depressed I would immediately—and this might be part of the symptoms of depression—would immediately think that I was worthless or that I was letting the disorder control me. I think that's definitely a huge piece. And there's been other times where I join a bunch of activities or connect to a lot of things and people tell me that I'm overcommitting myself and that I'm crazy and that I do too much, to which I usually respond 'yeah you're right. I'm clinically insane.' Which is not true. But I do sometimes identify myself as being those things when other people point out my abnormal behaviors.

Participant E described the process of differentiating between bipolar symptoms and normative emotional and situational responses:

And even if, let's say I go through something today, and I'm crying. And I'm just like 'why am I crying so much? Like, obviously maybe I need to take more medicine,' or something. And sometimes I don't give myself the credit I need. Like maybe I'm crying because I really am going through something and I need to let out these tears. Because crying is an emotion that every human has the right to feel. So something I think that I've just desensitized my emotions [pause] and sometimes I think I've given too much power to being bipolar and saying like 'the reason I feel this way is because I'm bipolar so I need to try to get this under control. I don't need to cry because maybe I'm overreacting.' So I think that I do it to myself sometimes subconsciously and I don't realize it. And then I have to go back and think about it and say 'okay, maybe I was feeling that way on purpose.' So it's a constant battle and I think I'll probably face that for the rest of my life [pause] knowing when it is my disorder and knowing when it is "normal." Whatever normal is.

Experience of Stigma and Labeling

All eight participants described stigma, self-stigma, and labeling as part of their experience of EOBD. Participants described stigma concurrent to diagnostic labeling within the healthcare system, as well as through family and peer relationships. Participants described stigma occurring in the absence of knowledge and understanding of illness, while having significant implications for identity development. Participants described internalizing stigma and diagnostic labeling, as well as efforts to challenge and reject stigmatizing messages.

Notably, each participant used the word 'crazy' multiple times throughout their interview across all themes in reference to themselves as well as symptomatic states. Six participants used the word 'crazy' as a component of stigma and three participants referred to themselves as 'crazy' when describing self-labeling and internalizing stigma

Labeling. All eight participants described experiencing stigma beginning at diagnosis and continuing throughout adolescence. Participants described family, peers, community, and the healthcare system as sources of stigma. Participants described stigma as unrelated to knowledge of illness, stating that stigmatizing beliefs occurred even in individuals who possessed knowledge of EOBD. Participants described an awareness that stigma associated with EOBD could be used against them to discredit them and devalue them.

Participant E described stigma as isolating and addressed the importance of addressing stigma through psychoeducation:

I think mental illness is something that is very stigmatized and very much needs to be talked about...The way I look at it is that I don't think that mental illness is fairly treated compared to other diseases...when it comes to something like mental illness, it's like "Ewww, that crazy person! I hope it's not schizophrenia and I hope they're not trying to kill me!"...So just because it's not physical, I think that people should understand mental illness and stuff that you can feel, that's emotional, should receive just as much attention and just as much, you know, praise and recognition to help people to get through it as other illnesses and diseases do. So I think stigma is definitely something that isolates people.

As previously introduced, Participant B sought help and support from friends and church leaders due to emerging EOBD symptoms. Participant B described experiencing stigma rather than support:

I did try telling several friends and leaders in my life, and a lot of them just had their own opinions so I got different reactions. Like some people saying 'you're going to be healed; you just need to pray it away' to people giving me advice that wasn't needed, I guess. And I had people try to diagnose me—like I had a person say 'oh you're schizophrenic, you're probably not just bipolar.' Just people thinking you're crazy, you're crazy. Not even understanding the disorder.

Participants described an association between stigma, secrecy, and selective disclosure. Participants specifically mentioned incorporating secrecy and selective disclosure of illness, as described earlier, to avoid experiencing discrimination and devaluation associated with stigma.

Participant A described being “undercover” to minimize her experience of stigma:

I feel the effects of stigma when I overhear people talking about people with mental illness and how difficult it is to interact with people who have mental illness so I feel like when I’m undercover and people don’t know, then I feel kind of stigmatized. But not like people directly telling me how they think bipolar disorder is after revealing that I have it.

Self-labeling. In addition to experiencing devaluation and discrimination from others, seven participants described internalizing stigmatizing messages that resulted in self-judgment and self-criticism.

Participant C described the process of internalizing stigma:

...they would say stuff like ‘bipolar people just are very, just like, they need medication and their emotions are completely out of whack.’ And I started to believe that kind of stigma of ‘oh, you’re emotions are just out of whack,’ and I started to believe that’s actually okay for emotions to be out of whack, because I had bipolar disorder. I was like ‘well I have this excuse to be moody anytime I want just because I’m diagnosed with bipolar disorder.’ And it allowed me to get frustrated over anything.

Participants additionally described an association between self-stigma, sense of self, and symptomatic improvement. Participant A described self-stigma as having a negative impact on symptomatic functioning:

...it’s got to be true that experiencing stigma worsens symptoms. Certainly identifying myself as crazy was not helpful in trying to recover. And also trying to think that—well, buying into stigma puts you in a deeper hole in trying to recover and trying to see that you can be something other than an image, to something other than an unstable kind of person. Um, yeah I think that stigma just makes it harder to change, so that would make the symptoms harder.

Challenging labeling. Five participants described efforts to challenge or reject stigma and self-stigma. Participants described their resistance toward stigmatizing beliefs as an ongoing struggle. Participants described challenging labeling and stigma from external sources such as community, social media, and peers; however, diagnostic labeling and stigma from the healthcare system were not mentioned.

Participant H described accepting EOBD while not defining himself by the illness:

I tried really hard not to identify myself as bipolar, but just to have it be a part of me but not who I am, if that makes sense.

Participant E described used the Olympics as an analogy when describing her efforts to challenge stigma:

I feel like obviously life is a race. Everybody's competing for something. Whether it's a good job, or finding love and getting married and having kids--everybody's competing for something. And it's funny that the Olympics are on right now, because I compare it to the Olympics or a race. And I say that I don't feel like I'm in like the Special Olympics for people who have a mental disorder. I don't put myself in that category of saying that I'm different from other people. I've always looked at myself like I'm still the exact same, like I'm still the same person. And I'm gonna finish this race and win and beat everybody else, and be in the normal race, and not put myself in a special race. So I kind of gave myself strength in not making myself seem different from other people, but finding people that were doing normal things and living their life, and I just— you know, you just change and adapt to it.

Presentation of Themes According to Research Questions

The phenomenology of EOBD is additionally presented as thematic responses to study research questions. While the research questions were developed to elicit participants' experiences of distinct components of EOBD as identified by theoretical framework and the literature review, analysis of findings revealed that the phenomenology of EOBD consisted

instead of an interconnected web of themes as illustrated in Figure 1. Participants did not experience EOBD, relationships, identity development, or labeling independently, but rather in a combined pattern that was consistent across all participants.

For each research question, themes and subthemes endorsed by five or more participants are presented as representative of the sample and overall experience of EOBD. Table 7 displays the themes and sub-themes characterizing participants' experience of EOBD as organized by research question.

Research Question 1: How do emerging adults describe the experience of EOBD during adolescence in terms of experience of symptoms; changes in individual, social, and family functioning caused by course of illness; and the experience and perception of stigma and self-stigma? Participants described their experience of EOBD across five themes: managing and coping with EOBD; effect on relationships, change and uncertainty; impact on identity; and experience of labeling.

Managing and coping with EOBD. Participants described their experiences of the illness itself. All eight participants described experiencing both manic and depressive symptoms. While seven participants described experiencing comorbid symptoms such as anxiety self-injury, eating disorders, and ADHD, only four endorsed comorbid symptoms in response to the first research question. Six participants described their experience with utilizing treatment and accessing the healthcare system, including psychiatric and therapeutic services, psychotropic medication, and provision of psychoeducation. Five participants described their own denial of illness as well as their family members' denial of EOBD diagnosis. Participants unanimously endorsed a pervasive lack of knowledge and understanding of EOBD—acknowledging their own confusion and lack of psychoeducation at onset of illness as well as deficits in knowledge and

Table 7. Presentation of Themes According to Research Question

Research Question	Themes	Sub-themes
1) How do emerging adults (ages 18-25) describe the experience of EOBD during adolescence (ages 13-17) in terms of experience of symptoms; changes in individual, social, and family functioning caused by course of illness; and the experience and perception of stigma and self-stigma?	Managing & Coping with EOBD	Experience of illness
		Treatment and engagement with healthcare system
		Knowledge and understanding of illness
		Seeking and receiving support
		Change in illness
2) How do emerging adults (ages 18-25) characterize the cumulative influence of interactions with healthcare systems and treatment interventions on their experience of EOBD?	Managing & Coping with EOBD	Emotional adjustment
		Labeling
		Experience of Illness
		Treatment and engagement with healthcare system
		Perceptions of healthcare and treatment
3) What are the characteristics of the relationship between EOBD, social and family relationships and the developmental transition to adulthood according to emerging adults?	Managing & Coping with EOBD	Knowledge & understanding of illness
		Use of coping skills
		Difficulty maintaining social functioning
		Seeking & receiving support
		Changes in relationships
4) How have stigma and self-stigma associated with EOBD affected the social, emotional, and cognitive development of emerging adults ages 18-25?	Managing & Coping with EOBD	Adaptation & integration
		Secrecy & Selective Disclosure of Illness
		Knowledge & understanding of illness
		Difficulty maintaining social functioning
		Change in identity
	Experience of Stigma and Labeling	Labeling
		Self-labeling

understanding from family, peers, and healthcare providers. Five participants described attaining an understanding of EOBD throughout adolescence as well as treatment by healthcare providers with knowledge of EOBD; however, participants described denial of illness persisting despite psychoeducation and knowledge of EOBD.

Effect on relationships. Five participants described seeking help and support in response to EOBD symptoms from family and peers. Five participants described experiencing support during adolescence, while four participants endorsed experiencing isolation and difficulty maintaining social relationships.

Change and uncertainty. Six participants characterized their experience of EOBD as a prolonged series of changes between symptomatic states. Participants described a lack of predictability and certainty in the duration and frequency of symptomatic episodes, time between episodes, and the nature of symptomatic episodes.

Impact on identity. Seven participants described experiencing an emotional response to receiving the EOBD diagnosis and to EOBD symptoms throughout adolescence. Participants described experiencing a wide range of emotions such as sadness, blame, anger, and fear, as well as feeling out of control over the illness and subsequently having difficulty differentiating between their sense of self and EOBD.

Experience of stigma and labeling. Participants unanimously described experiencing labeling and stigma associated with EOBD; this occurred in the form of diagnostic labeling as well as devaluation and discrimination from others associated with stigma.

Research Question 2: How do emerging adults characterize the cumulative influence of interactions with healthcare systems and treatment interventions on their experience of EOBD? All eight participants characterized the influence of healthcare and treatment with one

theme: managing and coping with EOBD. Participants described three sub-themes: experience of illness; treatment and engagement with the healthcare system, and perceptions of healthcare and treatment.

Five participants described their experiences of manic, depressive, and comorbid symptoms as a part of their experience with the healthcare system. All eight participants described accessing various levels and types of healthcare and treatment interventions for EOBD. Seven participants were prescribed psychotropic medication for EOBD during adolescence. Participants described beneficial aspects of medication, such as alleviating symptoms; as well as non-beneficial aspects such as exacerbating symptoms and disruptive or unpleasant side effects. Six participants described their perception of healthcare and treatment as beneficial, referring specifically to psychotropic medications that were considered effective and healthcare providers who were knowledgeable of EOBD. Six participants described their experience of healthcare and treatment as non-beneficial referring to medications that were ineffective, psychiatric hospitalization, and healthcare providers who did not understand EOBD. Four participants described healthcare and treatment of EOBD as both beneficial and non-beneficial; these participants described choosing to continue aspects of treatment that were effective (i.e., medication) while modifying or discontinuing aspects of treatment that were ineffective (i.e., changing providers). Participants' perceptions of healthcare influenced their decisions to maintain or avoid treatment for EOBD.s' experiences.

Research Question 3: What are the characteristics of the relationship between EOBD, social and family relationships and the developmental transition to adulthood according to emerging adults? Participants described the relationship between EOBD and

interpersonal relationships across four themes: managing and coping with EOBD; effect on relationships; change and uncertainty; and impact on identity.

Managing and coping with EOBD. Participants identified knowledge and understanding of EOBD as an important factor in interpersonal relationships throughout adolescence. All eight participants described feeling that their interpersonal relationships were affected by their own limited knowledge of EOBD and the lack of knowledge and understanding of EOBD by family members and peers. Three participants described denial of illness within their support system. Two participants described feeling that their family or peers understood their experience with EOBD during adolescence. Participants differentiated between knowledge of illness and support; and as discussed below, participants described feeling support from family and peers who did not understand EOBD. Five participants described employing the use of coping skills in the absence of direction and understanding of their support system.

Effect on relationships. While all participants described their interpersonal relationships as lacking knowledge and understanding of EOBD, each participant also endorsed receiving support from family and peers during adolescence. While this may appear paradoxical, participants indicated collectively that their family and friends often did not understand EOBD symptoms or course of illness yet remained largely supportive and helped to the best of their abilities. Two participants described a lack of support from family with greater support from peers and friends.

All participants additionally described experiencing difficulty in interpersonal relationships. Six participants described difficulty making and maintaining friendships and experienced relationships as a stressor, while four participants described experiencing isolation and avoidance of those who they felt did not support them.

Impact on identity. Six participants described EOBD as significantly impacting their identity and developmental transition into adulthood. Five participants described EOBD as a barrier and obstacle in interpersonal relationships and goal attainment throughout adolescence.

Change and uncertainty. Participants characterized their experience of EOBD and interpersonal relationships in terms of change. Participants described a bidirectional pattern in which changes and conflict in relationships were described as catalysts for changes in illness, as well as byproducts of changes in illness. All eight participants described changes occurring in interpersonal relationships as a mixture of normative adolescent life changes and changes occurring due to the onset of EOBD and course of illness. Five participants stated that their relationships did not change following EOBD diagnosis, as the changes had previously occurred intrinsically along with the onset of EOBD. Three participants described experiencing changes in symptoms associated with changes in relationships, such as increases in isolation and conflict as symptoms increase in severity.

Research Question 4: How have stigma and self-stigma associated with EOBD affected the social, emotional, and cognitive development of emerging adults ages 18-25?

Participants described their experience with stigma and EOBD across four themes: managing and coping with EOBD, effect on relationships, change and uncertainty; and experience of stigma and labeling.

Managing and coping with EOBD. Four participants associated lack of knowledge of EOBD and understanding of the adolescence experience with stigma and self-stigma, and stated a need for psychoeducation. However, two participants described experiencing stigma and labeling from healthcare providers and others who did possess knowledge of EOBD. Additionally, two participants described experiencing stigma in conjunction with denial of

illness; this included the experience of devaluation discrimination due to EOBD associated with cultural beliefs.

Effect on relationships. Six participants described difficulty maintaining social functioning due to stigma and self-stigma. Of the six participants, three described difficulty making and maintaining relationships, while three described isolating themselves from others in efforts to avoid judgment, rejection, and stigma.

Change and uncertainty. Six participants described experiencing change in identity associated with stigma and self-stigma. Four participants described experiencing a change in sense of self and viewing themselves as different or defective due to stigma associated with EOBD. Two participants described experiencing changes in thought, perspective, and behavior associated with internalizing stigma, such as choosing not to pursue goals and having a foreshortened sense of future.

Additionally, participants moderately endorsed experiencing a change in illness associated with labeling. Four participants described increases in depressive symptoms, isolation, and anxiety in response to experiencing and internalizing stigma.

Impact on identity. Four participants moderately endorsed stigma and self-stigma as affecting their identity and sense of self. Three participants described having difficulty trusting their own thoughts, emotions, reactions, and reality-testing in response to exposure to stigma, and described difficulty differentiating between EOBD and their own identities. One participant described internalizing stigma and feeling out of control over the illness and herself.

Labeling. All eight participants described experiencing diagnostic labeling and stigma; and six participants described internalizing stigma and endorsing labeling (i.e., “I am bipolar”).

All participants described experiencing devaluation and discrimination from family, peers, society, and healthcare associated with stigma and EOBD.

Summary of findings. Study findings are presented here in two parts. First, the composite textural-structural description of participants' experience is presented as the phenomenology of EOBD. Second, findings are presented in accordance with study research questions. Participants described EOBD as an interconnected experience in which symptomatology, interpersonal relationships, identity, and stigma were changing singularly and in multi-directional relationships; and ultimately, the interaction between EOBD and normative adolescent developmental processes.

Chapter 5: Discussion

In this chapter, study findings are reviewed concurrent to the study's theoretical framework, research questions, and the existing knowledge base as presented in Chapter 2.

The purpose of this study was to increase understanding of the experience of early-onset bipolar disorder (EOBD). To explore the lived experience of EOBD, the study employed a transcendental phenomenological design constructed around two questions: a) what is the essence of the experience of the phenomenon; and b) in what context(s) did the experience occur (Moustakas, 1994)? Semi-structured interviews were conducted with eight participants ages 18 – 25 who received a diagnosis of EOBD during adolescence (between ages 13 – 17). Interviews collected retrospective data regarding their experience of EOBD. While not built into the study design or research questions, participants discussed elements of their current experience of bipolar disorder in emerging adulthood during the course of their interviews. As previously indicated, this data was also transcribed and analyzed as a separate theme, emerging adulthood; and is included in a companion volume to this manuscript.

As previously discussed, analysis of participant data identified five themes of participants' experience of EOBD during adolescence: managing and coping with EOBD; effect on relationships; impact on identity development; experience of stigma and labeling; and change and uncertainty. These five themes and fifteen sub-themes were constructed and synthesized from raw codes and code families using ATLAS.ti output. Together, these five themes create the participants' collective lived experience of EOBD during adolescence: a period in which participants struggled to balance normative development with onset of illness, inception of

stigma, and changes in sense of self and interpersonal relationships. Each of the five themes was endorsed by all eight participants, indicating saturation of data.

While thematic findings of participants' experiences of bipolar disorder during emerging adulthood fall outside the scope of this study, the researcher has maintained the data due to its value and potential for inclusion in additional research.

Integration of Theoretical Framework and the Phenomenology of EOBD

The phenomenology of EOBD is supported by a multi-theoretical framework consisting of neurobiological theories, modified labeling theory, and theory of emerging adulthood. Integration of these theories provided a comprehensive perspective that was endorsed by participant data and study findings.

Neurobiological theories. Neurobiological theories provide etiological and biological explanations for the onset of EOBD symptoms and course of illness. Participants described their experiences of the illness, including age of onset of symptoms; age of diagnosis; manic and depressive symptoms; suicidality; length, duration, and frequency of episodes, and longitudinal course of illness. Five participants described a progression of illness that included onset of depressive symptoms and diagnosis of depression in early adolescence (ages 12-14), with onset of manic or hypomanic symptoms and diagnosis of EOBD between ages 14-17.

Seven participants described experiencing comorbid symptoms such as anxiety, self-injury, ADHD, and eating disorders. All participants viewed EOBD as a byproduct of neurotransmitter dysregulation ("a chemical imbalance") consisting of fluctuations in mood, energy, and emotion. Participants' understanding of basic components of neurobiological theories of EOBD appeared to serve as a foundation for understanding and treating the illness.

While causal explanations, genetic considerations, and etiology of EOBD were not addressed in interview questions, three participants reported presence of mental illness such as bipolar disorder and depression in first-degree relatives.

Modified labeling theory. Modified labeling theory explains the inception of stigma as an interactive process in which behaviors and beliefs associated with diagnostic labels are internalized. Individuals with the illness adopt behaviors associated with illness and impairment, while individuals without the illness adopt behaviors associated with discrimination and devaluation.

Participants' experience of EOBD reflected a pattern of labeling, stigma, and self-stigma consistent with modified labeling theory. All participants described experiencing discrimination and devaluation associated with EOBD labeling through interaction with interpersonal relationships (i.e., family and peers), society, and exchanges with the healthcare system and healthcare providers.

Seven out of eight participants described internalizing beliefs and behaviors associated with illness in the form of self-labeling and endorsing stigma. Participants described self-labeling as a process originating with reception of stigma; and additionally described self-labeling in conjunction with changes in identity (viewing self as different or defective) and interpersonal relationships (isolation and secrecy), as well as fear of judgment.

Theory of emerging adulthood. All eight participants described changes in their experience of bipolar disorder occurring as they transitioned into emerging adulthood. Within the theme of emerging adulthood, focusing on self and self-sufficiency was endorsed by all participants. Consistent with Arnett (2006a), all participants described experiencing changes in work, relationships, and behavior patterns that focused on increasing independence and self-

sufficiency. Participants described attaining an increase in knowledge of bipolar disorder and how to manage the symptoms to improve course of illness. Consistent with Arnett (2006b), each participant described experiencing varying degrees of recurrent symptomatology while experiencing increased self-esteem and sense of well-being. Participants described feeling empowered with greater ability to initiate life changes such as seeking out support and pursuing life goals. Participants' focus on self and self-sufficiency appeared as a contrast to descriptions of feeling out of control and confused during adolescence.

Four participants additionally described increased interest in enacting systemic change to improve the experience of bipolar disorder for others. These participants explained their interest in this study as prompted by their hope of participating in a movement for change. Participants described the need for increased understanding of EOBD and the adolescence experience to improve healthcare and treatment interventions.

Participants described additional changes occurring in emerging adulthood. All participants described experiencing normative changes associated with adulthood, including moving away from home, attending college, and pursuing a career. One participant strongly endorsed additional changes in identity and identity development occurring in emerging adulthood that included increased confidence and ability to reject stigmatizing messages. While all participants described a change in perspective associated with emerging adulthood, one participant described a sense of optimism "and hope for my adulthood" that they described was not present during their adolescence

Integration of Findings and Knowledge Base

This section compares study findings with the existing literature on EOBD. Study findings relevant to scope of EOBD, adolescent development, interactions with the healthcare system, interpersonal relationships, and stigma are presented.

Scope of EOBD. Participant descriptions of EOBD course of illness were consistent with current knowledge within the literature. Participants described experiencing onset of symptoms between 7 and 17 years of age ($M = 12.88$; $SD = 2.66$) and receiving EOBD diagnosis between ages 13 and 17 ($M = 15.56$; $SD = 1.50$). Five participants described polarity of first episode as depressive, while three participants described polarity of first episode as manic. Participants with manic onset were diagnosed and treated during psychiatric hospitalization and reported no prior symptoms of any kind. Participants with depressive onset describing receiving diagnosis from an outpatient provider and onset of symptoms prior to diagnosis.

Study participants described varying courses of illness, including differing duration and frequency of episodes. Study participants described seeking and receiving treatment within an average of three years of onset of symptoms ($M = 2.69$, $SD = 2.27$), as compared with ten years for adult-onset bipolar disorder (Torrey & Knable, 2002). Several participants reported receiving an initial diagnosis of depressive or anxiety disorder prior to EOBD diagnosis; this is consistent with a progressive onset of bipolar disorder illness in adolescents (Axelson et al., 2011); however due to small sample size no conclusions can be made.

Participants described an overall course of illness in contrast to that of McGorry (2010). Instead of a course of illness consistent with polarity of first episode, participants in this study with manic symptom onset described depressive symptoms as more disruptive to functioning over time; and conversely, several participants who described depressive symptoms at onset

identified manic episodes as more severe. Furthermore, participants did not describe an association between earlier age of diagnosis and improved course of illness.

Consistent with the findings of McMurrich et al. (2012), participants in this study described varying degrees of syndromic, symptomatic, and functional recovery in emerging adulthood (McMurrich et al., 2012). While some participants described an improved course of illness, others described continuing to experience persistent symptoms and challenges in treatment of bipolar disorder.

EOBD and adolescent development. Study participant descriptions of identity and social development between ages 13 – 17 were consistent with cognitive and psychosocial development as established within the literature (Kohlberg, 1963; Piaget, 1964; Steinberg, 2005). Participants in this study described their sense of identity and social functioning as significantly altered, and in some cases impaired, by the presence of EOBD symptomatology as proposed by multiple authors (e.g., Alreja et al., 2009; Birmaher et al., 2006; Miklowitz & Johnson, 2006). Consistent with findings of Farley and Kim-Spoon (2011) and Pederson et al. (2007), study participants described experiencing depressive symptoms in conjunction with peer rejection, isolation, and decreased self-regulation.

EOBD and interaction with the healthcare system.

Psychotropic medication. Consistent with multiple authors (e.g., Cerit et al., 2012; Garnham et al., 2007; Judd et al., 2013), participants in this study described taking psychotropic medication with varying results. While some participants described improvement in course of illness and reduction in symptoms they attributed to medication, other participants described continuing to experience symptomatic and functional impairment despite compliance with prescribed medications.

Therapeutic interactions. As previously stated, participants described responses to therapeutic interventions as both beneficial and non-beneficial. Participants who felt validated and supported by a provider that understood EOBD described a beneficial relationship; while other participants described the therapist as judgmental or lacking knowledge of EOBD and therefore described therapy as non-beneficial. While some participants described an improved sense of well-being, this study did not investigate improvement in treatment outcomes or symptomatology as identified by Miklowitz (2008).

EOBD and interpersonal relationships.

Informal and peer support. Study participants described peer relationships as a core component of their experience of EOBD. Participants described social functioning as influential to symptomatic functioning; and additionally described social relationship as impacted by EOBD symptomatology. The impact of peer and community support on empowerment, and role in stigma reduction, self-esteem, and risk of relapse (Brown et al., 2008; Corrigan et al., 2012; Davis, Kurzban & Brekke, 2012; Perlick et al., 2004) were not explored by participants; these are discussed as implications for future research, below.

Family support. Participants from the current study described family relationships as part of the construct of interpersonal relationships. As with informal and peer support, dimensions of family support such as family stress and conflict, family cohesion, and family functioning were not explored in relation to influence on EOBD symptomatology. Participant accounts are descriptive and include the meaning associated with family relationships and dynamic.

EOBD and stigma. Participants from the current study described their experiences with diagnostic labeling, stigma, and self-stigma. Consistent with Cerit et al. (2012), study participants described their experience of EOBD as both influencing and influenced by stigma

and self-stigma. As asserted by Crowe et al. (2012), study participants described feeling a loss of control over their lives, self-blame, and viewing ability to manage symptoms as part of their sense of self; .

Results are additionally consistent with findings by Moses (2009) and Camp, Finlay, and Lyons (2002). Participants in this study described experiencing rejection and difficulties in social functioning associated with stigma. In describing their efforts to reduce the impact of stigma, participants described adopting patterns of avoidance coping, including secrecy, isolation, and selective disclosure of illness.

Implications for Social Work Practice

The healthcare system is a gatekeeper for adolescents with EOBD. Providers assess and generate EOBD diagnoses and provide treatment. As the course of illness is indefinite and requires lifelong care, the role of healthcare remains pivotal throughout the lifespan in mediating the course of bipolar disorder. However, the healthcare system is often the site of origin of labeling and stigma, and therefore carries important implications for identity development and social functioning across the lifespan as well. Social workers are present throughout medical and mental healthcare settings, and therefore have a unique influence over the range of treatment for EOBD.

Lack of knowledge and understanding of EOBD emerged as the most frequently occurring invariant constituent (code) across all participants' experience of EOBD. Participants described lack of knowledge and understanding as a determinant in whether healthcare was beneficial, as influential within interpersonal relationships, and as a buffer against stigma and self-stigma. This carries powerful implications for providers; increasing individual and family

psychoeducation as well as provider education would greatly benefit adolescents as well as their support system.

Participants identified labeling and stigma as carrying significant implications for their developing sense of self and social functioning. Providers can minimize diagnostic labeling and inception of stigma through use of a collaborative method with the adolescent and parents that incorporates a strengths-based approach, as compared to traditional deficit-based medical models. Providers can additionally focus on integrating illness management with normative adolescent cognitive, emotional, and identity development. Participants described cognitive reframing—learning to reframe EOBD as an external experience that was not part of their identity and something they could learn to manage—as an important component of recovery, and one which they often accomplished with little support. Some participants additionally described providers as the primary or sole source of support.

The interconnectivity of themes present in participants' experience of EOBD necessitates clinical approaches that address and incorporate each of these themes in treatment approaches. Providing psychiatric treatment and medication without therapeutic treatment is insufficient and does not address the scope and needs of EOBD. Additionally, providing therapeutic services that do not include family or do not address interpersonal functioning or identity development are similarly insufficient. The incorporation of multiple treatment and theoretical frameworks, along with a treatment model that addresses the neurobiological and developmental components of EOBD are needed to accurately and effectively treat EOBD.

As a further consideration, due to the early age of onset many participants did not have a 'before' and 'after' diagnosis that are often incorporated into treatment of adult-onset bipolar disorder when reframing the illness, combating stigma, and preserving a sense of identity.

Instead, participants described one uniform, linear experience in which having bipolar disorder consumes much of their identity—leaving them with little else to identify with.

Finally, participants were eager to be informed of their illness, understand treatment options, and be an active part of treatment decisions; however, participants described being excluded from treatment team and decisions due to their age. Including adolescents in treatment decisions and explaining interventions can increase empowerment. Participants described seeking help upon noticing symptoms and described consistent coping efforts to improve well-being; allowing adolescents a more active role could facilitate greater improvement.

Social Work Education and Policy

According to the National Association of Social Workers and the Council on Social Work Education, social work best practices address the concerns presented above. The NASW Code of Ethics (2008) directs social workers to work with interdisciplinary teams when available (e.g., with healthcare providers such as psychiatrists and therapists), to maintain continuing education, maintain currency with research and emerging knowledge, engage in evidence-based practice, and refer out clients who they lack the specialization to treat. The CSWE Educational Policy and Accreditation Standards (EPAS; 2015) that informs and regulates social work education similarly instructs social workers to employ interdisciplinary knowledge and practice rooted in research and evidence-based practice. Educational content includes psychopathology and practice with individuals and families. Many social workers engage in clinical practice and hold state licenses. Licensure for clinical social work varies by state, but generally requires periodic continuing education and demonstration of advanced clinical skill.

The requirements for social work education, practice, and licensure address psychopathology and clinical practice at a broad level (NASW, 2006). At a micro level, agency

policies may enforce practice standards and require training specific to EOBD. However, the research and knowledge base for EOBD remain limited, and as such social workers' knowledge base and practice abilities are similarly limited. Within the health disciplines, other therapists and psychiatrists similarly may be lacking the specialized knowledge needed to treat EOBD.

The opportunity and responsibility, then, may rest with the production and dissemination of research of EOBD. Increased research and dissemination of findings would increase the availability and exposure of healthcare providers to current and emerging knowledge; which would then be incorporated into practice and improve treatment and care for EOBD. Ultimately, EOBD remains underresearched. This study presents an increased understanding of EOBD with the intent to inform future research, and ultimately direct practice.

Future Research

While previous studies have explored the etiology and treatment options for EOBD, much remains to be known about the impact of illness on developing identity and social functioning. The constructs of stigma and self-stigma in particular emerged from participant data with significant implications for the effects on identity development, social functioning, and inception within the healthcare system.

Stigma, self-stigma, and identity emerged as separate constructs with participants' experiences however, participants frequently identified changes in identity associated with diagnostic labeling, stigma, and self-stigma. Viewing oneself as different or defective has significant implications for social functioning in the form of avoidance coping such as isolation and secrecy. Furthermore, participants described experiencing changes in illness that accompanied stigma, self-stigma, and changes in identity. Cerit et al. (2012) asserted a

bidirectional relationship between stigma and increase in symptomatology in adults with bipolar disorder; however, this remains unexplored in the adolescent population.

Exploration of the influence of stigma in EOBD should include the identification of risk and protective factors for the development of self-stigma. Self-labeling in adolescence is associated with greater social, symptomatic, and functional impairment (Moses, 2009); yet also remains underresearched. Furthermore, participants' additional discussion of emerging adulthood indicated adolescent experiences of stigma and changes in identity and social functioning significantly affected the transition to adulthood. Additional research is needed to identify risk and protective factors as well as the nature of the relationship between diagnostic labeling, stigma, and identity development in EOBD.

Participants described experiencing stigma from within the healthcare system. While discrimination and devaluation associated with stigma are separate constructs than mere diagnostic labeling, participants often discussed them interchangeably. Furthermore, the inception of discrimination and devaluation within the healthcare system is troubling in and of itself, and carries the potential of powerful negative consequences for identity and social development adolescents with EOBD. Research studies of healthcare professionals' perspectives and practices with EOBD population could elicit a better understanding of the process of diagnostic labeling and inception of stigma; and in turn offer implications to improve healthcare services.

Additional prospects for further research that were not explored within this study include outcomes of EOBD on the family system; how social impairment associated with EOBD in turn affects normative adolescent cognitive development; and the concept of resilience in adolescence using ecological systems theory with implications for emerging adulthood . In summary, due to

the exploratory nature of this study and the volume of data collected, there are many avenues for continued research to improve conceptualization and treatment of EOBD.

Strengths and Limitations

Phenomenological study design facilitated exploration of participants' lived experiences. Semi-structured interview format provided participants with the ability to expand upon issues they wanted to emphasize. Data analysis allowed for participants' experiences to be captured authentically in their own wording to obtain the essence of their experiences. Each participant that reviewed his/her their narrative noted the accuracy in how their stories were told, and felt satisfied that they had been heard.

While eight participants yielded saturation of data, a larger sample size of 10 – 15 participants was desired. Challenges in recruitment resulted in a sample generated entirely through online advertising on a support group (DBSA) website and interviews completed via telephone. While it is uncertain if participants would have been as candid and open if the interviews were conducted in person, a face-to-face format would have been preferred.

Additionally, the study's original design included partnering with a clinical agency to serve as a referral source, sample site, and would provide follow-up clinical services to participants if needed. Through the informed consent process, the researcher provided participants with contact information for follow-up care (211), with an emergency plan to call 911 for a welfare check at the address the participant provided at the time of the interview if the participant indicated they were in a clinical crisis. While the interview questions explored participants' lived experience of EOBD, the interviews were equally clinical in nature; and clinical support and follow-up would have been preferred. While calling 911 was not needed, several participants reported being currently or recently depressed at the time of the interviews

and/or became tearful during the interview. The researcher debriefed with each participant briefly following phone interviews; however, an improved research design would coordinate with a clinical site to provide supportive services such as debriefing following interviews.

Furthermore, the study's sampling method and composition resulted in a reliance on retrospective data. While participants' provided experience of EOBD augmented with the perspective and maturity from adulthood, their descriptions of EOBD were less recent. A sample of current adolescents may provide additional or different perspective or information on EOBD.

While not a weakness in phenomenological design, the absence of triangulation to confirm participant EOBD diagnosis is perhaps an approach that could enhance the measurement of EOBD. Use of diagnostic quantitative measures or referral from clinical diagnostician in additional research of EOBD would assist in confirming EOBD diagnosis and maximizing study validity.

The goal of this phenomenological study was to generate an improved understanding of EOBD; and as such, generalizability of findings was not incorporated into the study's design. However, healthcare providers could aim to incorporate study findings into practice that are consistent with the literature and theoretical framework. Such examples include maximizing knowledge of EOBD, familiarity with adolescent developmental considerations, incorporation of support system, and therapeutic interventions to promote healthy sense of self and protect against internalizing stigma.

Conclusion

Current research and clinical knowledge base of EOBD consists primarily of quantitative inquiries of etiology, neurobiology, and pharmacology. First-person qualitative inquiries are absent within the literature; as a result, our knowledge and treatment of EOBD is severely

limited. Current conceptualization and treatment of EOBD consists of extrapolating and translating adult theoretical models to an adolescent population. This study explicates the lived experience of EOBD, bringing to light considerations for treatment and research such as the impact of labeling and stigma, the importance of knowledge and understanding of EOBD in facilitating effective healthcare, and factors affecting adolescent identity development.

Furthermore, participants' retrospective lens provides insights into treatment and experience of bipolar disorder transitioning into emerging adulthood.

Summary

Bipolar disorder occurs in approximately 1% of the population; and while the average age of diagnosis falls between ages 18 and 25, up to 66% of adults report onset of symptoms between ages 13 and 17 (Perlis et al., 2004). Within the last 20 years, the prevalence of bipolar diagnoses and pharmacological treatment for EOBD has increased; yet there is an absence of research into the phenomenology of EOBD.

Collectively, healthcare providers and researchers have largely viewed and treated EOBD by extending and applying conceptualization of adult-onset bipolar disorder—‘from the outside in.’ By exploring and utilizing auto-biographical, retrospective data to construct the phenomenology of EOBD, this research study begins the process of viewing and treating EOBD ‘from the inside out.’ Interviews with young adults who were diagnosed and treated for EOBD during adolescence provide a first-person perspective on not only the experience of the illness itself, but also the experience of labeling and stigma, identity development, interpersonal relationships, mediating factors and life changes, reactions and coping efforts; as well as insights into the transition from adolescence into adulthood.

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Appendix A

Study Research Flyer

Participants Needed – Research Opportunity

The Experience of Early-Onset Bipolar Disorder

Seeking adults ages 18-25 for research study on early-onset bipolar disorder (EOBD).

Eligibility Criteria

Adolescent (age 18 – 25) who received diagnosis of bipolar disorder as an adolescent (age 13 – 17)

Purpose of the Research

Increase our understanding of how early-onset bipolar disorder affects stigma, adolescent sense of self, and social and emotional development

Participants will

Be interviewed 1-2 times via telephone regarding their experiences with the healthcare system, symptoms, family, stigma, and social/personal development

Participants will receive \$20 gift card as compensation

with questions or to participate

CONTACT

Kristin Smyth, LCSW, ABD
Principal Investigator

407.865.2404



Research conducted through the University of South Florida

The Phenomenology of Early-Onset Bipolar Disorder
IRB#: Pro00017907

Appendix B

IRB Approval Letter



RESEARCH INTEGRITY AND COMPLIANCE
 Institutional Review Boards, FWA No. 00001669
 12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
 (813) 974-5638 • FAX (813) 974-7091

December 16, 2014

Kristin Smyth
 School of Social Work
 Tampa, FL 32714

RE: **Expedited Approval for Initial Review**
 IRB#: Pro00017907
 Title: The Phenomenology of Early-Onset Bipolar Disorder

Study Approval Period: 12/15/2014 to 12/15/2015

Dear Ms. Smyth:

On 12/15/2014, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents outlined below.

Approved Item(s):

Protocol Document(s):

[EOBD IRB Protocol](#)

Study involves children and falls under 45 CFR 46.404: Research not involving more than minimal risk.

Consent/Assent Document(s)*:

[Assent Form.pdf.pdf](#)

[SB Combined Parental Permission and Parent.pdf.pdf](#)

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR

56.110. The research proposed in this study is categorized under the following expedited review category:

- (6) Collection of data from voice, video, digital, or image recordings made for research purposes.
- (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kristen Salomon', followed by a horizontal line.

Kristen Salomon, Ph.D., Vice Chairperson
USF Institutional Review Board

Appendix C

IRB Verbal Informed Consent Form

Obtaining Verbal Informed Consent

Researchers at the University of South Florida (USF) study many topics. To do this, we need the help of people who agree to take part in a research study. We are asking you to take part in a research study that is called: The Phenomenology of Early-Onset Bipolar Disorder.

The person who is in charge of this research study is Kristin Smyth. This person is called the Principal Investigator.

You are being asked to participate because you received a diagnosis of bipolar disorder during adolescence (between ages 13 – 17). The purpose of this study is to improve our understanding of the experience of early-onset bipolar disorder.

If you take part in this study, you will be asked to participate in one telephone interview lasting approximately 45 – 60 minutes to discuss aspects of your experience of bipolar disorder as an adolescent. You may be contacted for a follow-up interview to provide clarification or additional information if needed.

You have the alternative to choose not to participate in this research study.

You should only take part in this study if you want to volunteer and should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

For any student participants: Your decision to participate or not to participate will not affect your student status or course grades.

We are unsure if you will receive any benefits by taking part in this research study.

This research is considered to be minimal risk.

Upon completion of your participation in this study via telephone interview, you will receive a \$20 gift card.

We must keep your study records as confidential as possible. We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything

else that would let people know who you are. However, certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator, the Advising Professor, and all other research staff.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.) These include:
 - The University of South Florida Institutional Review Board (IRB) and the staff that work for the IRB. Other individuals who work for USF that provide other kinds of oversight may also need to look at your records.
 - The Department of Health and Human Services (DHHS).

If you have any questions about this study, you can contact the investigator Kristin Smyth [407-865-2404 or kristinsmyth@usf.edu]. If you have question about your rights as a research participant please contact the USF IRB at 813-974-5638.

Would you like to participate in this study? [*PI will record if verbal consent is given*]

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Appendix D

Semi-Structured Interview

Today I'd like to ask you some questions to get a better understanding of your experience as a teenager with bipolar disorder.

- First, how old were you when you were diagnosed with bipolar disorder? How old are you now?
 - What was it like to receive the diagnosis of bipolar disorder? What did the illness mean to you at that time?
 - How would you describe your experience of bipolar symptoms during your teenage years? What were your manic episodes like? Your depressive episodes?
 - Did you feel that other people (friends, family, healthcare providers) understood your experience of bipolar disorder?
- Now I'm going to ask about some of the changes that may have taken place during your teenage years as a result of bipolar disorder.
 - After the onset of bipolar symptoms but prior to diagnosis, do you remember whether any changes occurred in relationships with your family or with friends during this time?
 - After receiving the diagnosis of bipolar disorder, do you remember any changes occurring in relationships with your family or friends during this time?
 - Do you feel that your sense of self (sense of identity) changed due to your experience of bipolar disorder during this time? If so, in what way?
 - Did you feel that you understood the changes in your life that were occurring due to bipolar disorder?
 - How did these changes affect you as you moved from adolescence into young adulthood?
- Now I'm going to ask about how bipolar disorder may have affected you during your teenage years.
 - What were your greatest supports during this time? What were your greatest challenges?
 - Do you feel that you encountered stigma or labeling associated with bipolar disorder during this time? If so, what was that like?

- Did you experience self-stigma, in which you label or judge yourself, during this time? If so, what was that like?
 - Do you feel that any of the changes you experienced in your support system or related to stigma or sense of self had an effect on your bipolar disorder and mental health during this time?
- Now I'm going to ask about your experience with the healthcare system during your teenage years.
 - Who diagnosed you with bipolar disorder? In what treatment setting (inpatient, outpatient)?
 - What events led up to the diagnosis?
 - Did you have a psychiatrist? A therapist? What was your experience with them?
 - Have you ever been hospitalized due to bipolar disorder? If so, what was that like?
 - Were you prescribed medication for bipolar disorder during this time? How would you describe your experience with medication?
 - Did you feel that the treatment you received was helpful? [Whether yes or no:] In what way?
 - Did your experience of bipolar disorder change during or after receiving treatment? If so, in what way?

Appendix E

Codebook

code	family	definition	specifiers	when to use the code	when not to use the code	example quotation
absence of labeling or stigma	labeling	absence of stigma	none	participant reports lack of stigma	do not use if stigma is endorsed	No, not from people close to me.
accessibility or use of healthcare/ treatment	healthcare	accessing/utilizing services; tx services are accessible to participant; <i>includes referrals or facilitation of healthcare use by others</i>	none	use of tx services or ability (tx is available to access)	see inverse: healthcare difficult to navigate	And I was lucky enough to get connected to the campus health system and start receiving treatment again
ambivalence or hesitation toward healthcare/ treatment	healthcare	participant states mixed feelings, indifference, or expressed hesitation toward healthcare services (including medication)	specify if psychotropic medication is source of ambivalence	reflects ambivalence, mixed feelings toward healthcare system or tx of any kind	if referring to withdrawal from tx or avoidance of healthcare, use <u>avoidance of healthcare system</u> or tx	... there's been good things about the medication and there's been bad things about the medication that I did really not sign up for.

avoidance of healthcare system or treatment	healthcare	avoidance of health services & tx (medication, psychiatry, therapist, hospitalization)	specify if psychotropic medication is what participant is avoiding	participant actively avoids or withdraws from tx or services (including psychotropic medication)	if referring to ambivalence or mixed feelings toward healthcare, provider, or tx, use <u>ambivalence or hesitation toward healthcare or tx</u>	And I was diagnosed with depression in 8th grade, but didn't take any antidepressants because I didn't believe in medication, and it was only until I got diagnosed with bipolar disorder when I was 17 that I considered taking medications
challenging or rejecting labeling	labeling	rejecting stigma; refusing to endorse labeling or apply to self as part of identity	none	participant, family, or peers is described as disagreeing with, challenging, or rejecting labeling or stigma associated with illness	do not use if participant endorses stigma or reports stigma	And it's funny that the Olympics are on right now, because I compare it to the Olympics or a race. And I say that I don't feel like I'm in like the Special Olympics for people who that have a mental disorder. I don't put myself in that category of saying that I'm different from other people.
change in illness	experience of illness	refers to change in symptomatic state; includes succession of symptoms or change in episodic mood states; increase or decrease in state of illness (symptoms); includes recovery/remission and recurrence of symptoms; note: if participant describes change in illness and identifies cause/trigger (i.e., relationships, stigma),	none	description is of the progression or succession of symptomatic/episodic states (stages) of illness (i.e., symptoms improving or worsening); includes participant description of cycling or changing between mood states	if referring to concurrent presence of non-bipolar symptoms, use comorbid symptoms/diagnoses	I experienced depression for weeks at a time. It would come and go. And then I have moments of anxiety, aggravation, and irritability. And I was really becoming passive-aggressive towards everybody around me.

		code both 'change in illness' and the identified trigger				
changes in decision-making	impact on identity	changes in focus, thought and behavior patterns before age 18	none	description of changes in perspective; can refer to maturity or growth	if code applies to experience over age 17, use EA version of code	I got into really bad habits. I started drinking at parties, and smoking, and getting into a lot of bad habits and getting in trouble a lot. And I felt like before the diagnosis I had good grades and everything, and then it all started to decline rapidly.
changes occurring in relationships	Interpersonal relationships	changes in structure or content of interpersonal relationships; can be positive, neutral, or negative; includes family and peers; can be attributed to symptoms or illness	specify peer or family relationships (or other)	participant is describing changes that have occurred with/among family members or peers; i.e., family members moving away	inverse: no change in relationships; if referring to participant's difficulty functioning socially, use 'social impairment'	But as far as family goes...yeah, my parents definitely treated me differently from after I got diagnosed.

comorbid symptoms / diagnoses	experience of illness	symptoms that are not bipolar (i.e., substance abuse, anxiety, self- injury); participant report of experiencing multiple symptomatology (bipolar + other); emphasis is on <u>concurrent</u> symptom states or presence of <u>non-bipolar symptoms</u>	none	participant refers to experiencing other mental health symptoms outside the scope of bipolar disorder (past or present);	do not use with bipolar symptoms; change in illness reflects <u>successive</u> change in symptomatic states (not concurrent symptoms)	So before I hallucinated, I remember we were watching a video on YouTube or something and I had a panic attack, and I couldn't breathe or anything, and I was like 'yo what is going on, like I just can't breathe.' And so anxiety is also something that goes along with a lot of disorders. Like literally, a panic attack.
denial of illness	reactions & coping	denial of illness; resistance to diagnosis (by participant, family, peers)	specify participant, family, peers, or other	description of denying, sublimating presence of illness (presence, symptoms, course of illness)	for avoidance or resistance to tx, use <u>avoidance of healthcare or tx</u> ; inverse: acceptance of illness	And my mom was also very adamant about the fact that she didn't want to have a child with mental illness, and thought that it would reflect on her as a parent if I did, and so she was also very invested in making sure that she mitigated my symptoms and basically just dismissed them
depressive symptoms	experience of illness	DSM-5 depressive symptoms	none	participant is recounting or describing depressive symptoms	all other symptoms	When I was depressed I remember laying in bed for months just watching tv, um, just showering was hard, anything like that. I played thoughts in my head over and over, like I wasn't good enough, like no one cared about me, and just stuff like that. I would cry a lot, so sometimes I would fall asleep crying and wake up crying.

difficulty in relationships	Interpersonal relationships	social impairment or difficulty functioning in interpersonal relationships; losing friends, inability to make friends, losing family relationships; interpersonal relationships present as significant stressor or challenge	specify participant, family, peers, or other	participant description of difficulty with interpersonal functioning due to symptomatic impairment; description of stress or conflict in interpersonal relationships	if participant is describing changes rather than conflict, use 'changes occurring in relationships'	I lost every single one of my friends in high school. People just saw me as a freak. They didn't like...they didn't like that I was just unstable. And I can see from their point of view. Who wants a friend, you know, who's going through a hard time? and they try to help and nothing they do helps. So basically a lot of friends would give up on me or people would just walk out immediately. They just don't want to deal with it, or they don't like it.
difficulty trusting self	impact on identity	experience of difficulty trusting their own thoughts, emotions, impulses, & reality-testing due to experience of symptoms or illness; related to distinction between self and illness; struggle to distinguish between normative emotions and symptomatic episodes	none	participant describing difficulty distinguishing self/sense of self from symptoms/illness	different from loss of self or loss of identity	let's say me and my boyfriend get into an argument. And I get kind of sad, right? I do sometimes question myself, and I'm like 'am I sad because I have a disorder? Or am I sad because this is how everybody else would be feeling given the circumstance that they had an argument with their boyfriend?
disclosure of illness	Interpersonal relationships	disclosure of illness or openness re: illness/symptoms to others (can be open disclosure in general or referring to a singular disclosure)	none	refers to participant's openness and disclosure of illness	for selective disclosure use ' <u>selective disclosure of illness</u> '	And my parents...I'm pretty open with them so I had talked about it with them pretty early on, so they knew that I was having these really severe bouts of sadness.

effecting greater change (EA)	emerging adulthood	focus or awareness of need for greater change/improvement in society or community; related to activism and advocacy; contributing to others -- after age 18	none	experience occurred age 18+	experience occurred ages 13-17	So it's been a challenge, but that's why I became a social worker, because I want to help other people. And that's what one of my friends says. She's like 'you know social workers...we become something that we didn't have growing up, that we didn't have ourselves. And so that that's what shows us to actually be that person that you wish you would've had. So that is why I'm a social worker. Because there are people out there that go through even worse things, and I'm like 'I'll help them get through it the way I helped myself get through it when I wished I had somebody to help me get through it.'
emotional response to illness	reactions & coping	description of emotional adjustment in response to diagnosis, symptoms, or illness itself; includes confusion, anger, shame, blame, disbelief, shock, sadness	none	description of emotional 'fallout' following symptomatic episode or diagnosis; emotional impact of illness	if participant refers to confusion (not understanding course of illness or situation) 'lack of knowledge/ understanding (confusion)	It kind of made me frustrated, because it was just like, damn I have a flaw now. That's what it was like. I was upset. That made me feel kind of weak, because I was upset that I could let something like that happen even though obviously you know it's genetic, and sometimes different environments and stuff like that...but I was kind of upset that it happened to me.
fear of illness	reactions & coping	expressing fear of illness or symptoms; related to fear of recurrence and fear of losing control over life due to illness	none	expression of fear of the illness itself, including feeling powerless and/or loss of control over self, future, or illness	if code applies to experience over age 17, use an EA code	I do always have this underlying feeling that something will go wrong, like the medication will stop working or something and I'll have to be dealing with it more heavily again. And I'm afraid of that.

feeling out of control	reactions & coping	feeling helpless or powerless; loss of control over life, symptoms, self due to illness; separate from confusion	none	sense of feeling powerless or helpless over life circumstances, self, or future	different from fear of illness--this code specifically addresses currently feeling a loss of control/ autonomy	And because I didn't know what was going on and because I didn't have control over myself I didn't want to hang out with anybody else
focusing on self & self-sufficiency (EA)	emerging adulthood	focus has changed to self and increasing self-sufficiency; changes in perspective on life, work, relationships, behavior patterns after age 18; refers to internal/intrinsic process moving into adulthood	specify if emphasis is on increased knowledge & understanding of illness	refers to change in mentality (maturity), not life changes	do not use code if participant is referring to changes in life circumstances or optimism/ possibility (future)	I felt that maybe it was time for me to focus, to really focus on what I wanted to achieve in life. Focus on my goals.
functioning or excelling despite illness	impact on identity	succeeding and/or maintaining level of functioning (e.g., in school) following onset of symptoms	none	discussing success / continuing functioning despite illness between ages 13-17	Do not use if participant is describing decline in functioning	I managed to keep really good grades
healthcare or treatment is beneficial	healthcare	discussion of experience of healthcare system or treatment interventions & outcomes as positive or beneficial (medication, therapy, psychiatry, hospitals) and/or healthcare providers	specify if participant identifies psychotropic medication or provider	description of healthcare treatment, providers, or services as resulting in positive outcomes	Inverse of healthcare of treatment is not beneficial	I just know that since I started taking the medication my life has improved immensely. And there has not been a point where I have gone off my medication and had issues. So I think that is—that has to be what is helping

healthcare or treatment is not beneficial	healthcare	discussion of experience of healthcare system or treatment interventions & outcomes as ineffective, detrimental, or negative; includes lack of supportive healthcare providers, negative experience with providers/facilities; medication side effects, etc.	specify if participant identifies psychotropic medication or provider	description of tx outcomes, providers, or services as ineffective or negative	Inverse of healthcare or treatment is beneficial	I had been seeing a psychologist earlier in the year who had not been very helpful and I had stopped seeing her.
healthcare system difficult to navigate	healthcare	experience of difficulty trying to find, access, or continue healthcare services	none	cannot find or access tx services (e.g., finances, insurance, healthcare restrictions, etc.)	partial inverse of accessibility or use of healthcare;	And a huge issue at my school is that the whole counseling and psychological services section is not well-funded and does not have many employees, so the wait to get in there is very long. So I saw them for about three months before they told me that I would need to get providers elsewhere. So I got a referral
identity development & exploration (EA)	emerging adulthood	description of identity development/growth and enhanced sense of self after age 18	none	focus is on identity/sense of self & growth	if referring to increased maturity or focus on independence, use focusing on self & self-sufficiency (EA) ; if referring to life changes, use life changes (EA)	Looking back I think I can see how significant those changes were, and how it really pushed me sort of to really develop a new sense of self and how that self has changed since college is also very interesting

identity development (merging old & new identities)	impact on identity	adjustment and adaptation or integration of illness with preexisting sense of self; creating a new normal	none	preserving sense of self while integrating 'new' identity w/ addition of illness	if over 18, use EA code	So previously I think my biggest challenge was really just accepting this and honestly figuring out how to make this fit with my life, and how to still enjoy life and explore it, as well as live with it responsibly and not have another breakdown.
illness as a barrier or obstacle	reactions & coping	illness/symptoms presenting as challenge, barrier, or obstacle toward goals or relationships	none	(life) goals are described as unattainable or difficult to attain due to illness	do not use if barrier is a factor other than illness	I think it was just hard because it added an extra layer of already stressful—because I was diagnosed my senior year, which is such a horrifically stressful year because you are applying to college and figuring out pretty much where the next step of your life was—the fact that I had this mental illness on top of it was just incredibly hard.
illness as a trauma	reactions & coping	experience of illness as traumatizing; lasting impact on identity; related to fear of recurrence	none	description of the experience of the illness (including symptoms and tx) as an actual trauma/traumatizing	does not include other traumatic experiences (use <u>trauma</u> code)	like I was so traumatized the first time that I found out I was bipolar that I never wanted anything like that to ever happen again
isolation or secrecy	Interpersonal relationships	deliberately limiting social contact with family and/or friends; also includes the sense of 'hiding' part of their self or identity from others in terms of vulnerability and self-protection	none	report of literal isolation, seclusion, and/or avoidance of social interaction; includes 'hiding' identity and self due to vulnerability	if referring to hiding illness (selective disclosure), use <u>selective disclosure</u>	So I literally just isolated myself and didn't want to talk to anybody

knowledge & understanding of illness	reactions & coping	knowledge & understanding of EOB; description of attaining/increasing knowledge of symptoms, course of illness; understanding what's going on (specific to experience of the illness itself)	can specify if participant, family, peer, provider	expressing or describing understanding of symptoms, course of illness, or symptoms; can refer to participant, family, peers, healthcare providers etc.	inverse: lack of knowledge or understanding (confusion)	No, I definitely felt like I understood it the whole time. The doctors explained to me what it meant, and I definitely could relate to exactly what they were saying about the symptoms of it, and about what was going on with me. So I could say like, 'yeah that's exactly what's going on with me, so these symptoms and this thing going on in my head, that must be bipolar disorder. That must be what I have,' you know?
labeling or stigma	labeling	description of labeling or stigma associated with bipolar disorder or mental illness; participant may specify source (culture, social/peers, family, healthcare system)	specify source of stigma - family, peer, community, culture, healthcare	participant identifies or describes experience of being labeled or stigmatized	if referring to internalized stigma, use 'self-labeling'	Mental illness is something that's so under-talked about that when you do see it or when you do hear it, nobody knows. Of course what people think they know....do you know what I'm saying? Homeless people are everywhere. So you see mental illness or some type of disorder everywhere. You see [them] there on the street and nobody's helping them. And nobody essentially cares. And even in other countries, if somebody is disabled or disordered or mental, 'oh they're demonic!' or 'oh they're possessed!' Stigma is just everywhere
lack of knowledge or understanding (confusion)	reactions & coping	absence / limited knowledge of illness; description of not understanding or having limited knowledge of symptoms, course of illness and related life changes; includes confusion related	can specify if participant, family, peer, provider	expressing confusion or describing lack of knowledge regarding illness and related symptoms or changes	inverse: knowledge/ understanding of illness	I think that at the time I knew very little about the disorder so most of what I was basing my experience off of was what I had heard of in the media and, um, I definitely didn't have a very good understanding of, like, the realities of bipolar disorder at the time.

		to/caused by the illness				
lack of support	Interpersonal relationships	absence of involvement of participant's support system	none	description of limited or no support (emotional, financial, guidance etc.); can refer to family or peers	if referring to healthcare, use 'lack of supportive healthcare providers' code	...and so I really didn't feel support sometimes. I really didn't feel support from family, and still don't really feel support from family.
life changes	mediating factors	changes in life circumstances between age 13 - 17	none	description of major life changes, such as moving, school change, changes in family structure, birth/death, etc.	does not include normative developmental changes	I moved from New York to North Carolina and that was a huge shock.
life changes (EA)	emerging adulthood	major life changes occurring after age 18; change in direction regarding interpersonal relationships, work and education goals	none	refers to literal (external) changes in circumstance, relationships, situation etc. after age 18	for intrinsic changes related to maturity and focus/goals, use focusing on self (EA) code; if referring to identity development, growth, or sense	But the path that I was on—all this partying and drinking—probably I would not be in the position that I am today had something not happened, had something not forced me to get my life together and forced me to focus on myself and my well-being, my mental health, physical health. Had something not happened I don't know where I would be today

					of self use identity development (EA)	
loss of autonomy due to healthcare system	healthcare	loss of independence or sense of identity during interactions with healthcare system (as a result of interaction with healthcare providers or tx)	none	participant expressing perceived loss of self or independence attributed to interactions with healthcare providers or tx system	loss of self or independence due to other factors	And so...from ages 14 to 16 I didn't administer my own meds. My dad was the one who gave them to me every night, and he kept them locked up. And I don't know if it was a lack of trust or what...and my dad would frequently come to my psychiatrist appointments and there were times, especially if I was really depressed, he would just talk to the psychiatrist instead of me. And that made me feel really not included in my own treatment plan.
loss of self	impact on identity	perceived loss of self or loss of identity due to illness and/or stigma	none	description of loss of self as a result of illness; 'self' is replaced or changed due to symptoms and/or stigma	differs from fear of illness (loss of self is current and code pertains to identity rather than illness); and loss of control (loss is the self vs autonomy or independence)	But after a while depression started to set in and I didn't feel like doing anything anymore. I felt like I lost who I was before, and things started to change around me.

manic and/or hypomanic symptoms	experience of illness	DSM manic and/or hypomanic symptoms	none	participant is describing manic or hypomanic symptoms	all other symptoms	I would say my manic episode probably started sometime right around when high school started, like the beginning of the year. And it only took me 6 to 8 weeks into high school to have full-blown manic feelings and to have my mom realize 'okay, you need to go to the hospital.' [laughs] But it was definitely a lot of classic symptoms of bipolar mania...it was like delusional thoughts, hard to relate to people in social situations, grandeur thoughts, grandiosity...towards the end was I was being hospitalized there were some hallucinations going on...just kind of out of touch, having that out of touch feeling...feeling like you're on top of the world, you can get anything done...just having really elated thoughts, elated emotions that were blown out of proportion. And just like overly emotional in situations, like no control over.
mistrust	Interpersonal relationships	inverse; lack of trust in family or peer relationships	none	description of mistrust in family or peers	distinct from 'lack of support' and 'conflict in relationships' refers to participant's explicit lack of trust	I mean, I jumped from therapist to therapist after that one therapist, because I didn't—I always thought they had different agendas so I didn't really trust a lot of them.
optimism/ sense of opportunity & possibility	reactions & coping	change in outlook that includes increased focus on opportunity and	none	expressing possibility of good and	if code applies to experience over age 17, use EA	So I feel like there is hope for my adulthood.

		possibility; optimistic		positivity	version of code	
optimism/ sense of opportunity & possibility (EA)	emerging adulthood	participant explicitly states hope/positive outlook for the future; discussion of increased sense of possibility, improvement of self & circumstance, and opportunity, independence, and increased autonomy -- after age 18	none	specific to increased sense of possibility in life and increased ability to enact change (after 18)	if referring to increased maturity or focus on independence, use focusing on self & self-sufficiency (EA) ; if referring to life changes, use life changes (EA) ; if referring to identity development, use identity development (EA)	I think it changed me for the better. Even though that's like...it's like a blessing in disguise.
others involved in treatment	Interpersonal relationships	participation or involvement of family or peers in tx of any kind	none	family member attends or participants in tx; facilitates appointments or medication	Does not refer to healthcare providers	” and then I had talked to a psychiatrist in there, and then they brought my family in. and so we had this group therapy counseling session ‘your daughter has bipolar disorder...can you recall’—and that I didn’t like—“can you recall when you think the symptoms started?” and that I didn’t like. I didn’t think I should’ve been in the room, but I was in the room. So it would be like my parents and siblings talking about when they thought I had episodes

psychoeducation	healthcare	provision of psychoeducation by healthcare provider to individual or family; discussion of illness & course of illness	none	referring to education on illness, symptoms, course of illness; can refer to psychoeducation of individual, family, peers etc.	do not use with other tx modalities (e.g., supportive psychotherapy)	Yes, they said it was a mood disorder mostly. Nothing to do with physical or real bad mental issues, but they said I would need to take medicine for it, come back for treatment, and basically get it in check to see if everything was okay.
psychotropic medication	healthcare	discussion of experience of medication (includes discussion of treatment and side effects)	none	participant discusses experience/ reaction to taking medication, impact of medication, side effects of medication (can be positive, neutral, or negative)	for other tx interventions, use <u>healthcare or treatment is/is not beneficial</u>	And so the one I switched to, I've been on it this whole time. I've had the same prescription, everything since I got diagnosed. And they said they can reduce it, and I was like 'no, let's not reduce it because I don't want to have another episode.' The medicine I'm on now is just like...it works, obviously.
relationships affecting identity	Interpersonal relationships	family/peer relationships impacting sense of identity	specify family or peer (or other) relationships	description of change in identity/sense of self due to family or peer relationships	report of no change in identity due to relationships	<p>And that was something that was so painful and hurtful that it made me feel different from my family, from my siblings. And it made me feel like I had something that was wrong with me.</p> <p>So that was rough. So that was one of the relationships that had changed that impacted how I identified my disorder and how I coped with it. Which is probably why I'm so private now, because even my own sibling had said that and I was like, wow okay, that was harsh.</p>

relationships not changing	Interpersonal relationships	no changes occurring in interpersonal relationships	none	participant reports no changes (positive, neutral, or negative) occurring in relationships	inverse: 'change in peer relationships' and/or 'change in family relationships'	I think it has been a problem that was ongoing for such a long time before I got the diagnosis that there wasn't really a significant change.
religion/ spirituality	mediating factors	discussion of the role of faith, religion, or spirituality in participant's experience - can be positive, neutral, or negative; can also refer to religion as a support or a challenge	none	participant discussing the impact or role of religion in experience of EOB	If not referring to impact on illness (i.e., general discussion)	My dad practices mindfulness and considers himself Buddhist, so we were very not wanting to medication for a long time.
seeking help/support	reactions & coping	voluntarily seeking support or treatment (from others or healthcare system); includes seeking healthcare providers, tx services, medication	none	Emphasis is on act of voluntarily seeking out support (clinical/tx or emotional) from healthcare or support system	if describing use of healthcare services, use <u>accessibility or use of healthcare/tx</u>	I voluntarily asked my parents to go to therapy when I was 17 because I knew something was wrong.
selective disclosure of illness	Interpersonal relationships	selective disclosure of illness <u>by</u> participant, family or peers OR <u>to</u> family or peers	none	participant, family members, peers are selectively disclosing or not disclosing illness (can have positive, neutral, or negative tone)	for open disclosure use 'disclosure of illness'	And even the person I'm dating now, they don't know that I'm bipolar.

self-labeling / endorsing stigma	labeling	participant has applied stigmatizing beliefs or labels to themselves; internalized/endorsed/self-directed labeling & judgment	none	participant identifies self-labeling or describes self-labeling or self-stigma (is endorsing stigma or labeling)	do not use if participant is referring to stigma stemming from outside source	Certainly identifying myself as crazy was not helpful [laughs] in trying to recover. And also trying to think that—well, buying into stigma puts you in a deeper hole in trying to recover and trying to see that you can be something other than an image, to something other than an unstable kind of person
suicidality	experience of illness	referring to the concept of suicide; can be abstract thought, ideation, or plan; can refer to participant, family, peer, healthcare provider etc.	none	discussion of suicide or possibility/though t of suicide	distinct from self-injury and depressive symptoms	And I always kind of knew I was kind of defeated and I wanted to defeat myself, I wanted to hurt myself, I wanted to end my life. I did several suicide attempts to try to do that. And all the suicide attempts that I have done have failed.
support	Interpersonal relationships	support from others (emotional, financial, guidance); family and/or peer relationships as source of strength and help	specify source of support - family, peer, community, school , etc.	description of emotional, financial support or guidance from family, peers, community	does not include family participation in tx but can include assistance obtaining tx	And people I became friends with when I was 17—so the same year I was diagnosed—are still some of my closest friends. They’ve kind of watched the whole process go through, and are really really supportive and were supportive then too
trauma	mediating factors	trauma or abuse experienced by the participant	none	participant description of trauma or abuse (i.e., domestic or family abuse, rape, physical abuse)	if participant describes additional symptoms caused by trauma (i.e., anxiety or ptsd), use <u>comorbid symptoms</u> to code the trauma-induced non-	Once again, with my specific situation it’s very hard to explain because there were days where I was literally not allowed to do anything by someone I used to live with. To the point that they would knock my door down if I wanted to escape and go to my room...

					bipolar symptoms	
use of coping skills	reactions & coping	Participants' use of coping skills or symptom management-based skills	none	discussing efforts to alleviate symptoms, interpersonal stressors, or cope with difficulty (situation-based or emotion-based)	Does not include medication management	(as far as supports) I was a writer too.
view of self as different or defective	impact on identity	description of feeling 'other' (liminality); different from peers and/or family; can also include feeling abnormal, damaged, defective, weak, or flawed	none	description of self as not being normal; weak, flawed or damaged; can include feeling 'undeserving, or defective in some way due to illness; refers to identity and sense of self	Do not use if participant is describing stigma	I knew there was something wrong, and because of that I thought I was like flawed and I didn't want to hang out with anybody. / I didn't think I was a good person.

Appendix F

Member Checking: Summary of Themes

Managing and Coping with EOBD

Experience of illness: Participants described their experience of EOBD itself, including symptoms and course of illness. Three participants described the polarity of their first episode as manic, while five participants described their first episode as depressive in nature. Participants described manic and hypomanic symptoms in terms of increased energy and productivity, impulsivity, decrease in rational decision-making, increase in risky behavior, increased social activity, increased energy and hyperactivity, racing thoughts, decreased sleep, euphoria and elation, agitation and aggression, delusional thoughts, grandiosity, and hallucinations. Participants characterized depression as low mood, sadness, social isolation, decreased focus and clarity of thought, decreased motivation, decreased ability to do things, crying, and spending a great deal of time in bed.

Seven of the eight participants described experiencing symptoms of diagnoses of other mental health conditions, including anxiety, self-injury, eating disorders, and substance abuse. Only one participant described experiencing exclusively manic and depressive symptoms throughout adolescence. Two participants reported experiencing suicidal ideation with suicide attempt.

Treatment and engagement with the healthcare system: Participants described their interactions with the healthcare system, providers, and treatment as a core components of their experience of EOBD. Participants reported receiving inpatient and outpatient care, including psychiatric hospitalization, psychiatrists, and therapists. Some participants reported avoidance of aspects of healthcare, including delay seeking treatment, medication noncompliance, and stopping treatment.

Psychotropic medication emerged as one of the largest components of participants' experience of EOBD. All participants reported taking medication. Most participants reported improvement in symptoms, while some reported medications appeared to make symptoms worse. Participants identified medication side effects as a significant challenge and the most commonly described reason for discontinuing medication. Most participants reported continuing medication throughout adolescence.

Perceptions of healthcare and treatment: Participants identified several components of healthcare and treatment as beneficial, including therapists with whom they felt rapport, psychiatry, and effective medication. Participants identified components of healthcare that were not beneficial, including psychiatric hospitalization, staff who were undereducated or did not understand, medication that was ineffective and/or had significant side effects, and judgment or labeling from healthcare providers. Some participants reported difficulty accessing healthcare due to considerations such as insurance, finding available providers (i.e., were wait-listed); getting medication on time; and coordinating between providers (i.e., between pharmacy and psychiatrist).

Use of Coping Skills: In addition to healthcare and treatment interventions, participants described their own efforts to alleviate and manage symptoms through use of coping skills such as writing/journaling, listening to music, playing sports, talking to others and utilizing support playing video games, and reading inspirational success stories of other people.

Knowledge and understanding of illness: Participants described knowledge (and lack of knowledge) of illness as an important component of illness management. Participants described not understanding the experience of prodromal symptoms, or onset of symptoms; participants' described attaining an increase in knowledge of EOBD throughout adolescence. Several participants described a sense of knowing that 'something was wrong' prior to receiving diagnosis. Participants described a general lack of understanding by family and peers. Participants reported receiving psychoeducation from providers as well as self-educating through their own research.

Lack of knowledge and understanding was the most common sub-theme across all participants and all domains of the study. Knowledge and understanding was described as the determining factor in whether healthcare was beneficial; participants described providers with knowledge/understanding of EOBD as helpful and beneficial, while providers perceived as lacking of knowledge of EOBD were considered non-beneficial.

Effect on Relationships

Difficulty maintaining social functioning: Participants described difficulties in maintaining relationships, social functioning, and experiencing conflict in family and peer relationships due to EOBD symptomatology and isolative behavior. Participants described isolation as a component of decline in social functioning through avoidance of social situations, pushing others away, and selectively leaving their ‘safe space’ (i.e., house or bedroom).

Seeking and receiving support: All participants described experiencing support in some form from family and/or peer relationships during adolescence. Support was described as others’ wanting the best interest of the participant, and was described as not contingent on possessing knowledge/understanding of EOBD. Some participants described feeling lack of support from family and peers, both prior to and following diagnosis; as well as from healthcare providers. Participants described voluntarily seeking treatment or reaching out to support system for help upon noticing prodromal symptoms. Involvement of others included referrals for treatment, participation in treatment sessions, coordination with providers, and administration of psychotropic medication.

Impact on Identity

Secrecy and selective disclosure of illness: Participants described experiencing a change in sense of self that included viewing EOBD as something to be kept secret and selectively disclosed to others. Participants described being ‘undercover’ to maintain their privacy; as well as hiding their illness and their identity in effort to minimize vulnerability to judgment, rejection, and harm from others.

Adaptation and integration: Participants described normative adolescent identity development as a challenge due to EOBD. Participants described experiencing confusion and struggling to maintain sense of self and self-image, and integration of ‘new’ self-image following diagnosis.

Participants described efforts to maintain portions of their sense of identity following diagnosis and experience of symptoms, most notably maintaining prior levels of academic performance and motivation for prior goals.

Emotional adjustment: Participants described a range of emotional responses to receiving EOBD diagnosis, including self-blame, frustration, shame, and feeling nervous and a sense of not knowing what to expect. One participant described the diagnosis as “heartbreaking” while another said it felt like their life would never be the same again. Participants described a fear of EOBD itself; specifically the fear that symptoms would return and would not remit. Participants described experiencing a perceived loss of self concurrent to symptomatic states and recovery from symptomatic episodes. Participants similarly described feeling out of control over EOBD; specifically inability to control symptoms and worrying the illness was controlling them.

Experience of Stigma and Labeling

Labeling or stigma: All participants described experiencing diagnostic labeling and stigma from healthcare providers, as well as stigma from family, peers, community, and culture/society.

Self-labeling: Participants described applying stigmatizing beliefs to self-label, and described increased distress, isolation, selective self-disclosure, and in some cases worsening of symptoms. Self-labeling and labeling were described in conjunction with secrecy and selective disclosure of illness, as well as perceived judgment and criticism from others.

Challenging or rejecting labeling: Participants described challenging and refusing to accept or endorse stigmatizing beliefs and self-labeling; participants associated labeling (and rejecting labeling) with resilience and significantly impacting their identity.

Change and Uncertainty

Change in illness: Participants’ overall experience of EOBD was characterized by change, uncertainty, and instability. Duration of episodes varied from days to weeks or months, as did the severity and frequency of symptoms experienced. The severity of manic and depressive episodes was described as ranging from disruptive to debilitating. While some participants described an experience dominated by depressive episodes, others described that manic episodes were more

disruptive to their lives in adolescence. The presence of comorbid symptoms and suicidal ideation were described as additional challenges to managing bipolar symptomatology.

Changes occurring in relationships: Participants described EOBD as disruptive of relationships. Changes in family and peer relationships included family members moving away or becoming estranged, changing friend groups and social patterns. Participants also described varying changes in dynamic with their parents following diagnosis, including increased support, increased stigma, and increased conflict.

Change in identity and sense of self: Participants described experiencing changes in thought, perspective, and behavior associated with EOBD diagnosis and illness. Changes included engaging in unhealthy behaviors (partying, substance use), choosing not to pursue goals, and change in coping patterns. Participants described a change in identity and view of self as defective, damaged, or different from others; sense of liminality and ‘otherness.’ Participants described feeling flawed, abnormal, worthless, and weak. Participants stated they felt there was something ‘wrong’ with them, that they were an outcast and different from their peers, and that they felt others may not know how to handle them if symptomatic.

Life changes: Participants reported experiencing significant life changes, often prior to onset of symptoms. Changes included moving, changes in school/beginning new school, and changes in family relationships. One participant described becoming a mother at age 15 as a significant life change.