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I am submitting herewith a thesis written by Melissa Sarah Coury entitled "Investigating the Effects of Depression and Bipolar Disorder on Social Support, Stigmatization, and Family Burden." I have examined the final electronic copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Child and Family Studies.

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**Investigating the Effects of Depression and Bipolar Disorder on Social
Support, Stigmatization, and Family Burden**

A Thesis Presented for
the Master of Science
Degree
The University of Tennessee, Knoxville

Melissa Sarah Coury
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ABSTRACT

Mental illnesses, including mood disorders, frequently affect many areas of the lives of both the patients and their families. Prior research has shown that in families in which a member has a mental illness, the level of stigmatization and family burden increases compared with families in which no member has a mental illness. Even though there is more need for social support when a family has a member who is mentally ill, the level of available social support actually decreases. I chose to study the effects of depression and bipolar disorder (a combination of depressive and manic episodes) on stigmatization, social support, and family burden. Using a large pre-existing data set, the National Comorbidity Survey Replication (NCS-R), I explored specifically how the intensity of the patients' illness impacts those factors. In analyzing frequency distributions, however, I noted that the variable stigmatization needed to be eliminated because not enough respondents had answered the two questions concerning it and one item was ambiguous. Results of the regression analyses affirmed what previous researchers had found: With a greater intensity of depression and mania, the level of social support decreased and family burden increased. The same was the case when a regression was run with only depression as the independent variable. However, when a regression was run with only mania (not depression) as the predictor variable, the predicted relationship was not supported. Thus, I concluded that, for this sample, mania by itself neither increased family burden nor decreased social support. This finding is not that surprising, given the assertion that is found in the literature that mania does not exist by itself (without episodes of depression). Finally, the independent variables in the models tested explained little of the variance in the dependent variables, so other factors need to be considered in future research. Problems encountered using this secondary data set are discussed.

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CHAPTER I INTRODUCTION

Mental illnesses are and always have been common human experiences over time. However, in recent decades, more attention has been paid to them as the topic has come out into the open more and as more people have sought help for various mental illnesses. There are many different types of mental illness, and they vary in intensity and in how much they affect a person's personal and family life. They can affect individuals and families in many ways, disrupting lives or at least causing people to have to make minor adjustments or major changes in their everyday lives. Just how a family is affected most likely depends on the type and intensity level of the mental illness. It is possible, for example, that a serious mental illness might affect a family very differently than would an anxiety disorder, such as panic disorder. In addition, one potentially could look at different areas of life, such as social or economic aspects, that a mental illness affects. In this study, I decided to examine the effect mental illness has on (a) stigmatization, (b) family burden, and (c) social support. I have sought to examine the effects a family member's illness has on both the individual with the mental illness and the family of that individual.

Depression is a common mood disorder that I focus on in this study. According to the Diagnostic and Statistical Manual of Mental Disorders: Text Revision (4th ed.; DSM-4-TR; 2000), it is referred to as a Major Depressive Disorder. Symptoms for people with this disorder can vary, but most of them have a persistently low mood and experience less ability to enjoy everyday life. It

can cause problems with functioning and can affect both the individual and those who care about him or her (National Institute of Mental Health [NIMH], 2008). Most commonly, it interferes with the person's life in the areas of work, sleep, studying, eating, and other activities. Someone with this disorder tends not to function as well as he or she ordinarily does. It can be serious, at times resulting in suicide or attempted suicide (NIMH, 2008).

Bipolar disorder is one of what are said to be two of the most serious mental illnesses, the other being schizophrenia (Kilbourne, McCarthy, Post, Welsh, & Blow, 2007). Bipolar disorder is a mood disorder that generally involves episodes of depression and mania, and these typically recur throughout a person's life. There are also usually periods of time, though, when the person is symptom-free (NIMH, 2008). It is a disorder that usually develops in late adolescence or young adulthood, although in some cases it develops earlier, in childhood, or later in life (Quinn, 2007). Usually, it is a long-term illness, and without medication, it often gets worse. However, there is treatment for it, and people have been known to lead fairly productive, full lives even with the illness (NIMH, 2008).

There are different types of bipolar disorder. They are grouped, broadly, into either Bipolar 1 disorder or Bipolar 2 disorder. According to the DSM-4-TR (2000), there are six different criteria sets for Bipolar 1 disorder, which are like different types of the disorder. They are (a) Bipolar 1 disorder, single manic episode; (b) Bipolar 1 disorder, most recent episode hypomanic; (c) Bipolar 1 disorder, most recent episode manic; (d) Bipolar 1 disorder, most recent episode

mixed; (e) Bipolar 1 disorder, most recent episode depressed; and (f) Bipolar 1 disorder, most recent episode unspecified (DSM-4-TR). Mixed episodes are ones in which a person has both depressive and manic symptoms concurrently. Sometimes this might be the case at the cusp, so to speak, as a person switches from a depressive to a manic episode. However, Bipolar 1 disorder is not the most prevalent type. More common is Bipolar 2 disorder. According to the DSM-4-TR, it is called Bipolar 2 disorder (recurrent major depressive episodes with hypomanic episodes). Hypomania is a mild form of mania. By some estimates, Bipolar 2 disorder is nearly as common as unipolar depression (Quinn, 2007). Some people who initially get diagnosed with unipolar depression turn out actually to have a bipolar disorder. Bipolar patients usually spend more time being depressed than being manic or hypomanic, and that is one reason that misdiagnosis easily can occur (Quinn, 2007). Hypomania might not seem very problematic and can even result in well functioning and high productivity. However, there are times when it can develop into severe mania if the person does not get treatment. A hypomanic episode is significantly different from a typical nondepressed mood. It generally involves an elevated, expansive, or irritable mood that lasts at least 4 days (Quinn, 2007).

Having a mental illness can affect how other people respond to the individual patient and his or her family. For one thing, it has been found that mental illnesses have a stigma attached to them, and this can lead to a sense of rejection. Feldman and Crandall (2007) found that mentally ill people often are stigmatized based on seven factors, specifically (a) dangerousness, (b)

disruptiveness, (c) being out of touch with reality, (d) personal responsibility, (e) rarity, (f) not being treatable with medication, and (g) degree of avoidability. The factors that were found to especially lead to rejection are personal responsibility, danger, and rarity (Feldman & Crandall). It has been found in addition that not only the individual with the mental illness but also his or her close relatives experience discrimination and stigmatization (Gonzalez-Torres, Oraa, Aristegui, Fernandez-Rivas, & Guimon, 2007).

Having a mental illness can place an increased burden on oneself as well as on one's close relatives. Busch and Barry (2007) noted that, in families with a mentally ill child, much more money and time is required to care for that child. Busch and Barry did a comparison study between families caring for a child with a mental illness and families caring for a child with some other type of illness (e.g., physical illness). They found that families of mentally ill children also tended to both cut back on their work hours in order to care for the child and spend more time arranging care for the child.

Social support is an important consideration for the mentally ill, as it can affect how well the mentally disordered person fares. Most people consider their primary social support to come from family and friends. It has been found that mentally ill people are more likely to recover or to experience a lessening of symptoms if they have social support (Kilbourne et al., 2007). An association has been found between having a larger social network and experiencing a higher quality of life (Hansson & Bjorkman, 2006). Perhaps at least in part because of the stigma attached to mental illnesses, however, the mentally ill

often do not have adequate social support (Feldman & Crandall, 2007).

Stigmatization and discrimination seem likely to lead to decreased social support.

Kilbourne et al. (2007) found that mentally ill persons had less of each three dimensions of social support: structural, instrumental, and emotional. They were found to be more likely to have no close friends, no one to help with routine chores, no one to help with transportation, and no one to help when they are sick (Kilbourne et al.). This dynamic could be especially problematic since a mentally ill person is likely to need social support more than the average person.

I would hypothesize that people with a greater intensity level of depression or bipolar disorder and their close relatives experience more stigmatization and a greater sense of family burden than people with less intense levels of the disorder do. I also would hypothesize that their level of social support is lower than that of individuals and their families with a less intense level of disorder and that this also leads to a greater sense of family burden. See Figure 1 for a diagram of this conceptual model.

For this thesis project, I chose to run regression analyses to find out how close the observed process in a national sample is to my predicted hypotheses. Examining the intensity level of a mental illness (e.g., low intensity versus high intensity) and what difference that makes within groups of people with the same mental illness is a topic that has not been studied as much as some of the other topics concerning mental illnesses. It is that examination that I contribute with this thesis project.

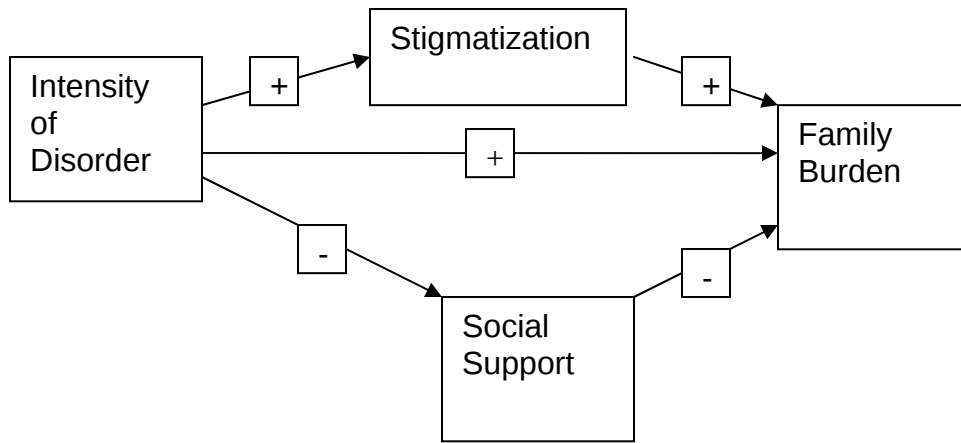


Figure 1. The conceptual model of this study.

CHAPTER II LITERATURE REVIEW

Mental Illness

I will first describe the literature related to the two mental illnesses that are the focus disorders in my study. Following that, I will examine the literature related to three variables of interest to this project: social support, stigmatization, and family burden.

Depression

One mood disorder that this study focuses on is depression. According to the DSM-4-TR (2000), it is referred to as a Major Depressive Disorder.

Symptoms for people with this disorder can vary, but most of them have a persistently low mood and experience less ability to enjoy everyday life. It can cause problems with functioning and can affect both the individual and those who care about him or her (NIMH, 2008). Most commonly, it interferes with the person's life in the areas of work, sleep, studying, eating, and other activities. Someone with this disorder tends not to function as well as he or she ordinarily would. It can be serious, at times resulting in suicide or attempted suicide (NIMH, 2008).

Depression is thought to result from a variety of different factors, including genetic, biochemical, environmental, and psychological factors. Some research reports show that it is a disorder of the brain (NIMH, 2008). According to brain imaging technologies, there are differences in the brains of people with depression compared with those without the disorder. Depression also has been

found to be associated with impairment (Kessler, Akiskal, Ames, Birnbaum, Greenberg, Hirschfeld, Jin, Merikangas, Simon, & Wang, 2006).

Dysthymic disorder is a type of depression, but it is milder with less severe symptoms. In order to meet the diagnostic criteria for it, one needs to have had it for at least 2 years (DSM-4-TR, 2000).

Bipolar Disorder

The literature on bipolar disorder and the effect it has on families has been proliferating over recent decades. Bipolar disorder, like depression, is a mood disorder. There are different types of the disorder (See Chapter 1). About 19% of people with bipolar disorder die from suicide (Isometsa, Suominen, Mantere, et al., 2003). Out of the bipolar patients who are hospitalized for manic episodes, approximately 30% stay unemployed for at least 6 months.

Bipolar 2 disorder (recurrent major depressive episodes with hypomanic episodes) is fairly common, more so than Bipolar 1 disorder. Hypomania, one of the key features of Bipolar 2 disorder, often is denied or just not reported, contributing to the disorder not getting diagnosed at times (Berk & Dodd, 2005). Bipolar disorder, in general, sometimes goes undiagnosed. The most common misdiagnosis of it is unipolar depression (Lewis, 2005). Kessler et al. (2006) affirmed that, since people with bipolar disorder usually spend more time being depressed than manic, there can be some confusion when it comes to making a diagnosis.

An inverse relationship has been found between the prevalence of the disorder and the severity of it: Greater prevalence usually means the disorder is

not as severe (Berk & Dodd, 2005). People with the disorder often have high rates of dysfunction, especially concerning occupation, leisure, and relationships. Rates of family dysfunction and divorce or separation are higher in cases of Bipolar 2 disorder than in Bipolar 1 disorder (Berk & Dodd). Bipolar 1 disorder and Bipolar 2 disorder have approximately the same age of onset, though at times it may be later for Bipolar 2 disorder. People who have an earlier age of onset for Bipolar 2 disorder tend not to fare as well; their condition is often more severe, and they do not respond to treatment as well. Bipolar 1 disorder is not as much of a recurrent disorder as is Bipolar 2 disorder. Bipolar 2 disorder also often has a more chronic course. Bipolar 2 disorder patients tend to experience more sensory overload than do those who have Bipolar 1 disorder (Berk & Dodd).

For Bipolar 1 patients, what at times has resulted in it being less likely to be recognized and diagnosed were a lower age when first symptoms appeared, rapid symptoms cycling, less manic and depressive episodes, more lifetime anxiety disorder, and less substance use disorder. For Bipolar 2 patients, factors that were found to result in less likelihood of the disorder getting recognized and diagnosed were (a) a lack of psychotic symptoms while depressed, (b) less depressive episodes, and (c) shorter times in treatment (Mantere, Suominene, Arvilommi, Valtonen, Leppamaki, & Isometsa, 2008).

Individual and Family Functioning

Social Support

The literature shows that social support can make a difference for the better for persons who are mentally ill. Most people consider their primary social support to come from family and friends. Mentally ill people are more likely to recover or to have a lessening of symptoms when they have a strong social support network (Kilbourne et al., 2007). An association also has been found between having a large social network and experiencing a higher quality of life (Hansson & Bjorkman, 2006). Social support can come in different forms. Three common forms of social support are structural, instrumental, and emotional support. The research reports supporting the benefits of social support could lead one to conclude that less social support results in a lower quality of life. Indeed, low social support has been found to be associated with negative outcomes. However, the mentally ill tend to have less emotional and social support (Kilbourne et al., 2007).

The article by Kilbourne et al. (2007) focused on social support among veterans with a serious mental illness. The authors wondered if mentally ill people have less social support than the rest of the population. Their method of finding participants included recruiting patients from the Veteran Administration's (VA's) National Psychosis Registry who met the diagnoses of bipolar disorder or schizophrenia. Only ongoing VA patients were included; a total of 8,547 people met their criteria. All of them also had completed the VA's Large Health Survey of Veteran Enrollees, a large national survey that included assessments of social

support and demographic variables. This survey included items on all three dimensions of social support that Kilbourne et al. were interested in: structural, instrumental, and emotional.

Kilbourne et al. (2007) found that their study's participants tended to be less likely to be married or employed and also were more likely to live alone than people without a mental illness. The sample reported less social support on all three dimensions of social support. Some of the specifics were that they were more likely to have no close friends, no one to help with routine chores, no one to help with transportation, no one to relax with, and no one who could help when they were sick (Kilbourne et al.).

The article by Hansson and Bjorkman (2006) focused on the subjective quality of life of mentally ill people, but the authors also were interested in social factors. They wanted to find out what predicts subjective quality of life, as well as to discover if there is a pattern of sociodemographic, clinical, social, or self-related factors connected with subjective quality of life. Their study took place over a 6-year period in Sweden. There were a total of 92 participants who completed the entire study. They were interviewed three times—at baseline, after 18 months, and at the 6-year follow-up. Each time, an assessment was taken on their subjective quality of life, social network, psychosocial functioning, needs for care, psychiatric symptoms, and social and demographic characteristics. The Lancashire Quality of Life Profile (LQOLP) was administered to them; it measures family relations, social relations, and living situation, among other things. A few other measures also were used. These included the Strauss

Carpenter scale (to measure psychosocial functioning) and the Camberwell Assessment of Needs Short Assessment (CANSAS) interview (to assess needs for care). The latter of those was administered at baseline and at the 18-month follow-up. The Hopkins Symptom Check List-90 (SLC-90) was used to assess symptoms related to mental illness.

Hansson and Bjorkman (2006) found that the participants' social and clinical situation improved over time in several ways. Their subjective quality of life and satisfaction with work, living situation, family situation, and health had improved while their number of unmet needs and psychiatric symptoms had lessened over time. Analyses showed that social network and self-reported symptoms were associated with the subjective quality of life, but not always to the same extent at the three times of measurement. As for social network, it was found to be related to their quality of life cross-sectionally. Its importance increased over time, but the level of unmet needs and symptoms became less important as time went by (Hansson & Bjorkman). The authors hypothesized that this might be the case because symptoms and unmet needs might seem more important when the patient is doing badly clinically, but when the patient is improving, he/she might focus more on emotional and social relations and their importance.

In a study of bipolar patients by Johnson, Winett, Meyer, Greenhouse, and Miller (1999), it was found that people with high social support needed less time for recovery than people with low social support (238.27 days versus 1 year). Those people with high social support also were found to be less likely to

have increases in depression. However, although social support had positive effects, it did not buffer the effects of stress encountered in the subject's daily life. Johnson et al. speculated that perhaps more intensive social support might be needed for that. Also, they found that social support and life events have more of influence on depression than on mania. In fact, social support had little, if any, effect on mania (Johnson et al.).

In a study by Johnson, Lundstrom, Aberg-Wistedt, and Mathe (2003), it was found that people with Bipolar 1 disorder essentially had the same level of social support as people with Bipolar 2 disorder. They also found that those participants who did not have a partner or significant other when the illness first developed were more likely to experience only partial remission (Johnson et al.). However, whether or not one lived with a significant other or had a partner at the beginning of the study was found to be not correlated with the amount of social support the participants had. Patients with low social support were also more likely to have relapsed by the year follow-up (Johnson et al.).

A study of Bipolar 1 patients by Cohen, Hammen, Henry, and Daley (2004) also found that less social support results in a greater likelihood of recurrence. Their study included only on Bipolar 1 patients, however. They also found that more stress could increase the likelihood of recurrence. As pointed out before, some people with bipolar disorder still could be considered to have the disorder but might have periods of time when they are symptom-free, including times when, due to being on appropriate medication, the patients are considered to be symptom-free, which can be for long periods of time (NIMH,

2008). As with the study by Johnson et al. (1999), Cohen et al. (2004) found that social support did not have much of an effect on mania. Lower levels of social support were found to have an effect on depressive episodes but not on manic episodes (Cohen et al.). Low levels of social support can be considered to be a risk factor for recurrence of depressive episodes, the authors concluded.

Bertera (2005) performed a study on mental health and social support. She focused not only on positive social support but also on negative social support. She found that social exchanges were associated with several areas of life, including health, and also with social areas and demographics. Higher education and higher income were associated with perceiving more positive social support. Mood disorders in particular were found to have associations with social, demographic, and health factors (Bertera). They affected the number of episodes there were. However, factors such as gender, education, and income did not account for much of the variation in mood disorders. When there was social negativity with spouses and other relatives, it was likely to have a greater negative impact than when the social negativity was with friends.

Stigmatization

Mentally ill persons appear to often face stigmatization and discrimination. According to Elgie and Morselli (2007), people often discriminate against others who are different because of ignorance, prejudice, and fear. According to Elgie and Morselli, 43% of the bipolar participants in their study reported that they felt ashamed or embarrassed about having that disorder, and 52% reported feeling that they were treated differently because of it by people such as employers.

Other studies have found similar results. A 2001 U.S. study published as Lewis (2003) found that more than half of all patients reported that they felt ashamed or embarrassed when receiving their diagnosis. A European study found that over half of mentally ill patients reported experiencing problems with stigmatization. Many of the patients also reported feeling rejected by their environment (Morselli & Elgie, 2003).

An article by Feldman and Crandall (2007) focused on the mental illness stigma and attempted to answer the question of whether or not mental illness causes social rejection. They concluded that it does and specified that mental illness causes not only harm that comes from the disease itself but also harm from the stigma that comes with it, in terms of both social rejection and interpersonal difficulties. The researchers focused on six different dimensions of mental illness to more accurately assess which ones are stigmatizing. The dimensions were (a) concealability, (b) course, (c) disruptiveness, (d) origin, (e) aesthetics, and (f) peril.

Results showed that the participants gave the highest social distance ratings for Antisocial Personality Disorder, Pedophilia, and Factitious Disorder. They gave the lowest ratings for Narcolepsy, Female Sexual Arousal Disorder, and Posttraumatic Stress Disorder. Regression analyses revealed that the characteristics that were most likely to result in stigmatization were, in order, personal responsibility, dangerousness, and rarity. Responsibility was defined as the extent to which people think that someone is at fault for the illness; dangerousness is how much of a threat people think someone with a mental

illness is; and rarity is how much people believe that a mental illness is unusual or out of the ordinary. However, a majority of the mental illnesses (75%) were found to lead to overall rejecting attitudes, even if it was not to the same extent as these top three.

Another article (Gonzalez-Torres et al., 2007) also focused on stigma and discrimination towards people with schizophrenia, as well as stigma towards their family members. The researchers pointed out that schizophrenia, one of the most serious mental illnesses, tends to be especially prone to stigmatization. Labeling, negative stereotyping, separation, and loss of status are four stages through which the stigmatization and discrimination process can go. The researchers wanted to do a qualitative study to explore stigmatization and discrimination in people with schizophrenia and their family members. They used focus groups, each having 6 to 12 participants. In these groups, the participants discussed issues and listened to what others had to say. There were a total of 44 participants, and these consisted of 18 schizophrenic patients and 26 family members. Audio- and video-recordings of their sessions were done. (Gonzalez-Torres et al.)

The results showed that the patients had noticed that people had certain stigmatizing ideas about them. There were seven areas in general in which they felt they had been stigmatized. These include the following: (a) mental illness vs. lack of willpower, (b) prejudice related to dangerousness, (c) over-protection—infantilization, (d) daily social discrimination, (e) discrimination in health care, (f) descendants, and (g) avoidance—social isolation. The family members, most of

whom were women, also reported experiencing discrimination in various ways: (a) prejudice, (b) labor discrimination, (c) discrimination by friends, (d) isolation-protection, and (e) abandonment—nihilism. Both family members and patients many times tried to conceal the illness, feeling a sense of shame about it. Family members also reported tending to feel some guilt and blame about the illness. They even experienced some discrimination in health care settings (Gonzalez-Torres, 2007). Elgie and Morselli (2007) pointed out that stigma also can have negative effects on recovery for people with a mental illness such as bipolar disorder.

Many bipolar patients might be quite aware of social stigma, according to Hayward, Wong, Bright, and Lam (2002). This was the case for participants in their study. They also felt as if they are part of a stigmatized group, and, in addition, they needed help in coping with the disorder. Some of the participants were found to feel capable when it came to something such as work and relationships, but others felt hindered and not as capable as people without such an illness. Mood appeared to have had an effect on just how capable someone felt (Hayward et al.). The ones who felt less capable tended to be depressed or to be going through a depressive episode. Participants who were euthymic (perhaps due to medication) or who were manic did not feel less capable. The ones with lower self-esteem also tended to feel more stigmatized.

Volkenstein and Meyer (2008) studied people's attitudes towards depression and mania by giving them case vignettes. They asked them not only for how they themselves would respond but also how they thought others would

respond. They found that how people responded depended on what kind of case vignette they were shown. People tended to be more likely to describe pity and a desire to help when someone with depressive symptoms was mentioned than when someone with manic symptoms was mentioned. They associated mania more with dangerous attributes, such as aggression and unpredictability. They reported less of a need or desire to stay away from someone with depression than from someone with mania. Their self-reports (how they said they would respond) were also more positive and less rejecting than their observer-ratings (how they thought others would respond).

Norman, Sorrentino, Windell, and Manchanda (2008) wanted to find out how beliefs about mental illness and what are considered to be social norms might affect the social distance people prefer from the mentally ill. Their particular study, however, focused on schizophrenia and depression, not bipolar disorder. People were found prefer a greater social distance from individuals with schizophrenia than from those with depression. People did not think that individuals with depression were as dangerous or would be likely to exhibit such socially inappropriate behavior as those with depression.

Stjernsward and Ostman's (2008) article also affirmed that the relatives of people with a mood disorder such as depression frequently do experience stigmatization as well. This can take place in different settings and from different people. It can come from friends, other family members, and colleagues. It can come in the form of negative, unsupportive attitudes or a lack of understanding. As a result, they might become more isolated.

Family Burden

Some of the research articles I found focused specifically on the burden experienced by family members of mentally ill patients. One of these was an article by Busch and Barry (2007), in which the authors focused on the burden on families of children with mental disorders. The study emphasized the economic and time burdens on these families, noting that much more of each is required when caring for a mentally ill child. Economic costs could be even higher than for children with other illnesses for various reasons, such as the fact that mental health services are not always covered as well or at all by private health insurance. Mental illnesses also tend to be less predictable than some other disorders, and there is more stigma involved. Stigma, as other authors had pointed out, can lead to all sorts of problems and discrimination, and the health care setting is unfortunately no exception.

Busch and Barry (2007) analyzed data from the State and Local Area Integrated Telephone Survey (SLAITS) National Survey of Children with Special Health Care Needs (NS-CSHCN). They focused on what effect raising a mentally ill child would have in creating financial burden, labor-market burden, and time burden. They wanted to do a comparison study between families of children with mental health care needs and families of children with other special health care needs. Demographic characteristics also were taken note of, as were insurance coverage and just how severe the mental illness of the child was. Logistic regression analysis was conducted.

Busch and Barry found that families with a mentally ill child, indeed, experienced a larger financial burden than families of children with other health care needs. They were likely to spend more than \$500 more of their own money each year on the child's health care. However, public insurance costs were about the same. There were also labor-market differences found. The families of mentally ill children also tended to cut their work hours more in order to care for the child. Concerning the time burden, there were no significant differences found between the two groups when it came to providing care for the child, spending on average over 4 hours each week. However, parents of the mentally ill children were more likely to spend more than 4 hours each week on *arranging* for care for their child. (Busch & Barry, 2007)

Another research study (Heru, 2000) about burden on family members focused specifically on family functioning and rewards, in addition to burden, for those caring for chronically mentally ill family members. The researcher in this study reviewed literature, focusing especially on expressed emotion (EE), which is the attitude a family member might have towards a fellow family member who has a mental illness. The expressed emotion is not necessarily positive, as it can include criticism, hostility, or emotional over-involvement and has been found to be related to an increase in relapses of the mentally ill person. Families rated as high in expressed emotion had patients with relapse rates four times greater than families with low expressed emotion rates. High levels of expressed emotion, however, were found to be more common in families once a mental illness had become chronic rather than during a first episode. It also was found to be more

common in families who knew less about mental illness, such as schizophrenia, and who thought the disorder was due to the patient's laziness. (Heru, 2000)

McKenry and Price (2005) drew similar conclusions that patients in families with high expressed emotion are more likely to have relapses and that their relatives think the patient is responsible for the illness. High expressed emotion thus appears to be counterproductive by setting up a vicious cycle for the patient and his or her family. Some relatives might think they are helping the patient without realizing that they actually are hindering him/her from making better progress and, it seems likely, even triggering relapses. By blaming a mentally ill person, directly or indirectly, they may be more likely to vent their frustrations on the patient. The mentally ill person might feel not only guilty but also hopeless about the disorder, since the nature of family interactions would be more negative.

Heru (2000) noted that expressed emotion is not a family trait but, instead, a process of family dysfunction. Sometimes criticism from relatives does not come until later on in the patient's disorder. I would guess that this might be due to frustration with the continuation of the illness and with the demands on the family. Daughters with high expressed emotion who were caregivers for mentally ill parents reported experiencing more strain and distress than those who reported low levels of expressed emotion (Heru). It seems that (a) the relatives may have responded to them that way because of frustration and (b) feeling burdened, and experiencing high expressed emotion, in turn, frustrated the daughters.

Burden was another particular variable of interest in both Heru's (2000) and McKenry and Price's (2005) work. Two different types of burden were mentioned, namely objective burdens and subjective burdens. Objective burdens tend to be more tangible, observable things, such as financial costs. Subjective burdens have to do with how the person views the situation, what his/her perception of it is. This would be a lot like the C factor in Hill's (1958) ABC-X model of family stress, as the C factor is the family's perception of the stressor. The mental illness would clearly represent the A factor, the stressor. Just how the family and the ill person experience the stressor (the C factor) working together with what kinds of resources they have or do not have available to them (i.e., objective burden, or the B factor) determines the degree of stress or crisis the family experiences (the X factor). Some of what Heru found showed that high objective burden was not always associated with high subjective burden. In many cases, however, the two were related, such as when objective burden (e.g., higher medical and other financial costs) is greater and the family might think of that as being more stressful and burdensome.

However, Heru (2000) also found that not all family members found caring for an adult child with a mental illness (in Heru's study, schizophrenia) burdensome. Some experienced some rewards in the process, such as a sense of intimacy and gratification, and few conflicts or burdens. It is possible that these families may have been more resilient to begin with. According to Boss' (2002) contextual model of family stress, it is also possible that these family members' perception of the stressor was more positive because of factors such

as the psychological and philosophical contexts of their family system. Feelings of being burdened apparently are not inevitable for those caring for a mentally ill family member, yet they seem to occur frequently.

Johnson (2000) also researched how families cope when a member has a serious mental illness. He used data from the Family Support Project. In the project, 180 families were interviewed, meaning there were 180 ill family members and also some of their other family members who were not ill in the sample. Most of the ill participants had graduated from high school, and a good number (42%) had gone beyond a high school education. More than half (62%) had never married. All of them had been hospitalized at least once. Their diagnoses included thought disorders (such as schizophrenia), mood disorders, thought and mood disorders, a thought disorder plus substance abuse, a mood disorder and substance abuse, and all three disorders (thought and mood disorders plus substance abuse). Family members went through an interview in which they were asked about what it was like for them to deal with and help the mentally ill family member. Johnson or one of four staff members interviewed them for at least 2 hours each. (Johnson, 2000)

Johnson's (2000) project was qualitative in nature, possibly making the responses more difficult and time-consuming to code than what might have been the case with quantitative responses. However, since the researcher likely was able to get richer responses this way, the effort was worthwhile. Since respondents came from a variety of economic classes (lower class, lower-middle class, upper- middle class), the results would be representative of different SES

levels. This, I think, is good, as the results could be checked to see if they were related in part to economic status. Including patients with different diagnoses also seems like a good idea because family members may find it easier to deal with a person with one mental illness compared with another.

Johnson (2000) found that family members interpreted the patient's illness in different ways. Fathers often had a harder time accepting the illness than did mothers. A parent was usually the primary caretaker, though at times it was a sibling, adult child, or spouse. Siblings were thought to be more invested than spouses because they had had more of a history with the mentally ill person, but they tended to be less invested than the parents. A small number of spouses (6%) were the primary caretakers. Some of the mentally ill patients divorced after the onset of the illness.

There were differences in economic levels also, with most of the people who were willing to participate in the study coming from lower-middle class families. Families with a mentally ill member from the other two classes were not only harder to find, but they also were less willing to participate in the study (Johnson, 2000). It may have been that some of the people from the lower social classes were suspicious of the researcher's motives. People from some of the higher economic classes evidently did not like admitting there was a problem. In the case of a serious illness, parents might very well be the ones who find it most natural to be the primary caretaker of their adult child, even though the illness is a non-normative event. Parents, because of their history with the person and their biological bond, might find it easier to accept the person even after such an

illness has become apparent. Spouses may have rarely been the primary caretaker, perhaps at least in part, because the situation might have been too difficult for them to handle in cases where the ill person was physically present but psychologically absent (Boss, 2002).

As the authors of some of the other studies had mentioned, Johnson (2000) also found that stigma was present for the families of the mentally ill. The family members especially felt as if mental health professionals did not treat them well and did not show much concern. Stigma varied, though, among the economic classes. The upper-middle class participants expressed embarrassment about having a mentally ill family member, whereas participants from the other two SES classes in this study focused more on the stigma they encountered from professionals (Johnson). It is possible that the upper-middle class family members felt as if more was expected of them by neighbors and society, thus producing embarrassment.

Reupert and Mayberry (2007) also focused on families dealing with mental illness, but in this case, it was the parents who were the ones who were mentally ill. Reupert and Mayberry's study was a literature review that focused largely on the effects of parental mental illness on children. An emphasis was placed on how the rest of the family, especially the children, were affected by that. This is different from some of the previous research studies I have discussed, where usually the mentally ill family member was a child (often an adult child living with a parent). As previous authors had pointed out, other family members also are affected by the mental illness—and this includes children.

Children living with a mentally ill parent were found to be affected negatively in some ways, according to the literature that Reupert and Mayberry (2007) examined. The children's risk for having poorer social, emotional, and physical health has been found to be greater than other children's. They are more likely to experience problems, such as developmental or emotional problems (Reupert & Mayberry). However, being at a greater risk, of course, does not make it inevitable that they will develop problems; it only increases the likelihood.

Reupert and Mayberry (2007) pointed out that having a good relationship with at least one parent can serve as a protective factor when it comes to children's psychological health. Having a good friend to talk to also can be helpful. Outside relationships and other social support seems to be quite important, perhaps because a mentally ill parent might not always be able to provide the same kind of support that a healthy parent can provide. While this could potentially be problematic, having social and emotional support from other sources can serve as a buffer for the children of a mentally ill parent.

The extent to which a mentally ill parent still can function and is able to assume parental responsibilities varies from person to person and can have an effect on their children's outcomes. Reupert and Mayberry (2007) pointed out that having social and emotional support is important for the parents as well as their children, and a number of others researchers have noted that as well. It is clear that having sufficient support can be problematic for both mentally ill adults and their children.

In a study by Reinares, Colom, Martinez-Aran, Torrent, Comes, Goikolea, Benabarre, Daban, and Sanchez-Moreno (2006) on the burden experienced by caregivers of bipolar patients, the researchers sought to assess the caregiver's subjective burden. Their study included bipolar patients who were euthymic and not currently symptomatic. Within the sample used for their study, the researchers found that what caused the caregivers the most distress was the patient's behavior; next most stressful was distress concerning the negative effects of the illness on other people; and the patient's role performance was considered to cause the lowest distress level. Hyperactivity was identified to be the behavior that most often was distressing, and withdrawal was a behavior that also was troubling. However, the patient being dysfunctional with regard to household management was not found to be very stressful for the caregivers. (Reinares et al.)

Concerning subjective burden, the caregivers in Reinares et al.'s (2006) study reported experiencing a moderate level, found to be related to poor social and occupational functioning for the caregiver by the person with a bipolar disorder. Subjective burden also was found to be associated with other factors, such as the caregiver being responsible for supervising the patient's medication intake, a history of rapid cycling of the disorder, and the presence of an episode in the last 2 years (Reinares et al.). Close to 70% of caregivers claimed that the illness had affected their own emotional health and their life in general in ways they found upsetting or distressing. In such situations, changes often have to be made in household, social and leisure activities, employment, and finances (Dore

& Romans, 2001; Fadden, Bebbington, & Kuipers, 1987). Some partners of bipolar patients also said that if they had known more about the disorder and what kinds of effects it has, they would not have entered into the relationship with the person (Dore & Romans, 2001; Targum et al., 1981.). Having poorer social and occupational functioning was found to be related to the illness running a more negative course (Reinares et al., 2006).

Stjernsward and Ostman (2008) also affirmed that a mood disorder like depression affects the depressed person as well as those around him or her, particularly close relatives. They found that with a greater degree of the illness, relatives assumed a greater responsibility for things such as household responsibilities. They often assumed a caregiver role. This was consistent with what I had hypothesized. Living with a depressed relative affected their lives in other spheres too, such as privately, socially, and professionally. Their relationships with healthcare professionals were affected also, and some had had negative experiences with the healthcare field.

In summary, it is apparent that mental illness does lead to stigmatization of the patient and, at least sometimes, the patient's family. The burden on the family seems to increase as the intensity of the illness increases. Also, at a time when the mentally ill and their families need more social support, in actuality they tend to receive less social support.

CHAPTER III METHOD

The story of my process for determining a specific topic for this research project and some of the problems I encountered is given in Appendix A. In this appendix, I describe why I chose to use and what I have learned about the limitations imposed by using an existing data set as the basis of my study. Because of the limitations imposed by the data set I was using, what I had anticipated would be a standard hypothesis-testing project developed into more of an exploratory study.

Exploratory studies are research projects that are conducted in order to explore a topic that is either unfamiliar or is familiar but approached in an uncommon way. In the social sciences, exploratory studies are considered to be particularly useful when one is trying to break new ground. They often result in one getting full—or at least satisfying—answers to one's questions about a particular phenomenon in order to (a) gain a better understanding about the topic, (b) test whether or not a more in-depth study would be possible, or (c) develop methods that can be used in future studies. (Babbie, 2007)

Germane aspects of the research process involved in the evolution of this thesis project are described in this chapter. The process lays the groundwork for a more in-depth study at a later date.

The Data Set

The data I am using are secondary data. This data set comes from the Collaborative Psychiatric Epidemiology Surveys (CPES) (Inter-University

Consortium for Political and Social Research [ICPSR], 2003), which uses three data sets that are fairly similar and combines them into one. These are called the National Comorbidity Survey Replication (NCS-R), the National Survey of American Life (NSAL), and the National Latino and Asian American Study (NLAAS). These three surveys all asked participants about various mental problems and difficulties they have had. Not only mania and depression (the two predominant features of bipolar disorder) were investigated, but also various other disorders, such as anxiety disorders. Broadly, the disorders in these surveys include disorder of mood, anxiety, substance abuses, and impulse control (ICPSR, 2003). The surveys were collected from 2001 to 2003. Out of these three surveys, the one I am specifically focusing on is the National Comorbidity Survey Replication (NCS-R).

The main objective of these surveys was to collect data about the prevalence of mental disorders and the problems associated with them. The NCS-R was carried out 10 years after the original 1992 NCS was conducted. The NCS-R is similar and has many of the same questions as the original survey. However, it also tried to expand on issues that had been raised previously. The NSAL had as its main objective to investigate racial and ethnic differences in mental disorders. The goals of the NLAAS were to describe the prevalence of psychiatric disorders and the rates of mental health services use for Latino and Asian Americans. The researchers also hoped to assess social position and to compare the lifetime and 12-month prevalence of psychiatric disorders (ICPSR, 2003).

The combined survey, CPES, was based in part on the World Health Organization's (WHO) expanded version of the Composite International Diagnostic Interview (CIDI), which had been developed for the World Mental Health (WMH) Survey Initiative, the WMH-CIDI. The three CPES surveys used a modified version of the WMH-CIDI.

While the individual surveys do not have bipolar disorder listed as a specific disorder, they do have depression and mania listed. According to the DSM-4-TR (2000), mania is not a disorder in and of itself. Instead, it is a part of bipolar disorder. In fact, within the different types of bipolar disorder, there is one in which mania is the predominant feature. Therefore, one can conclude that the people answering *yes, they have mania*, in one of the individual surveys would be classified as having a form of bipolar disorder. In the combined survey, bipolar disorder is listed by its more common name, bipolar disorder. People with unipolar depression were not included in the bipolar diagnosis, as they did not report having any episodes of mania (ICPSR, 2003).

Sample

The sample that I used in my study is a subsample of the NCS-R sample and included both primary and secondary adults in the household. The primary adults were the identified patients, the ones with the mood disorder. The secondary adults were family members of the mentally ill person.

The sample in my study was made up of 5,236 persons with 2,161 men and 3,075 women. In terms of marital status, 2,950 respondents answered that they were married or cohabiting; 1,115 were divorced, separated, or widowed;

and 1,171 had never married. There were 3,387 responses to a question about the number of times they had been married: 2,435 people answered once, 731 answered twice, and 221 answered three or more times. The age range of the respondents was from 18 to 98. There were 444 persons between the ages of 18 and 21, 879 from 22 to 29 years old, 1,109 from 30 to 39 years old, 1,146 from 40 to 49 years old, 830 from 50 to 59 years old, 445 from 60 to 69 years old, from 70 to 79 years old, 89 from 80 to 89 years old, and 11 from 90 to 98 years old. The average age of the sample was 43.6 years.

Regarding this sample's number of years of education, 732 answered 0-11 years, 1,566 answered 12 years, 1,602 answered 13-15 years, and 1,336 answered "greater than or equal to 16 years."

Regarding their employment status, 3,475 indicated they were employed, 412 were unemployed, and 1,318 stated they were not in the labor force. Breaking the sample down into primary (patients) and secondary adults in the household, there were 2,411 primary respondents who indicated they were employed, 207 who were unemployed, and 1,001 who stated they were not in labor force. There were 1,064 secondary respondents who indicated they were employed, 205 were unemployed, and 317 who stated they were not in labor force. When asked about their current employment situation, there were 4,311 responses: 2,683 answered employed, 326 answered self-employed, 353 answered retired, 279 answered homemaker, 110 answered student, 560 answered other, and 4 refused to answer. There were 4,021 valid responses to

the question about household income. The amount of the household income ranged from \$0 to \$197,000, and the mean household income was \$58,481.

When asked what their race or ancestry was, 89 answered Asian, 480 answered Mexican/Hispanic, 661 answered African American/Afro-Caribbean, 3,826 answered non-Latino White, and 180 answered “all other.” When asked what region of country of the country they lived in, 942 answered that they lived in the Northeast; 1,428 answered Midwest; 1,734 answered in the South; and 1,132 answered in the West.

When asked what their religious preference was, there were 4,515 responses. Of these, 403 people answered “Protestant/Protestant, no denomination mentioned,” 798 answered “Baptist (all types),” 230 answered “Lutheran,” 255 answered “Methodist (all types, including United Brethren),” 106 answered “Pentecostal,” 96 answered “Presbyterian,” 502 answered “Protestant, other (please specify),” 688 answered “Catholicism/Catholic, no denomination mentioned,” 302 answered “Catholic, Roman,” 31 answered “Catholic (all others),” 62 answered “agnostic or atheist,” 296 answered “no religious preference,” 356 answered “no religion,” 390 answered “other (specify),” 10 refused to answer, and 5 answered “don’t know.”

Measures

The primary adult sample was taken from the larger NCRS sample if they indicated they had either depression or mania or both. The secondary adult sample were adults present in the household of a patient. The variable I used to

make the sample distinction between the primary adult (the patient) and secondary adult in the household is (a) PS_FLAG: *Primary/Secondary adult in household*. The answer choices are 1 for primary adult in household and 2 for secondary adult in household. I have assumed the secondary adult is a family member related to the patient, although I am aware that may not always be the case. We attempted to get the information from the CPES (specifically the NCS-R) researchers to be able to match each secondary adult with the primary adult in the specific household but were unsuccessful.

Depression

For depression, I chose six items. The first of these is (a) D24A: *Severe depressive episode--felt depressed most days*. The exact wording of this question is,

In answering the next question, think about the period of several days/two weeks or longer during that episode when your sadness/or/discouragement/or/lack of interest and other problems were most severe and frequent. During that period, which of the following problems did you have most of the day, nearly every day: Did you feel sad, empty, or depressed most of the day, nearly every day during that period of several days/two weeks?

The answer choices were 1 for yes or 5 for no.

Another item is (b) D1: *Sad/depressive episode—discouraged about life*. The exact wording is,

Earlier in the interview, you mentioned having periods of time that lasted several days or longer when you felt sad, empty, or depressed most of the day. During episodes of this sort, did you ever feel discouraged about how things were going in your life?

The answer choices were 1 for yes or 5 for no.

A third item is (c) D1A: Sad/depressive episode—lost interest in enjoyable things. The exact wording is, “During the episodes of being sad, empty, or depressed, did you ever lose interest in most things like work, hobbies, and other things you usually enjoy?” The answer choices were 1 for yes and 5 for no.

A fourth item is (d) D26CC: *Severe depressive episode—thought about suicide*. The exact wording is, “Did you ever think about committing suicide?” The answer choices were also 1 for yes and 5 for no.

A fifth item is (e) D26FF: *Severe depressive episode—unable to cope with daily responsibilities*. The exact wording is, “Did you feel that you could not cope with your everyday responsibilities?” The answer choices were 1 for yes and 5 for no.

The sixth item is (f) D28A: *Severe depressed episode—unable to perform daily activities*. The exact wording is, “How often during that episode were you unable to carry out your daily activities because of your sadness/or discouragement/or/lack of interest—often, sometimes, rarely, or never?” The answer choices were 1 for often, 2 for sometimes, 3 for rarely, and 4 for never.

Mania

Since bipolar disorder typically consists of episodes of both depression and mania, the indicators of this variable would be divided into those two separate categories. For the mania, I have chosen five items. The first of these is (a) M1: *Behavioral changes during episode of excitement*. The exact wording is,

Earlier in the interview you mentioned having episodes lasting four days or longer when you felt more excited and full of energy than usual and your mind went too fast. People who have episodes like this often have changes in their thinking and behavior at the same time, like being more talkative, needing very little sleep, being very restless, going on buying sprees, and behaving in ways they would normally think are inappropriate. Did you ever have any of these changes during your episodes of being excited and full of energy?

The answer choices were 1 for yes and 5 for no.

The second item is (b) M3: *One episode where large # of behavior changes stand out*. The exact wording is,

Please think of the one episode when you were very excited and full of energy and you had the largest number of changes like these at the same time. Is there one episode of this sort that stands out in your mind?

The answer choices were 1 for yes and 5 for no.

The third item is (c) M9: *Episode plus problems affected work/social/relations*. The exact wording is,

Let me review. You had episodes when you were very excited and full of energy/irritable or grouchy and also had some problems like (Key phrase of 3 “yes” responses in M7 series). How much did these episodes ever interfere with either your work, your social life, or your personal relationships – not at all, a little, some, a lot, or extremely?

The answer choices were 1 for not at all, 2 for a little, 3 for some, 4 for a lot, and 5 for extremely.

A fourth item is (d) M9A: *Unable to do normal activities due to episode plus problems*. The exact wording is, “How often during these episodes were you unable to carry out your normal daily activities--often, sometimes, rarely, or never?” The answer choices were 1 for often, 2 for sometimes, 3 for rarely, and 4 for never.

The fifth item is (e) M7D: *Irritable episode—inappropriate behavior*. The exact wording is,

During that episode, which of the following behavior changes did you experience: Did you behave in any other way that you would ordinarily think is inappropriate—maybe talking about things you would normally keep private, or acting in ways that you'd usually find embarrassing?

The answer choices were 1 for yes and 5 for no.

Family Burden

For the variable family burden, I also chose several items, eight in particular. One of these is (a) FB8: *Extent health of relative affects your life*. The exact wording of the question is,

The next questions are about how your life is affected by the health problems of your relative/relative(s). Taking into consideration your time, energy, emotions, finances, and daily activities, would you say that his/her/their health problems affect your life a lot, some, a little, or not at all?

The answer choices were 1 for a lot, 2 for some, 3 for a little, and 4 for not at all.

Another item is (b) FB9B: *Help relative with practical things due to health problems*. The exact wording of the question is, “Do you help him or her/them with practical things, like paper work, getting around, housework, or taking medications?” The answer choices were 1 for yes or 5 for no.

A third item is (c) FB12: *Amount of time average week do things related to health problems*. The exact wording of the question is, “About how much time in an average week do you spend doing things related to his or her/their health problems?” The answer choices could vary.

A fourth item is (d) FB14: *Extent health problems cause worry and anxiousness*. The exact wording is, “How much do his or her/their health problems cause you to be worried, anxious, or depressed—a lot, some, a little, or not at all?” The answer choices were 1 for a lot, 2 for some, 3 for a little, and 4 for not at all.

A fifth item is (e) SN4: *How often relatives make too many demands on you*. The exact wording is, “Not including your husband/wife/partner, how often do your relatives make too many demands on you--often, sometimes, rarely, or

never?” The answer choices are 1 for often, 2 for some, 3 for rarely, and 4 for never.

A sixth item is (f) SN5: *How often your relatives argue with you.* The exact wording is, “Not including your husband/wife/partner, how often do your relatives argue with you--often, sometimes, rarely, or never?” The answer choices are 1 for often, 2 for some, 3 for rarely, and 4 for never.

A seventh item is (g) SN9: *How often friends make too many demands on you.* The exact wording is, “How often do your friends make too many demands on you--often, sometimes, rarely, or never?” The answer choices are 1 for often, 2 for some, 3 for rarely, and 4 for never.

An eighth item is (h) SN10: *How often your friends argue with you.* The exact wording is, “How often do your friends argue with you—often, sometimes, rarely, or never?” The answer choices are 1 for often, 2 for some, 3 for rarely, and 4 for never.

Stigmatization

For the stigmatization variable, two items were used. The first of these is (a) FB13: *Extent health problems cause embarrassment.* “How much do his or her/their health problems cause you embarrassment--a lot, some, a little, or not at all.” The answer choices are 1 for a lot, 2 for some, 3 for a little, and 4 for not at all.

The other item is (b) SN16: *Others reluctant to get too close/won't stay with me/scare away.* The exact wording is,

Now the third statement. “I find that others are reluctant to get as close as I would like. I often worry that people who I care about do not love me or won’t want to stay with me. I want to merge completely with another person, and this desire sometimes scares people away.” How much does this sound like you--a lot, some, a little, or not at all?

The answer choices are 1 for a lot, 2 for some, 3 for a little, and 4 for not at all.

Social Support

For social support, seven items were chosen. The first of these is (a) SN2: *Frequency rely on relatives who don’t live with you for serious problem*. The exact wording is, “Not including your husband/wife/partner, how much can you rely on relatives who do not live with you for help if you have a serious problem—a lot, some, a little, or not at all?” The answer choices are 1 for a lot, 2 for some, 3 for a little, 4 for not at all.

The second item is (b) SN7: *How much can rely on friends when have serious problem*. The exact wording is, “How much can you rely on your friends for help if you have a serious problem--a lot, some, a little, or not at all?” The answer choices are 1 for a lot, 2 for some, 3 for a little, and 4 for not at all.

The third item is (c) SN14: *Easy to get close to and depend on others/no fear of abandon*. The exact wording is,

Next, I will read three statements and ask how much each one sounds like you. First, “I find it relatively easy to get close to other people. I am comfortable depending on others and having them depend on me. I don’t

worry about being abandoned or about someone getting too close to me.”

How much does this sound like you--a lot, some, a little, or not at all?

The answer choices are 1 for a lot, 2 for some, 3 for a little, and 4 for not at all.

The fourth item is (d) SN1: *Frequency talk on phone/get with relatives who don't live with you*. The exact wording is,

The next few questions are about your social life. (Not including your husband/wife/partner.) How often do you talk on the phone or get together with relatives who do not live with you – most every day, a few times a week, a few times a month, about once a month, or less than once a month?

The answer choices are 1 for most every day, 2 for a few times a week, 3 for a few times a month, 4 for once a month, and 5 for less than once a month.

The fifth item is (e) SN3: *Frequency can rely on relatives who don't live with you to discuss worries*. The exact wording is, “(Not including your husband/wife/partner) how much can you open up to relatives who do not live with you if you need to talk about your worries--a lot, some, a little, or not at all?” The answer choices are 1 for a lot, 2 for some, 3 for a little, and 4 for not at all.

A sixth item is (f) SN6: *How often talk on phone or get together with friends*. The exact wording is, “How often do you talk on the phone or get together with friends--most every day, a few times a week, a few times a month, about once a month, or less than once a month?” The answer choices are 1 for most every day, 2 for a few times a week, 3 for a few times a month, 4 for once a month, and 5 for less than once a month.

A seventh item is (g) SN8: *How much can you open up to friends and talk about worries*. The exact wording is, “How much can you open up to your friends if you need to talk about your worries--a lot, some, a little, or not at all?” The answer choices are 1 for a lot, 2 for some, 3 for a little, and 4 for not at all.

Demographic Variables

Originally, we planned to use several demographic variables in the model tested in this study. Because of complications with the core model that developed during the course of this project, the demographic items described here were dropped from the testing and are given here solely because they provide information about the sample.

One of the demographic items was (a) RANCEST: *Race/Ancestry*. The answer options were 1 for Vietnamese, 2 for Filipino, 3 for Chinese, 4 for all other Asian, 5 for Cuban, 6 for Puerto Rican, 7 for Mexican, 8 for all other Hispanic, 9 for Afro-Caribbean, 10 for African American, 11 for Non-Latino Whites, and 12 for all other.

Three items representing the variable of household income also were asked. The first of these is (a) HHINC: *household income*. There are over 100 discrete values for income that respondents could choose from. A second item is (c) WKSTAT3C: *work status 3 categories*. The answer choices are 1 for employed, 2 for unemployed, and 3 for not in labor force. A third item is (c) EM7_101: *Current employ situation: 1st mention*.

Another demographic variable describes gender. The item for this is (a) SEX: *sex*. The answer choices for this are 1 for male and 2 for female.

A variable describing education is the item (a) ED4CAT: *years of education*. The answer choices for this are 1 for 0-11 years, 2 for 12 years, 3 for 13-15 years, and 4 for greater than or equal to 16 years.

Analyses

Creating Indexes and Checking Their Reliability

When I chose multiple items to represent a variable I was interested in examining in this thesis project, I was creating an index. Indexes are composite measures of variables, based on more than one data item. They are ordinal measures that rank-order units of analysis and are made by accumulating scores assigned to individual attributes. Thus, they represent a more general dimension. (Babbie, 2007)

Garson (n.d., "Scales and Standard Measures") described indexes in the following way:

Indexes are sets of items which are thought to measure a latent variable. Normally indexes are simple additive sums of their constituent items, but they may be normed (ex., to vary from 0 to 100), weighted, or made to be a multiplicative or other function of one another. Items in an index will normally be more intercorrelated with each other than with other items.

Garson identified so-called *Likert scales* as really being indexes.

A reliability and validity check was run for each multi-item index used in this study to see if it hung together in terms of reliability (i.e., internal consistency) and validity (i.e., does the scale make sense and seem to be getting at what I am saying it represents?) (Huck, 2004, 2000). Checking validity meant examining

the nature of each item to see if it logically represented the phenomenon of interest.

Cronbach's alpha was the statistical measure we used to check the reliability of the indexes. "Cronbach's alpha is the common test of whether items are sufficiently interrelated to justify their combination in an index" (Garson, n.d., "Scales and Standard Measures"). Garson continues,

Cronbach's alpha can be interpreted as the percent of variance the observed scale would explain in the hypothetical true scale composed of all possible items in the universe. Alternatively, it can be interpreted as the correlation of the observed scale with all possible other scales measuring the same thing and using the same number of items. (Garson, n.d., "Internal Consistency Reliability")

What is considered the standard for deeming a given index to be reliable varies with the type of research being conducted and how rigorous the researcher must be. "By convention, a lenient cut-off of .60 is common in exploratory research; alpha should be at least .70 or higher to retain an item in an 'adequate' scale; and many researchers require a cut-off of .80 for a 'good scale'" (Garson, n.d., "Internal Consistency Reliability"). The indexes I created for this study were not established measures, so we were in an exploratory mode. In this exploratory study, we decided to try to use multi-item indexes, post-hoc creating variables from the questions used in the existing data set. When the Cronbach's alphas are low, as would prove to be the case with the

depression index, it means that the items available are not tapping as well as one would hope into the variables the researcher wants to study.

A variety of variable levels were used in this study. Some were dichotomous (nominal), consisting of yes and no answers, whereas others were ordinal (categorical), being measured on a Likert-type scale (index). And two of our variables were continuous, necessitating that we convert them to categorical variables by recoding the responses into ordinal groups. Garson (n.d., “Regression”) has described the process of dummifying a dichotomous (nominal) variable for use in regression analysis as follows:

Dummy variables are a way of adding the values of a nominal or ordinal variable to a regression equation. The standard approach to modeling categorical variables is to include the categorical variables in the regression equation by converting each level of each categorical variable into a variable of its own, usually coded 0 or 1.

The developers of the NCS-R data set had created the dichotomous response options such that yes = 1 and no = 5, which are extremes of a 5-point categorical variable and in the same valence order as the other categorical variables' response options. We discussed this situation with Mike O'Neil, my statistics consultant, and concurred that this was likely the way the data set researchers had intended to dummy the dichotomous variables and that we would use them in this way.

Regression Analysis

We determined that regression analysis would be the most appropriate method for testing my hypothesis because it would allow us to test how far from the predicted values the observed scores are (Garson, n.d., "Multiple Regression"). In preparing to conduct regression tests, we first recoded the mania and depression variables by sorting them into levels of illness intensity (low to high) because I planned to look at the degree of illness. It had been hypothesized, after all, that families with a greater intensity of bipolar disorder or depression would experience more stress than those families with a lower degree of the illness.

Reporting either bipolar disorder or depression was the sample criterion variables that we used to select those respondents whose data we would use as the primary subsample in the analysis. Some of the secondary adult participants also have one or both of these mood disorders, and some do not.

The independent variables are related; they represent the degree of disorder that the mentally ill family member experiences. We knew all the primary adults had indicated having either depression or mania or else they would not be in our sample. If they said yes to mania, we assumed they exhibited depression as well because both are needed to qualify under the definition of bipolar disorder. Mania is not a disorder in and of itself; it is a part of bipolar disorder. But the reverse cannot be said of depression. When someone said yes to depression, we could not assume mania would be present as well, since some people do have unipolar depression.

We examined how many valid cases (i.e., number of respondents who answered all the items) there would be for the indexes I had created for this study and came up with too few qualifying cases ($n = 16$). This led us to standardizing (centering) data for the variables of interest. We took the mean score of each social support, family burden, depression, mania, and stigmatization indicator in order to create a single indicator for each.

When frequencies were run for the groups, we found the mean of the depression items that allowed us to determine a depression score for use in the analysis. The mean of the mania items also was found in order to get an overall score for the concept to handle the missing data. The next step involved identifying how many people answered the items for each variable. We took the average of those who did answer, then compared the mean of those who answered to the predicted model. The Z score (like ZM1) indicates that item M1 has been standardized. In statistical terms, we transformed the data using the “save standardized values as variables” option. Items were identified to make up the variable of depression. The variables M1, M3, M9, M9A, and M7D were used to create an index for mania. The same was done for social support, forming the items into one score.

For this thesis project, I used regression analysis to find out how close the observed process is to my predicted hypothesis. In regression analysis, one has a dependent variable and at least one independent variable. The dependent variable is a response variable, and the independent variable(s) is(are) the explanatory variable(s).

Regression can be used for such as things as predicting regression to the mean or hypothesis testing. In this study, I wanted to test hypotheses. In regression equations, the dependent variable is a function of the independent variables. The number that precedes each predictor variable is called a regression coefficient (Huck, 1974), or b coefficient (Garson, n.d., "Multiple Regression").

Prediction equations are often in the form $Y' = .15 + .70X$. Y' is the variable that is being predicted, and it is called the criterion or dependent variable. X is the variable that is used to make the prediction, and it is called the predictor or independent variable. The equation is intended to provide an estimate of a phenomenon, such as how well persons applying to college might do academically (Huck, 1974).

CHAPTER IV RESULTS AND DISCUSSION

Results

Frequencies

Frequencies were run on all of the variables. Table 1 shows the number of respondents in my sample as a whole who answered each item of the variables of interest. The numbers represent the number of valid responses. Frequencies were run first for the group as a whole with primary and secondary groups combined. The second time, they were run with the primary and secondary groups split into the two groups. In addition, crosstabulations of primary and secondary household adult members in the full NCS-R data set ($N = 9,282$ participants surveyed) were run and examined for each variable of interest to this study (see Appendix B for a summary of the results).

Whole-Group frequencies. The frequencies for this study's sample ($N = 5,236$) as a whole included respondents' answers if they answered in such a way that their responses were valid. Both refusals and "don't know" responses, while they were recorded, did not fit that description (see Appendix C for full information).

Depression. For the question *Severe depressive episode—felt depressed most days*, 2,162 respondents answered yes, and 133 respondents answered no ($n = 2,295$ respondents). For the question *Sad/depressive episode—discouraged about life* ($n = 4,054$ respondents), 3,816 answered yes and 238 answered no. For the question *Sad/depressive episode—lost interest in*

Table 1. Numbers of Respondents Answering Each Item of the Variables of Interest (N = 5,236).

Variable	Item	Primary	Secondary	Total <i>n</i>
Depression	Severe depressive episode— felt depressed most days	1,931	364	2,295
	Sad/depressive episode— discouraged about life	3,354	700	4,054
	Sad/depressive episode—lost interest in enjoyable things	3,219	589	3,808
	Severe depressive episode— thought about suicide	1,907	357	2,264
	Severe depressive episode— unable to cope with daily responsibilities	1,907	355	2,262
	Severe depressive episode— unable to perform daily activities	1,837	343	2,180
Mania	Behavioral changes during episode of excitement	1,113	234	1,347
	One episode where large number of behavior changes stand out	865	168	1,033
	Episode plus problems affected work/social/relations	905	184	1,089
	Unable do normal activities due to episode plus problems	464	70	534
	Irritable episode – inappropriate behavior	1,042	204	1,246
Family burden	Extent health of relative affects your life	747	267	1,014

Table 1, cont.

Variable	Item	Primary	Secondary	Total <i>n</i>
	Help relative with practical things due to health problems	285	118	403
	Amount of time average week do things related to health problems	192	76	268
	Extent health problems cause worry and anxiousness	285	118	403
	How often relatives make too many demands on you	2,819	945	3,764
	How often your relatives argue with you	2,821	944	3,765
	How often friends make too many demands on you	2,820	945	3,765
	How often your friends argue with you	2,820	945	3,765
Stigmatization	Extent health problems cause embarrassment	285	118	403
	Others reluctant to get too close/won't stay with me/scare away	3,105	1,408	4,513
Social support	Freq rely on relatives who don't live with you for serious problem	2,817	944	3,761

Table 1, cont.

Variable	Item	Primary	Secondary	Total <i>n</i>
	How much can rely on friends when have serious problem	2,809	941	3,750
	Easy to get close to and depend on others/no fear of abandon	3,103	1,408	4,511
	Freq talk on phone/get with relatives who don't live with you	2,819	946	3,765
	Freq can rely on relatives who don't live with you to discuss worries	2,819	943	3,762
	How often talk on phone or get together with friends	2,819	946	3,765
	How much can you open up to friends and talk about worries	2,817	942	3,759

enjoyable things ($n = 3,808$ respondents), 2,749 answered yes and 1,059 answered no. For the question *Severe depressive episode—thought about suicide* ($n = 2,264$), there were 743 yes responses and 1,521 no responses. For the question *Severe depressive episode—unable to cope with daily responsibilities* ($n = 2,262$ respondents), 1,300 answered yes and 962 answered no. For the question *Severe depressed episode—unable to perform daily activities* ($n = 2,180$ respondents), 634 answered “often,” 728 answered “sometimes,” 464 answered “rarely,” and 354 answered “never.”

Mania. For the question *Behavioral changes during episode of excitement* ($n = 1,347$ respondents), 1,038 answered yes and 309 answered no. For the question *One episode where large number of behavior changes stand out* ($n = 1,033$ respondents), 637 answered yes and 396 answered no. For the question *Episode plus problems affected work/social/relations* ($n = 1,089$ participants), 230 answered “not at all,” 325 answered “a little,” 286 answered “some,” 184 answered “a lot,” and 64 answered “extremely.” For the question *Unable do normal activities due to episode plus problems* ($n = 534$ participants), 137 people answered “often,” 185 answered “sometimes,” 143 answered “rarely,” and 69 answered “never.” For the question *Irritable episode—inappropriate behavior* ($n = 1,246$ participants), 530 answered yes and 716 answered no.

Family burden. For family burden, there are two groups of items. The first of these includes the family burden (FB) items, and the second group includes the social network (SN) items. For the question *Extent health of relative affects your life* ($n = 1,014$), 170 answered “a lot,” 233 answered “some,” 233

answered “a little,” 378 answered “not at all.” For the question *Help relative with practical things due to health problems* ($n = 403$), 138 answered “yes” and 265 answered “no.” For the question *Amount of time average week do things related to health problems* ($n = 268$), we recoded the responses into four groups: 57 answered “a lot,” 69 answered “some,” 60 answered “a little,” and 82 answered “negligible.” For the question *Extent health problems cause worry and anxiousness* ($n = 403$), 88 answered “a lot,” 150 answered “some,” 95 answered “a little,” and 70 answered “not at all.” For the question *How often relatives make too many demands on you* ($n = 3,764$), 415 answered “often,” 750 answered “some,” 1,327 answered “rarely,” and 1,272 answered “never.” For the question *How often your relatives argue with you* ($n = 3,765$), 218 answered “often,” 587 answered “some,” 1,524 answered “rarely,” and 1,436 answered “never.” For the question *How often friends make too many demands on you* ($n = 3,765$), 120 answered “often,” 432 answered “some,” 1,327 answered “rarely,” and 1,272 answered “never.” For the question *How often your friends argue with you* ($n = 3,765$), 54 answered “a lot,” 349 answered “some,” 1,460 answered “rarely,” and 1,902 answered “never.”

Stigmatization. For the variable stigmatization, there was only one item that we decided was usable. This was the question *Extent health problems cause embarrassment* ($n = 403$), and 10 participants answered “a lot,” 26 answered “some,” 29 answered “a little,” and 338 answered “not at all.”

Social support. For the variable social support, there were several items. For the question *Frequency rely on relatives who don't live with*

you for serious problem ($n = 3,761$), 2,256 answered “a lot,” 748 answered “some,” 412 answered “little,” and 345 answered “not at all.” For the question *How much can rely on friends when have serious problem* ($n = 3,750$), 1,733 answered “a lot,” 1,100 answered “some,” 526 answered “little,” and 391 answered “not at all.” For the question *Easy to get close to and depend on others/no fear of abandon* ($n = 4,511$), 1,428 answered “a lot,” 1,588 answered “some,” 856 answered “a little,” and 639 answered “not at all.” For the question *Frequency talk on phone/get with relatives who don’t live with you* ($n = 3,765$), 747 answered “most every day,” 1,094 answered “a few times a week,” 956 answered “a few times a month,” 400 answered “once a month,” and 568 answered “less than once a month.” For the question *Frequency can rely on relatives who don’t live with you to discuss worries* ($n = 3,762$), 1,679 people answered “a lot,” 1,036 answered “some,” 596 answered “a little,” and 451 answered “not at all.” For the question *How often talk on phone or get together with friends* ($n = 3,765$), 856 answered “most every day,” 1,199 answered “a few times a week,” 855 answered “a few times a month,” 313 answered “once a month,” and 540 answered “less than once a month.” For the question *How much can you open up to friends and talk about worries* ($n = 3,759$), 1,767 answered “a lot,” 1,121 answered “some,” 524 answered “a little,” and 347 answered “not at all.”

Split-Group frequencies. The frequencies in which the respondents were split into primaries (identified patient, or P) and secondaries (family members, S) also were run. The frequencies for the split group included

respondents' answers if they answered in such a way that their responses were valid. Both refusals and "don't know" responses, while they were recorded, did not fit that description (see Appendix D for full information).

Depression. For the question *Severe depressive episode—felt depressed most days* ($n = 2,295$), for P (primary adult in household), there were 1,824 yes responses and 107 people answered no. For the same item, for S (secondary adult in the household), 338 answered yes and 26 answered no. For the question *Sad/depressive episode—lost interest in enjoyable things* ($n = 4,054$), for P, there were 3,225 yes responses and 129 no responses. For S, there were 591 yes responses and 109 no responses. For the question *Sad/depressive episode—lost interest in enjoyable things* ($n = 3,808$), for P, there were 2,345 yes responses and 874 no responses. For S, there were 404 yes responses and 185 no responses. For the question *Severe depressive episode—thought about suicide* ($n = 2,264$), for P, there were 628 yes responses and 1,279 no responses. For S, there were 115 yes responses and 242 no responses. For the question *Severe depressive episode—unable to cope with daily responsibilities* ($n = 2,262$), for P, there were 1,117 yes responses and 790 no responses. For S, there were 183 yes responses and 172 no responses. For the question *Severe depressed episode—unable to perform daily activities* ($n = 2,180$), for P, 551 people answered "often," 614 answered "sometimes," 388 answered "rarely," and 284 answered "never." For S, 83 people answered "often," 114 answered "sometimes," 76 answered "rarely," and 70 answered "never."

Mania. For mania, for the question *Behavioral changes during episode of excitement* ($n = 1,347$), for P, 870 people answered yes and 243 people answered no. For S, 168 people answered yes and 66 answered no. For the question *One episode where large # behavior changes stand out* ($n = 1,033$), for P, 533 people answered yes and 332 answered no. For S, 104 people answered yes and 64 answered no. For the question *Episode plus problems affected work/social/relations* ($n = 1,089$), for P, 185 people answered “not at all,” 256 answered “a little,” 248 answered “some,” 158 answered “a lot,” and 58 answered “extremely.” For S, 45 people answered “not at all,” 69 answered “a little,” 38 answered “some,” 26 answered “a lot,” and 6 answered “extremely.” For the question *Unable do normal activities due to episode plus problems* ($n = 534$), for P, there were 121 answer responses for “often,” 159 for “sometimes,” 127 for “rarely,” and 57 for “never.” For S, there were 16 answer responses for “often,” 26 for “sometimes,” 16 for “rarely,” and 12 for “never.” For the question *Irritable episode—inappropriate behavior* ($n = 1,246$), for P, there were 453 for yes and 589 for no. For S, there were 77 yes and 127 no.

Family burden. For family burden, for item FB8: *Extent health of relative affects your life* ($n = 1,014$), for P, there were 119 responses for “a lot,” 166 for “some,” 161 for “a little,” and 301 for “not at all.” For S, there were 51 responses for “a lot,” 67 for “some,” 72 for “a little,” and 77 for “not at all.” For the question *Help relative with practical things due to health problems* ($n = 403$), for P, there 97 responses for yes and 188 for no. For S, there were 41 responses for yes, 77 for no. For the question *Amount of time average week do things*

related to health problems ($n = 268$), for P, there were 39 responses for “a lot,” 53 for “some,” 45 for “a little,” and 55 for “negligible.” For S, there were 18 responses for “a lot,” 16 for “some,” 15 for “a little,” and 27 for “negligible.” For the question *Extent health problems cause worry and anxiousness* ($n = 403$), for P, there were 67 responses for “a lot,” 107 for “some,” 66 for “a little,” and 45 for “not at all.” For S, there were 21 responses for “a lot,” 43 for “some,” 29 for “a little,” and 25 for “not at all.” For the question *How often relatives make too many demands on you* ($n = 3,764$), for P, there were 336 responses for “often,” 560 for “some,” 990 for “rarely,” and 933 for “never.” For S, there were 79 responses for “often,” 190 for “some,” 337 for “rarely,” and 339 for “never.” For the question *How often your relatives argue with you* ($n = 3,765$), for P, there were 172 responses for “often,” 462 for “some,” 1,143 for “rarely,” and 1,044 for “never.” For S, there were 46 responses for “often,” 125 for “some,” 381 for “rarely,” and 392 for “never.” For the question *How often friends make too many demands on you* ($n = 3,765$), for P, there were 96 responses for “often,” 349 for “some,” 1,117 for “rarely,” and 1,258 for “never.” For S, there were 24 responses “for often,” 83 for “some,” 386 for “rarely,” and 452 for “never.” For the question *How often your friends argue with you* ($n = 3,765$), for P, there were 1,105 responses for “rarely,” 1,410 for “never.” For S, there were 9 responses for “often,” 89 for “some,” 355 for “rarely,” and 492 for “never.”

Stigmatization. For stigmatization, there was only one item that we decided was usable: item FB13: *Extent health problems cause embarrassment* ($n = 403$). For P, there were 8 responses for “a lot,” 20 for

“some,” 24 for “a little,” and 233 for “a lot.” For S, there were 2 responses for “a lot,” 6 for “some,” 5 for “a little,” and 105 for “not at all.”

Social support. For the variable social support, for the question *Frequency rely on relatives who don't live with you for serious problem* ($n = 3,761$), for P, there were 1,669 responses for “a lot,” 556 for “some,” 315 for “little,” 277 for “not at all.” For S, there were 587 responses for “a lot,” 192 for “some,” 97 for “little,” and 68 for “not at all.” For the question *How much can rely on friends when have serious problem* ($n = 3,750$), for P, there were 1,262 responses for “a lot,” 825 for “some,” 401 for “little,” and 321 for “not at all.” For S, there were 471 responses for “a lot,” 275 for “some,” 125 for “little,” and 70 for “not at all.” For the question *Easy to get close to and depend on others/no fear of abandon* ($n = 4,511$), for P, there were 869 responses for “a lot,” 1,102 for “some,” 635 for “little,” and 497 for “not at all.” For S, there were 559 responses for “a lot,” 486 for “some,” 221 for “little,” and 142 for “not at all.” For the question *Frequency talk on phone/get with relatives who don't live with you*, for P, there were 577 responses for “most every day,” 843 for “a few times a week,” 696 for “a few times a month,” 289 for “once a month,” and 414 for “less than once a month.” For S, there were 170 responses for “most every day,” 251 for “a few times a week,” 260 for “a few times a month,” 111 for “once a month,” and 154 for “less than once a month.” For the question *Frequency can rely on relatives who don't live with you to discuss worries* ($n = 3,762$), for P, there were 1,259 responses for “a lot,” 760 for “some,” 445 for “little,” and 355 for “not at all.” For S, there were 276 responses for “some,” 151 for “little,” and 96 for “not at all.” For

the question *How often talk on phone or get together with friends* ($n = 3,762$), for P, there were 661 responses for “most every day,” 906 for “a few times a week,” 628 for “a few times a month,” 224 for “once a month,” and 400 for “less than once a month.” For S, there were 197 responses for “most every day,” 293 for “a few times a week,” 227 for “a few times a month,” 89 for “once a month,” and 140 for “less than once a month.” For the question *How much can you open up to friends and talk about worries*, for P, there were 1,293 responses for “a lot,” 853 for “some,” 403 for “little,” and 268 for “not at all.” For S, there were 474 responses for “a lot,” 268 for “some,” 121 for “little,” and 79 for “not at all.”

Reliability and Validity Checks on Indexes

As I stated in Chapter 3, indexes are composite measures of variables, based on more than one data item (Babbie, 2007). We conducted a reliability and validity check for each multi-item index used in this study to see if it was internally consistent and seemed to make sense by getting at what I was saying it represented (Huck, 2004, 2000). Cronbach’s alpha was the statistical measure we used to check the reliability the indexes, using a cut-off of approximately .60 is that is commonly employed in exploratory research (Garson, n.d., “Internal Consistency Reliability”).

There were six items assessing depression I chose for use in this study; the Cronbach’s alpha for the created index was found to be .51, which my statistics consultant, Mike O’Neil, deemed to be marginally acceptable. Ordinarily, running this index in a regression in such a situation might not be advisable. In this case, however, I had reasons from my reading of the literature

review to expect my hypotheses to be supported, and we were curious to continue working with this data set to see how the model would work for this sample. I also did not have many other options unless I was willing to stop the current investigation and start all over with a different data set.

For the five mania items, the Cronbach's alpha was found to be .003, which is extremely low, which led us to examine this index very carefully. We reran a reliability check for the mania index, this time leaving out the items M7D and M3. For the remaining three items (M1, M9, and M9A), the Cronbach's alpha is .387 (still unreliable, although indicating more intercorrelation among the items). The reliability check was run once more, this time with M9A being reverse coded because we noted that its valence was the opposite of the others and with items M7D and M3 still left out. The Cronbach's alpha, in that case, was -.071. Previously, we had run a regression with the mania index as the predictor variable and the social support score as the dependent variable, even though the Cronbach alpha was very low for the mania index. When the resulting regression coefficients were very low, we examined the items comprising the mania index, by going back through the frequencies and doublechecking by running crosstabulations. We noted strong evidence that participants were not asked questions M9 and M9A if they had said no to question M1, which raised major questions about how the survey interviews were conducted. At this point, we decided to eliminate four of the original five items, leaving mania as a single-item variable (M1: *Behavioral changes during episode of excitement*) in the final model analysis.

For the family burden variable, the eight items were divided into two categories. First, item FB12: *Amount of time average week do things related to health problems* was recoded into FB12new in order to make this continuous variable into a categorical one with four categories with 4 meaning *negligible*, 3 meaning *a little*, 2 meaning *some*, and 1 meaning *a lot*. The four family burden items (collectively called *fb1*) were in one category (comprised of items FB8, FB9B, FB12new, and FB14), and the four social network items (collectively called *fb2*) were in another category (comprised of items SN4, SN5, SN9, and SN10). The Cronbach's alpha for *fb1* was .376. While this might not be considered totally unreliable because it does indicate some correlation among the items, we decided to eliminate it from the final model analysis, leaving *fb2*, with a Cronbach's alpha of .634, as the reliable four-item index used in this study.

For the two items in the original stigmatization index, a Cronbach's alpha was found to be .212. The two items, however, conceptually did not hang together very well, and we decided that only the item FB13: *Extent health problems cause embarrassment* should be kept.

For the social support variable, the seven items proved to have a Cronbach's alpha of .709. This is a high value, and we decided that all seven items should be kept.

Regression Analyses

Regression analyses were performed to determine the nature of the relationships among the variables in the predicted model, to see if the observed

data fit the model. The first step was to obtain descriptive statistics regarding those items that needed to be centered for the analysis to be meaningful.

Standardized variables. For primary adults in the household, the standardized family burden score was $n = 2,823$, with a minimum of -2.65 and a maximum of 1.06. For secondary adults, it was $n = 945$ with a minimum of -2.65 and a maximum of .98.

The standardized depression score for primary adults was $n = 3,482$, with a minimum of -.93 and a maximum of 4.03. For secondary adults, it was $n = 736$ with a minimum of -.93 and a maximum of 4.03.

The standardized impact of depression score for primary adults was $n = 747$, with a minimum of -1.45 and a maximum of 1.07. For secondary adults, it was $n = 267$ with a minimum of -1.45 and a maximum of 1.07.

The mania score for primary adults was $n = 1,249$, with a minimum of -1.34 and a maximum of 1.83. For secondary adults, it was $n = 264$ with a minimum of -1.34 and a maximum of 1.83.

The standardized social support score for primary adults was $n = 3,116$, with a minimum of -1.13 and a maximum of 2.00. For secondary adults, it was $n = 1,413$ with a minimum of -1.13 and a maximum of 2.00.

The stigmatization score for primary adults was $n = 285$, with a minimum of -3.94 and a maximum of .40. For secondary adults, it was $n = 118$ with a minimum of -3.94 and a maximum of .40.

The original conceptual model for this study (given in Figure 1) developed into a somewhat different research model (Figure 2). Only 93 people who were

the primary adult in the household had answered all of the questions of these six constructed variables, and only 10 people who were the secondary adult in the household had answered all of the questions. After going back and examining the pattern of missing data in the raw data set, we decided to drop the impact variable and the stigmatization variable from the model.

In order to test the study's research model (Figure 2), we did regressions following Figure 3's (see Figure 3) two models. The criterion p -value used in the study is $\leq .05$.

Regression Series #1 (whole sample). When regression analysis was performed using the whole sample as the group with the depression score as the independent variable and the social support score as the dependent variable, an R-Square of .013 was obtained, meaning only 1.3% of the variance was explained. R-Square is "the percent of the variance in the dependent [variable] explained uniquely or jointly by the independents" (Garson, n.d., "Multiple Regression"). A significance level of .001 was yielded, so the relationship was found to be significant. The unstandardized coefficient (b) for the depression score when run with social support as the dependent variable was -.089. This coefficient indicates that, for each unit of change in the independent variable (in this case the depression variable), there is -.089 unit of change in the social support variable. The significance level of this relationship was .001, indicating it was significant.

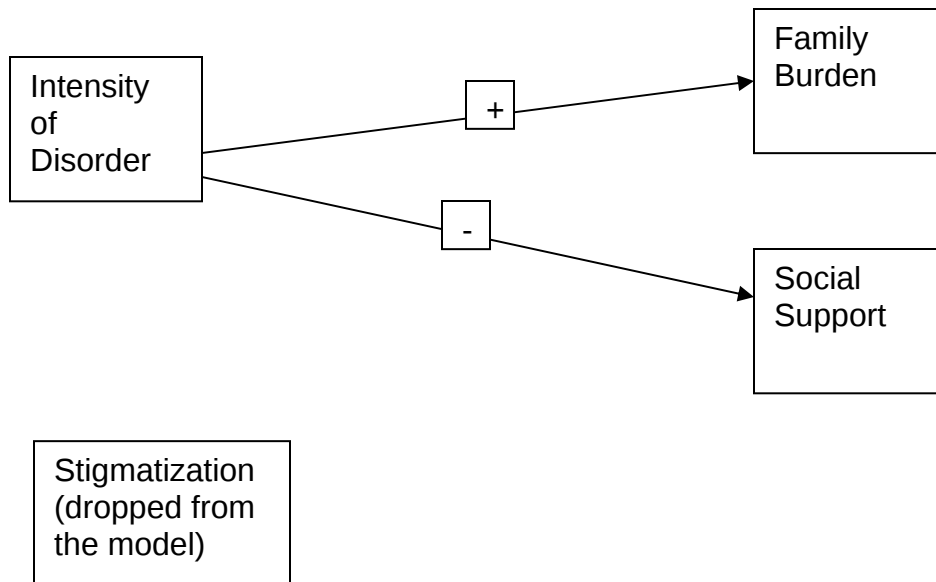


Figure 2. The research model in this study.

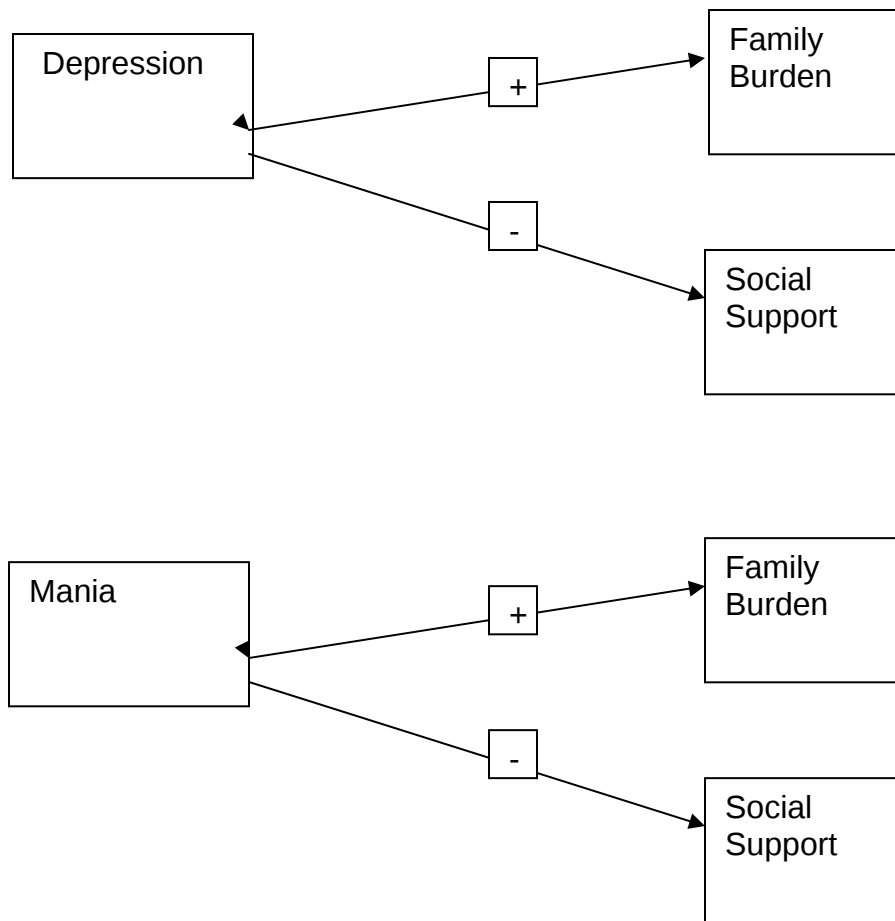


Figure 3. Models tested in this study.

When the regression was run with the new single-item mania score as the predictor variable and the social support score as the dependent variable, an R-Square of .001 was yielded. The significance level was .340, which is not significant. The unstandardized regression coefficient was .020, and the significance level for the coefficient was also .340.

When a regression was run with the depression score and the new mania score as the predictor variables and the social support score as the dependent variable, an R-Square of .019 was yielded. The significance level was .001, so the relationship was found to be significant. The unstandardized regression coefficients were -.117 for depression (the significance level was .001), and .018 for mania (the significance level was .394). In this case, the relationship was significant for depression but not for mania.

Regression Series #2 (whole sample). When the family burden score was the dependent variable and the predictor was the depression score, the R-Square value was .014. The significance level was found to be .001. The unstandardized regression coefficient for the relationship was .110, which is small but in the predicted direction, and the significance level for the coefficient was .001.

For a regression with the new mania score as the predictor variable and family burden as the dependent variable, the R-Square was .001. Only 0.1% of the variance was explained. The significance level was .225 (not significant), the

unstandardized regression coefficient was .028, and the significance level for the coefficient was .225 as well.

For a regression with depression and mania as the predictor variables and the family burden score as the dependent variable, the R-Square was .011. The significance level was .006, which is significant. The unstandardized regression coefficient for the depression-family burden relationship was .097 (with a significance level of .003), and for the mania score-family burden relationship, it was .025, with a significance level of .304. This means that the relationship was found to be significant for depression but not for mania.

Regression Series #3 (split sample). The social support score was used as the dependent variable and the depression score was entered as the predictor variable for the first regression using the sample split into primary and secondary adults in the household. The R-Square was .013 for primary adults and .016 for secondary adults. The significance level was .001 for primary adults and .001 for secondary adults so the model was significant for both primary and secondary adults. For the unstandardized regression coefficients, for primary adults the score was -.121 and for secondary adults it was -.059. The significance level was .001 for primary adults and .001 for secondary adults. Again, this showed significance of the relationships for both primary and secondary adults.

A regression was run with the new mania score as the predictor variable and the social support score as the dependent variable. This yielded an R-Square of .001 for primary adults in the household and an R-Square of .001 for

secondary adults. The significance level for primary adults was .313 and, for secondary adults, it was .620, and neither of these scores was significant. The unstandardized regression coefficient for primary adults was .023 (the significance level was .313), and for secondary adults, the unstandardized regression coefficient was .022 (the significance level was .620). These also were not significant scores.

For a regression with the new mania score and the depression score as the predictor variables and the social support score as the dependent variable, the R-Square was .014 for primary adults and .042 for secondary adults. More of the variance was explained for secondary adults than for primary adults. The significance level was .002 for primary adults and .032 for secondary adults, both of these scores being significant. The unstandardized regression coefficient for primary adults were .013 for mania (significance level .570) and -.107 for depression (significance level .001). For secondary adults, the unstandardized regression coefficients were .050 for mania (significance .336) and -.141 for depression (significance level of .011). This means that the model was significant for depression and not for mania for both groups.

Regression Series #4 (split sample). The family burden score was run as the dependent variable with the depression score as the predictor for both primary and secondary adults as groups. The R-Square was found to be .018 for primary adults and .011 for secondary adults, and the significance level was found to be .001 for primary adults and .012 for secondary adults. The unstandardized regression coefficients were .152 for the depression-family

burden relationship (the significance level was .001) for primary adults and .060 (significance level of .012). Both of these scores were significant.

When a regression was run with the new mania score as the predictor variable and family burden as the dependent variable, the R-Square for primary adults was .001, and for secondary adults, it was .002 with a significance level of .302 for primary adults and .558 for secondary adults, indicating that neither of these relationships was significant. The unstandardized regression coefficients were .027 (the significance level was .302) for primary adults and .030 (the significance level was .558) for secondary adults, also not showing significance.

Finally, in a regression with the depression score and the new mania score as the predictor variables and the family burden score as the dependent variable, an R-Square of .011 was yielded for primary adults and an R-Square of .014 for secondary adults. The significance level for primary adults was .013 and for secondary adults it was .364. The scores, in this case, were significant for primary adults but not for secondary adults. The unstandardized regression coefficients, for primary adults were .034 for the mania-family burden relationship (the significance level was .198) and .099 for the depression-family burden relationship (the significance level was .008). For secondary adults, the unstandardized regression coefficients were -.023 for the mania-family burden relationship (the significance level was .706) and .097 for the depression-family burden relationship (the significance level was .158). Thus, the model was found to be significant only for primary adults, only with regard to depression.

Discussion

In the regression analysis with the depression score as the predictor variable and the social support score as the dependent variable, the resultant R-Square was very low, but the model was significant, indicating that the relationships among the variables were going in the predicted direction.

For the regression analysis with the mania score as the predictor and the social support score as the dependent variable, almost none of the variance was explained. In addition, the relationship was not significant. The coefficient significance score was not significant. Mania did not appear to affect social support in this sample.

Regression was done with the social support score as the dependent variable and the predictor variables being the depression score and the mania score. The regression scores were significant for this sample, showing that depression and mania did have an effect on social support. For the coefficients, the significance held for depression but not mania. The standardized coefficient for the depression score indicated that having both depression and mania data in the model increased the amount of variance being explained.

When the demand score was the dependent variable and the predictor was the depression score, the R-Square value was not very noteworthy, although significant. The depression score was small but in the predicted direction. The significance for the coefficients showed that depression did have an effect on the demand score.

When the predictor was the mania score and the dependent variable was the demand score, the regression was not significant. For the coefficients, the significance level was also not significant. What this means is that mania did not affect the demand score at all in this sample.

When regression was run with the demand score as the dependent variable and the predictor variables as the depression and mania, the regression was significant. For the coefficients, the significance was all for depression and none for mania. This shows that only depression had an effect on the demand score.

When the depression score was the predictor, with primary and secondary adults in the household separated, and the dependent variable was the social support score, the R-Squares showed that, for secondary adults, slightly more of the variance is explained. However, the variance scores were very low for both primary and secondary adults. When a regression was run, significance was shown for both primary and secondary adults. For the coefficients, for the depression score, were significant for both primary and secondary adults. This shows that depression did have an effect on social support.

When the dependent variable was the social support score and the mania score was entered as the predictor, the R-Square very small for both primary and secondary adults and was not significant for either primary or secondary adults. The coefficients for both primary and secondary adults for mania were not significant. This shows that mania did not have a significant impact on social support.

When the predictor variables were the depression score and the mania score and the dependent variable was the social support score, regression revealed the R-Squares were low for both the primary and secondary adults and therefore did not explain much of the variance, even though the relationships were significant for both primary and secondary adults. Depression but not mania had an effect on social support for primary adults and also for secondary adults.

A regression was run with the depression score as the predictor variable and the demand score as the dependent variable. In this case, the R-Squares again were low, not explaining much of the variance but significant. The coefficients were significant for the depression score for both primary and secondary adults. Depression did have an effect on the demand score.

When regression was done with the mania score as the predictor and the demand score as the dependent variable, the R-Square was very low for both primary and secondary adults. The regression scores were not significant. The mania score did not have any influence on the demand score in this sample.

In another regression, the depression and mania scores were run as the predictor variables and the demand score as the dependent variable. The R-Squares were very low for both primary and secondary adults and were significant for the primary adults but not the secondary adults. For the primary adults, the depression score coefficient was low although significant, and for secondary adults, the depression score was not significant. Therefore, one

cannot consider either of them to be contributing. Depression and mania did not appear to have important impact on demand.

Some general trends can be observed in examining the findings of this study. For most of these regressions, the R-Square values were very low. They did not explain much of the variance. However, as far as the significance scores went, they varied. In some cases, they were significant, whereas in others, they were not. Depression tended to be more likely to have a significant impact on the other factors when it was the predictor variable. Mania often did not have a significant impact on the other variables when it was the predictor variable. However, when both depression and mania were the predictor variables, they often had a significant impact on the dependent variable. Depression was what affected the variables of social support and family burden (demand) in this sample.

In situations where variables were split into primary and secondary adults, results were fairly similar for both. For example, when a regression was run with mania as the predictor variable and demand as the dependent variable, the R Square was the same for primary and secondary adults. The significance was also fairly similar for primary and secondary adults. In other situations, however, different results were yielded for primary adults than what had been the case for secondary adults. This was the case when depression and mania were the predictor variables and social support was the dependent variable. The results were significant for primary adults but not for secondary adults. Depression and

mania had a significant impact on social support for primary adults, but not for secondary adults.

In summary, the item stigmatization had to be dropped from the final analysis. Depression and mania, when combined, increased family burden while decreasing social support. Thus, they had the predicted effect on social support and on family burden. They explained little of the variance, though. Depression, without mania, also had this effect on family burden and social support. However, mania without depression did not have that effect. It was not a salient variable in the model with this sample.

CHAPTER V

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

So, what do these results all mean—or fail to mean?

This study was started with the idea that a mood disorder such as bipolar disorder or depression could affect not only the people with that disorder but also their close relatives. I thought that, with greater levels of a mood disorder, people and their close relatives would experience more stigmatization and a greater family burden than people with lower levels. I also thought that the level of social support would decrease as the intensity of depression or bipolar disorder increases.

One of the ideas behind these notions was that having a family member with a mood disorder would result in the other members of the family having or being expected to take on more responsibility with helping to take care of the ill family member. Thus, the family burden would be greater. I hypothesized that the greater the intensity of the disorder, the greater would be the burden on the family. The literature review showed that this indeed can be the case.

My findings showed that this was true in this sample, but not nearly as strongly as had been predicted to be the case. Depression and mania, when run together as the predictor variables, did have a significant effect on demand (family burden), the dependent variable. Depression run without mania as the predictor variable also had a significant effect on family burden. However, mania run without depression as the predictor variable did not have a significant effect

on family burden. When depression and mania were run together with the file sample split into primary and secondary adult household members, it was found that there was a significant effect for primary adults but not for secondary adults. In general, depression appeared to have more impact on increasing the level of family burden than did mania.

When descriptive statistics were examined, it was found that not many people had answered the questions concerning stigmatization. Therefore, we decided that this variable should not be included in the regression analysis. This change in the analysis created an unforeseen issue, as we had hoped to include stigmatization in the model. The literature review showed that mental illnesses, including mood disorders, do carry with them a stigma. This applies to the individual with the mental illness as well as to his or her close relatives, meaning that families in which a household member has a mental illness face stigmatization from others in society. It had been expected that both depression and mania would be found to have significant effects on stigmatization. Having to rule out this variable meant it could not be included in the regression analyses. This may have been in part because there were only two items available for stigmatization, which I will discuss further in the limitations section. Additionally, people might have been reluctant to answer questions about stigmatization. This could be due to a number of different reasons. Perhaps they did not want to answer the questions or did not know how to answer the questions, for example.

Concerning social support, the literature review showed that people with mental illnesses can benefit from increased social support. A solid grounding of

social support is beneficial and decreases their chances of having relapses. However, ironically, people with mental illnesses tend to have less social support than people who are not mentally ill, and one of the reasons for that is stigmatization.

In the present study, there were found to be relationships between the mental illnesses and social support in this sample. Regression analyses revealed that depression and mania did affect social support. Depression alone also affected social support in the predicted direction. However, mania did not have that effect on social support. Instead, this confirmed the hypothesis partially and only fairly weakly.

Mania did not have much impact on factors such as stigmatization, family burden, and social support in this study. One would think, though, that potentially mania could have a negative impact on those areas of a person's life. One reason why it did not, in this study, could be that perhaps the participants did not have severe mania. Their mania may have been mild to mid-range. Some evidence pointing to this is that many of them were employed and were able to hold down jobs. In our society, mild mania is not always seen as being problematic. It may even heighten interactions. Some people with mild mania might not even want to take medication to put a stop to that. More severe mania, however, possibly can be more debilitating with greater negative consequences. Perhaps if more of the participants in this study had severe mania, the results might have been different.

Limitations of This Study

There are some limitations concerning the indicators of the variables used in this study. One of the limitations is that it is not obvious if the variable FB8, *Extent health of relative affects your life*, concerns the health of the identified patient or if it concerns the health of someone else in the family, perhaps someone with a broken hip, for instance. It does not specify that it is asking about mental health issues of the identified patient. The variable SN4, *How often relatives make too many demands on you*, is also ambiguous in that it potentially could be negatively coded as social support instead of being put into the family burden category.

Another limitation is that there are only two items for stigma in the data set. One of these, SN16, *Others reluctant to get too close/won't stay with me/scare away*, does not even describe stigmatization very well. The reader cannot know the reason for others' reluctance to get close. While it indeed could be due to the mental health status, it as easily might be due to something else.

Another limitation that I encountered in this study is that there was not a variable that we could find in the data set that the UT Library had access to that would allow us to match family members (the secondary adult in the household) up with the patients (the primary adult in the household). We contacted the people who are responsible for the data set about the possibility of such a variable being created and shared with us, but that did not happen quickly. Indeed, several months later, the information still has not been made available to us, regardless of the diligence shown by Eleanor Read, the UT reference

librarian who specializes in databases. However, because of the query we have begun, I hope that the CPES team might yet decipher a way for people using this data set in the future to be able to access this information.

Something that is also a weakness in this study is that secondary data were used. This meant that I was limited to using data someone else had collected. I could not make up my own questions and determine what to put into the study. Instead, I was limited to using the information that was available from the CPES study.

Strengths of This Study

A strength of this study is that the data set used for this study is a large one. There are many variables and items to choose from. When one idea did not work, it did not automatically mean ruling out the data set. Instead, it meant doing more searching for other items within that same data set.

Another strength of the study is that the other variable, *FB13 Extent health problems cause embarrassment*, describes stigma well.

Recommendations

The general stigma encountered by all of the family members in the study might be a problem that family members of the mentally ill encounter all too often in society. Since they encountered that especially in the mental health setting, it seems possible that further educating people working in the mental health profession about mental illnesses might be a good idea. Steps should be taken to reduce bias and discrimination.

It is also possible that if people use this data set in the future, they might have access to the variable matching family members up with patients due to my query into the issue. This might make things easier for them.

Working with secondary data often has its limitations, since one is limited to work other researchers have done, to factors such as using only the variables they had used in their study. One recommendation would be for people to consider the possibility of gathering their own data and essentially conducting their own study on mental illness. This would require careful preparation and probably being creative with finding a sufficiently large sample of participants for the study. However, the path might also be clearer as one can choose what variables to include and what questions to ask.

They could construct their own stigmatization variable, for example. Questions for this variable might include ones about discrimination, being treated differently, and what opportunities one might not have as a result of discrimination. Social ostracism and the fact that some of the symptoms of mental illnesses can create fear could also be taken into consideration.

If the scales were sound and variance good, a more sophisticated model would include stigmatization, even in the final analysis. It would take into consideration the effect of depression and mania on stigmatization. It might be possible to include some additional variables as well, such as the effect of the mental health care system, the effect of medication, and neighborhood context.

Some demographic variables that could be taken into consideration might be race, age, gender, education, and income level. Frequencies had been run

on variables of that sort in this thesis, but they were not included in the final analysis because of the difficulties I ran into on the core model. A more sophisticated model would include them as exogenous variables, and the results of this exploratory project shows merit in this approach.

Future researchers might also want to consider using a qualitative approach instead. They might be able to obtain more detailed responses from participants, allowing them and those reading their study to have a more in-depth idea of what life with a mental illness is really like for individuals and their family members.

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APPENDICES

APPENDIX A

the story of my experiences developing my thesis project

This is the story of my Master's thesis project. I knew that I wanted to study the impact of an individual with a problematic syndrome or disorder on her or his family. I had been a psychology major as an undergraduate, so it was natural for me to want to combine what I knew from that field with my new field of child and family studies.

I started out in November 2007 with the idea of examining identity formation and social development in adolescents with Asperger's syndrome, which is a mild form of autism that affects an estimated 0.26 persons per 1,000 (Fombonne, 2007). Dr. Julia Malia, my thesis chair, had suggested that one idea for me to try was a qualitative approach in order to explore with adolescent Asperger's syndrome patients and their families issues they have experienced such as feeling stigmatized and burdened by the disorder's presence in their lives. However, I was not confident that I would be able to find enough adolescent Asperger's syndrome patients in the Knoxville vicinity who, along with one or more family members, would be willing to take part in my study because of the condition's relative rarity.

At a meeting for Child and Family Studies graduate students at the end of October 2007, someone mentioned that it takes much longer to gather one's own data and that it is less time consuming to use data that have been gathered already by someone else. In mid-November 2007, I consulted with Eleanor Read, the University of Tennessee reference librarian who is the main data sets

consultant, to see if there would be an existing regional or national data set that included adolescent Asperger's syndrome patients and their families in the sample. She and I were unable to find any fitting data set to be available. Consequently, I chose to study more common mood disorders: depression and bipolar disorder.

Again, because I wanted to explore the experiences of feeling stigmatized and burdened by these mood disorders' presence in patients' and their families' lives, Dr. Malia suggested that one option I could consider would be to take a qualitative approach to my study—since there would be a much larger pool of patients with one of these disorders living and being treated in the Knoxville area. Or, if I wanted to conduct a quantitative study, I could do my own data collection, she said. A third option that Dr. Malia let me know I could take—and what I ultimately decided to do—was to seek out an existing quantitative data set. I chose this option because of my lack of experience in conducting this sort of research and because I thought it would be less time consuming. However, the course of progress on the project did not run as smoothly as I had hoped.

In the spring of 2008, I met with Eleanor Read again to try to find a data set for my new topic of mental illness and family stress. I planned to focus on the mental illness schizophrenia, as I knew some things about it, had known a couple of people who had it, and as an undergraduate student had written a short paper on it. A data set she recommended was the Collaborative Psychiatric Epidemiology Surveys (CPES) data set because it had information about mental illnesses. We did not find many other options at the time. As I looked through

that data set, though, I found out that it did not contain information about the mental illness schizophrenia. It did have information, however, about depression and mania. I was willing to be flexible at this point, and I decided I could do a thesis on mood disorders as the mental illnesses of choice instead of schizophrenia. The CPES data set did include information about family burden, so I realized I could still focus on family stress in my study, as planned.

I gathered data about bipolar disorder and depression, checking out some books on the topics and also looking at academic journal articles and other Internet sources. With the help of Dr. Malia and Eleanor Read, I also started picking out variables from the CPES data set to use for the study.

Dr. Malia and I had come up with some models depicting the direction of the study. An early model included the degree of illness and how that impacts society's stigmatization of the identified patient and his/her family, social support, family burden, and coping behaviors, with it ultimately leading to how successfully the illness is managed.

I tried to find several items for each of the variables in the CPES data set. The CPES data set was comprised of three individual data sets as well as the combined CPES data set. It became obvious that, because of the data set's large size, it would take some work to deal with it. Dr. Malia suggested focusing on just one of the data sets, the National Comorbidity Survey Replication (NCS-R), because it was the only one of the three that asked questions about family burden. This use of only the NCF SR data set did mean, however, that I would

have to make some changes to other variables I had chosen. I went on another search to find variables from the NCS-R data set.

Over the summer, Dr. Malia and I met with Mike O'Neil, a statistician at UT. Our model had changed by this time. It still started off with the degree of the disorder (low, medium, or high) and the effect it would have on stigmatization as well as the effect it would have on social support, and how those would both combine to affect the perception of family burden. Working with Mike O'Neil, we started running statistics. We focused on frequencies early on, with our ultimate goal being to run regressions that would test the hypothetical model.

Also that summer, Dr. Malia, Eleanor Read, and I started contacting the CPES staff about some questions we had that had come up in the course of working on the project. Eleanor Read helped give us guidance about where to find answers to questions we had. One time she helped me find the correct wording for a question we wanted to ask the people in charge of CPES, and another time she was the one to e-mail them with questions. A question I asked them on August 25, 2008, was about how to identify people as being either the identified patient or the family member of an identified patient. In a question I e-mailed CPES on September 11, 2008, I asked if there is a variable linking the responses of the secondary respondent with the primary respondent in the households that had two adults selected. They e-mailed back saying that the variable I would need in order to identify the second person in the household is V09435. Dr. Malia commented this was good news.

However, on September 16, 2008, there was another e-mail from CPES letting us know that the item V09435 would not let us link household membership. The person who had sent the e-mail, Beth-Ellen Pennell, also mentioned that they did plan on creating such a variable, though, but that it would be in their restricted access file. I would have to apply for access to that file.

By October 2008, we still had not heard back from CPES that the variable had been created. On October 10, Eleanor Read e-mailed them to ask if the variable had been created yet. She also asked if the restricted file was now available and if I should get started on applying for access to the restricted data. Beth-Ellen Pennell e-mailed back to say I should get started on the application process because it takes some time. I downloaded several application documents and began reading them and filling out the request forms. Ms. Read e-mailed Brenda Lawson at the UT Office of Research to ask if UT has an NIH MPA Certification number. She also asked who at UT would have to sign the data agreement document. Brenda Lawson provided the certification number and said that the person at UT who would have to sign the document would be E. Christine Cox, who is the Director of the Office of Research. I completed the request form and left it for Dr. Cox to process.

Realizing we might not get the information about the variable promptly enough to be used in this initial project, Dr. Malia and I scheduled another appointment with Mike O'Neil to finish the statistical work already begun by running regression analyses on the hypothetical model. We had to drop the variable stigmatization because not many people had answered the questions for

it and also one item had questionable validity. Our final model included the impact of the intensity of the illness (either depression or mania) on social support and family burden, with stigmatization dropped from the picture.

APPENDIX B

Full NCS-R Data set split-group frequencies

Crosstabulations of primary and secondary household adult members in the full NCS-R data set were run and examined for each variable of interest.

Depression. For the variable depression, for item D24A: *Severe depressive episode – felt depressed most days*, there were 2,329 valid responses. For P, there were 1,824 “yes” and 141 “no” responses. For S, there were 338 “yes” and 26 “no” responses. For item D1: *Sad/depressive episode – discouraged about life*, there were 4,573 valid responses. For P, there were 3,225 “yes” and 648 “no” responses. For S, there were 591 “yes” and 109 “no” responses. For item D1A: *Sad/depressive episode – lost interest in enjoyable things*, there were 3,808 valid responses. For P, there were 2,345 “yes” and 874 “no” responses. For S, there were 404 “yes” and 185 “no” responses. For item D26CC: *Severe depressive episode – thought about suicide*, there were 2,285 valid responses. For P, there were 628 “yes” and 1,300 “no” responses. For S, there were 115 “yes” and 242 “no” responses. For item D26FF: *Severe depressive episode – unable to cope with daily responsibilities*, there were 2,283 valid responses. For P, there were 1,117 “yes” and 811 “no” responses. For S, there were 183 “yes” and 172 “no” responses. For item D28A: *Severe depressed episode – unable to perform daily activities*, there were 2,199 valid responses. For P, there were 551 “often,” 617 “sometimes,” 391 “rarely,” and 297 “never” responses. For S, there were 83 “often,” 114 “sometimes,” 76 “rarely,” and 70 “never” responses.

Mania. For mania, for the item M1: *Behavioral changes during episode of excitement*, there were 1,470 valid responses. For P, there were 870 “yes” and 366 “no” responses. For S, there were 168 “yes” and 66 “no” responses. For item M3: *One episode where large # behavior changes stand out*, there were 1,033 valid responses. For P, there were 533 “yes” and 332 “no” responses. For S, there were 104 “yes” and 64 “no” responses. For item M9: *Episode plus problems affected work/social/relations*, there were 1,095 valid responses. For P, there were 185 “not at all,” 259 “a little,” 250 “some,” 159 “a lot,” and 58 “extremely” responses. For S, there were 45 “not at all,” 69 “a little,” 38 “some,” 26 “a lot,” and 6 “extremely” responses. For M9A: *Unable do normal activities due to episode plus problems*, there were 537 valid responses. For P, there were 121 “often,” 161 “sometimes,” 128 “rarely,” and 57 “never” responses. For S, there were 16 “often,” 26 “sometimes,” 16 “rarely,” and 12 “never” responses. For M7D: *Irritable episode – inappropriate behavior*, there were 1,257 valid responses. For P, there were 453 “yes” and 600 “no” responses. For S, there were 77 “yes” and 127 “no” responses.

Family burden. For the variable family burden, for item FB8: *Extent health of relative affects your life*, there were 1,705 valid responses. For P, there were 183 “a lot,” 325 “some,” 317 “a little,” and 613 “not at all” responses. For S, there were 51 “a lot,” 67 “some,” 72 “a little,” and 77 “not at all” responses. For item FB9B: *Help relative with practical things due to health problems*, there were 625 valid responses. For P, there were 160 “yes” and 347 “no” responses. For S, there were 41 “yes” and 77 “no” responses. For

FB12new: *Amount of time average week do things related to health problems*, there were 357 valid responses. The measurement was in the form of hours, and it ranged from 0 to 168 hours per week. For P, there were 290 responses. For S, there were 67 responses. For FB14: *Extent health problems cause worry and anxiousness*, there were 624 valid responses. For P, there were 88 a lot, 195 some, 121 a little, and 102 not at all responses. For S, there were 21 “a lot,” 43 “some,” 29 “a little,” and 25 “not at all” responses. For item SN4: *How often relatives make too many demands on you*, there were 5,278 valid responses. For P, there were 418 “often,” 790 “some,” 1,546 “rarely,” and 1,579 “never” responses. For S, there were 79 “often,” 190 “some,” 337 “rarely,” and 339 “never” responses. For item SN5: *How often your relatives argue with you*, there were 5,279 valid responses. For P, there were 224 “often,” 630 “some,” 1,690 “rarely,” and 1,791 “never” responses. For S, there were 46 “often,” 125 “some,” 381 “rarely,” and 392 “never” responses. For item SN9: *How often friends make too many demands on you*, there were 5,279 valid responses. For P, there were 117 “often,” 502 “some,” 1,663 “rarely,” and 2,052 “never” responses. For S, there were 24 “often,” 83 “some,” 386 “rarely,” and 452 “never” responses. For SN 10: *How often your friends argue with you*, there were 5,280 valid responses. For P, there were 61 “often,” 369 “some,” 1,628 “rarely,” and 2,277 “never” responses. For S, there were 9 “often,” 89 “some,” 355 “rarely,” and 492 “never” responses.

Stigmatization. For the variable stigmatization, for item FB13: *Extent health problems cause embarrassment*, there were 624 valid responses.

For P, there were 14 “a lot,” 28 “some,” 39 “a little,” and 425 “not at all” responses. For S, there were 2 “a lot,” 6 “some,” 5 “a little,” and 105 “not at all” responses. (For item SN16: *Others reluctant to get too close/won't stay with me/scare away*, there were 6,597 valid responses. For P, there were 148 “a lot,” 398 “some,” 695 “little,” and 3,948 “not at all” responses. For S, there were 23 “a lot,” 60 “some,” 164 “little,” and 1,161 “not at all” responses.)

Social support. For the variable social support, for item SN2: *Frequency rely on relatives who don't live with you for serious problem*, there were 5,269 valid responses. For P, there were 2,661 “a lot,” 815 “some,” 452 “little,” and 397 “not at all” responses. For S, there were 587 “a lot,” 192 “some,” 97 “little,” and 68 “not at all” responses. For item SN7: *How much can rely on friends when have serious problem*, there were 5,259 valid responses. For P, there were 1,992 “a lot,” 1,241 “some,” 637 “little,” and 448 “not at all” responses. For S, there were 471 “a lot,” 275 “some,” 125 “little,” and 70 “not at all” responses. For item SN14: *Easy to get close to and depend on others/no fear of abandon*, there were 6,595 valid responses. For P, there were 1,683 “a lot,” 1,806 “some,” 975 “little,” and 723 “not at all” responses. For S, there were 559 “a lot,” 486 “some,” 221 “little,” and 142 “not at all” responses. For SN1: *Frequency talk on phone/get with relatives who don't live with you*, there were 5,279 valid responses. For P, there were 902 most every day, 1,312 a few times a week, 1,062 a few times a month, 430 “once a month,” and 627 “less than once a month” responses. For S, there were 170 “most every day,” 251 “a few times a week,” 260 “a few times a month,” 111 “once a month,” and 154 “less than once

a month” responses. For item SN3: *Frequency can rely on relatives who don’t live with you to discuss worries*, there were 5,273 valid responses. For P, there were 2,027 “a lot,” 1,155 “some,” 633 “little,” and 515 “not at all” responses. For S, there were 420 “a lot,” 276 “some,” 151 “little,” and 96 “not at all” responses. For SN6: *How often talk on phone or get together with friends*, there were 5,278 valid responses. For P, there were 978 “most every day,” 1,426 “a few times a week,” 995 “a few times a month,” 351 “once a month,” and 582 “less than once a month” responses. For S, there were 197 “most every day,” 293 “a few times a week,” 227 “a few times a month,” 89 “once a month,” and 140 “less than once a month” responses. For item SN8: *How much can you open up to friends and talk about worries*, there were 5,264 valid responses. For P, there were 1,962 “a lot,” 1,334 “some,” 610 “little,” and 416 “not at all” responses. For S, there were 474 “a lot,” 268 “some,” 121 “little,” and 79 “not at all responses.”

APPENDIX C

this study's whole sample frequencies

Frequencies were run for the group as a whole (with primary and secondary groups combined). The frequencies for the group as a whole included respondents' answers if they answered in such a way that their responses were valid. Both refusals and "don't know" responses, while they were recorded, did not fit that description.

Depression. For item D24A: Severe depressive episode—felt depressed most days, 2,162 respondents answered yes, and 133 respondents answered no, so a total of 2,295 respondents answered the question. One person refused to answer, and 4 people had an answer response of "don't know." For item D1: Sad/depressive episode—discouraged about life, 4,054 people responded; of these, 3,816 answered yes and 238 answered no. Two people responded with "don't know". For item D1A: Sad/depressive episode—lost interest in enjoyable things, 3808 responded, with 2,749 answering yes, 1,059 answering no, and 8 answered "don't know." For item D26CC: Severe depressive episode – thought about suicide, 2,264 was the number of total responses. There were 743 yes responses, 1,521 no responses, 1 person refused to answer, and 4 people responded with don't know. For item D26FF: *Severe depressive episode – unable to cope with daily responsibilities*, 2,262 people responded: of these, 1,300 answered yes, 962 answered no, and 7 responded with "don't know." For item D28A: *Severe depressed episode – unable to perform daily activities*, 2,180 people responded: 634 answered

“often,” 728 answered “sometimes,” 464 answered “rarely,” and 354 answered “never.”

Mania. For item M1: Behavioral changes during episode of excitement, 1,347 people responded: 1,038 answered “yes,” 309 answered “no,” 2 refused to answer, and 3 responded with “don’t know.” For item M3: *One episode where large number of behavior changes stand out*, 1,033 people responded: 637 answered “yes,” 396 answered “no,” and 5 answered “don’t know.” For item M9: *Episode plus problems affected work/social/relations*, 1,089 people responded: 230 answered “not at all,” 325 answered “a little,” 286 answered “some,” 184 answered “a lot,” and 64 answered “extremely.” For item M9A: *Unable do normal activities due to episode plus problems*, 534 answered. Of these, 137 people answered “often,” 185 answered “sometimes,” 143 answered “rarely,” and 69 answered “never.” For M7D: *Irritable episode – inappropriate behavior*, 1,246 responded: 530 answered yes, 716 answered no, and 1 person answered don’t know.

Family burden. For family burden, there are two groups. The first of these includes the family burden (FB) items, and the second group includes the social network (SN) items. For item FB8: *Extent health of relative affects your life*, 1,014 people responded; 170 answered “a lot,” 233 answered “some,” 233 answered “a little,” 378 answered “not at all,” 1 refused, and 8 answered “don’t know.” For item FB9B: *Help relative with practical things due to health problems*, 403 people responded; 138 answered “yes” and 265 answered “no.” For item FB12New: *Amount of time average week do things related to health*

problems, 268 responded; 57 answered “a lot,” 69 answered “some,” 60 answered “a little,” and 82 answered “negligible.” For item FB14: *Extent health problems cause worry and anxiousness*, 403 people responded; 88 answered “a lot,” 150 answered “some,” 95 answered “a little,” and 70 answered “not at all.”

For item SN4: *How often relatives make too many demands on you*, there were 3,764 valid responses, 415 answered “often,” 750 answered “some,” 1,327 answered “rarely,” 1,272 answered “never,” 1 refused to answer, and 5 answered “don’t know.”

For item SN5: *How often your relatives argue with you*, 3,765 people responded; 218 answered “often,” 587 answered “some,” 1,524 answered “rarely,” 1,436 answered “never,” 1 refused to answer, and 4 answered “don’t know.”

For item SN9: *How often friends make too many demands on you*, 3,765 people answered; 120 answered “often,” 432 answered “some,” 1,327 answered “rarely,” 1,272 answered “never,” 1 refused to answer, and 5 answered “don’t know.”

For item SN10: *How often your friends argue with you*, there were 3,765 valid responses; 54 answered “a lot,” 349 answered “some,” 1,460 answered “rarely,” 1,902 answered “never,” 1 refused to answer, and 4 answered “don’t know.”

Stigmatization. For the variable stigmatization, there was only one item. This was FB 13: *Extent health problems cause embarrassment*, and there were 403 valid responses for it; 10 answered “a lot,” 26 answered “some,” 29 answered “a little,” and 338 answered “not at all.”

Social support. For the variable social support, there were several items. For item SN2: *Frequency rely on relatives who don’t live with you*

for serious problem, 3,761 responded. Of these, 2,256 answered “a lot,” 748 answered “some,” 412 answered “little,” 345 answered “not at all,” 1 refused to answer, and 8 answered “don’t know.” For item SN7: *How much can rely on friends when have serious problem*, 3,750 responded. Of these, 1,733 answered “a lot,” 1,100 answered “some,” 526 answered “little,” 391 answered “not at all,” 1 refused to answer, and 19 answered “don’t know.” For item SN14: *Easy to get close to and depend on others/no fear of abandon*, 4,511 people responded. Of these, 1,428 answered “a lot,” 1,588 answered “some,” 856 answered “little,” 639 answered “not at all,” 5 refused to answer, and 15 answered “don’t know.” For item SN1: *Frequency talk on phone/get with relatives who don’t live with you*, 3,765 people gave valid responses; 747 answered “most every day,” 1,094 answered “a few times a week,” 956 answered “a few times a month,” 400 answered “once a month,” 568 answered “less than once a month,” and 5 answered “don’t know.” For item SN3: *Frequency can rely on relatives who don’t live with you to discuss worries*, there were 3,762 responses. There were 1,679 people who answered “a lot,” 1,036 who answered “some,” 596 who answered “little,” 451 answered “not at all,” 1 refused to answer, and 7 answered “don’t know.” For item SN6: *How often talk on phone or get together with friends*, 3,765 people answered; 856 answered “most every day,” 1,199 answered “a few times a week,” 855 answered “a few times a month,” 313 answered “once a month,” 540 answered “less than once a month,” and 5 answered “don’t know.” For SN8: *How much can you open up to friends and talk about worries*, there were 3,759 valid responses; 1,767 answered “a lot,”

1,121 answered “some,” 524 answered “little,” 347 answered “not at all,” 1 answered refused to answer, 10 answered “don’t know.”

Demographic variables. For the demographic variables, we also ran frequencies. For the item WKSTAT3C: *Work Status 3 categories*, there were 5,205 valid responses: 3,475 answered “employed,” 412 answered “unemployed,” and 1,318 answered “not in labor force.” For item MAR3CAT: *Marital Status – 3 categories*, there were 5,236 responses: 2,950 answered that they were “married/cohabiting,” 1,115 answered they were “divorced/separated/widowed,” and 1,171 answered they had “never married.” For item ED4CAT: *Years of education – 4 categories*, there were 5,236 total responses: 732 answered 0-11 years, 1,566 answered 12 years, 1,602 answered 13-15 years, and 1,336 answered “greater than or equal to 16 years.” For item MR16A: *# times married*, there were 3,387 responses: 2,435 people answered 1, 731 answered 2, and 221 answered 3 or more. For item AGE: *Age*, there were 5,236 responses, ranging from the age of 18 to 98. For item RANCEST: *Race/Ancestry*, there were 5,236 responses: 89 answered “all other Asian,” 310 answered “Mexican,” 170 answered “all other Hispanic,” 30 answered “Afro-Caribbean,” 631 answered “African American,” 3,826 answered “Non-Latino Whites,” and 180 answered “all other.” For the item REGION: *Region of country*, there were 5,236 responses: 942 answered “Northeast,” 1,428 answered “Midwest,” 1,734 answered “South,” 1,132 answered “West.” For the item SEX: *Sex*, 5,236 people answered: 2,161 answered “male” and 3,075 answered “female.” For the item EM7_101: *Current employ situation: 1st mention*, there were 4,311 responses: 2,683 answered “employed,” 326 answered “self-employed,” 353 answered “retired,” 279 answered “homemaker,” 110 answered “student,” 560 answered “other,” and 4

refused to answer. For item HHINC: *Household income*, there were 4,021 valid responses. There were also 1,215 missing responses. The amount of the household income ranged from \$0 to \$197,000. For item DA31B_101: *Religious preference: 1st mention*, there were 4,515 responses: 403 answered “Protestant/Protestant, no denomination mentioned,” 798 answered “Baptist (all types),” 230 answered “Lutheran,” 255 answered “Methodist (all types, including untied brethren),” 106 answered “Pentecostal,” 96 answered “Presbyterian,” 502 answered “Protestant, other (please specify),” 688 answered “Catholicism/Catholic, no denomination mentioned,” 302 answered “Catholic, Roman”; 31 answered “Catholic (all others),” 62 answered “agnostic or atheist,” 296 answered “no religious preference,” 356 answered “no religion,” 390 answered “other (specify),” 10 refused to answer, and 5 answered “don’t know.” For item DM19: *# marriages ended in divorce/annulment*, there were 15 valid responses. There were also 5221 missing responses. Of the valid responses, 1 answered 0, 8 answered 1, 5 answered 2, and 1 answered 3 or more. For item DM23: *# other living children including step/adopt/raised 5+ years*, there were 687 responses: 602 answered zero, 27 answered one, 29 answered two, 17 answered three, 5 answered four, 3 answered six or more, and 1 answered don’t know.

APPENDIX D

Split sample frequencies

Frequencies of the various variables in this study when the respondents were split into primaries (identified patient) and secondaries (family members) were run, with results as follows.

Depression

For item D24A: *Severe depressive episode – felt depressed most days*, for P (primary adult in household), there were 1,931 valid responses: there were 1,824 “yes” responses, 107 people answered “no.” There was also 1 person who refused to respond, 4 who answered “don’t know.” For the same item, for S (secondary adult in the household), there were 364 valid responses; 338 answered “yes,” and 26 answered “no.” For item D1: *Sad/depressive episode – lost interest in enjoyable things*, for P, there were 3,354 valid responses, 3,225 “yes” responses and 129 “no” responses. For S, there were 700 valid responses; 591 “yes” responses and 109 “no” responses. For item D1A: *Sad/depressive episode – lost interest in enjoyable things*, for P, there were 3,219 valid responses; 2,345 “yes” responses and 874 “no” responses. For S, there were 589 valid responses; 404 “yes” responses, 185 “no” responses. For D26CC: *Severe depressive episode – thought about suicide*, for P, there were 1,907 valid responses; 628 “yes” responses and 1,279 “no” responses. For S, there were 357 valid responses; 115 “yes” responses and 242 “no” responses. For item D26FF: *Severe depressive episode – unable to cope with daily responsibilities*, for P, there were 1,907 valid responses; 1,117 “yes” responses and 790 “no”

responses. For S, there were 355 valid responses; 183 "yes" responses and 172 "no" responses. For item D28A: *Severe depressed episode – unable to perform daily activities*, for P, there were 1,837 valid responses; 551 answered "often," 614 answered "sometimes," 388 answered "rarely," 284 answered "never." For S, there were 343 valid responses; 83 answered "often," 114 answered "sometimes," 76 answered "rarely," 70 answered "never."

Mania. For mania, for item M1: *Behavioral changes during episode of excitement*, for P, there were 1,113 valid responses; 870 answered "yes," 243 answered "no." For S, there were 234 valid responses; 168 answered "yes," 66 answered "no." For item M3: *One episode where large # behavior changes stand out*, for P, there were 865 total valid responses; 533 answered "yes," 332 answered "no." For S, there were 168 valid responses; 104 answered "yes," 64 answered "no." For item M9: *Episode plus problems affected work/social/relations*, for P, there were 905 valid responses; 185 answered "not at all," 256 answered "a little," 248 answered "some," 158 answered "a lot," 58 answered "extremely." For S, there were 184 total responses; 45 answered "not at all," 69 answered "a little," 38 answered "some," 26 answered "a lot," 6 answered "extremely." For item M9A: *Unable to do normal activities due to episode plus problems*, for P, there were 464 valid responses: a total of 121 for "often," 159 for "sometimes," 127 for "rarely," 57 for "never." For S, there were 70 valid responses: a total of 16 for "often," 26 for "sometimes," 16 for "rarely," 12 for "never." For item M7D: *Irritable episode – inappropriate behavior*, for P,

there were 1,042 valid responses: a total of 453 for “yes” and 589 for “no.” For S, there were 204 valid responses: a total of 77 for “yes” and 127 for “no.”

Family burden. For family burden, for item FB8: *Extent health of relative affects your life*, for P, there were 747 valid responses: a total of 119 for “a lot,” 166 for “some,” 161 for “a little,” and 301 for “not at all.” For S, there were 267 valid responses: a total of 51 for “a lot,” 67 for “some,” 72 for “a little,” and 77 for “not at all.” For item FB9: *Help relative with practical things due to health problems*, for P, there were 285 valid responses: a total of 97 for “yes,” 188 for “no.” For S, there were 118 valid responses: a total of 41 for “yes,” 77 for “no.” For FB12new: *Amount of time average week do things related to health problems*, for P, there were 192 valid responses: a total of 39 for “a lot,” 53 for “some,” 45 for “a little,” and 55 for “negligible.” For S, there were 76 valid responses: a total of 18 for “a lot,” 16 for “some,” 15 for “a little,” and 27 for “negligible.” For item FB14: *Extent health problems cause worry and anxiousness*, for P, there were 285 valid responses: a total of 67 for “a lot,” 107 for “some,” 66 for “a little,” and 45 for “not at all.” For S, there were 118 valid responses: a total of 21 for “a lot,” 43 for “some,” 29 for “a little,” and 25 for “not at all.” For item SN4: *How often relatives make too many demands on you*, for P, there were 2,819 valid responses: a total of 336 for “often,” 560 for “some,” 990 for “rarely,” and 933 for “never.” For S, there were 945 valid responses: a total of 79 for “often,” 190 for “some,” 337 for “rarely,” and 339 for “never.” For SN5: *How often your relatives argue with you*, for P, there were 2,821 valid responses: a total of 172 for “often,” 462 for “some,” 1,143 for “rarely,” and 1,044

for “never.” For S, there were 944 valid responses: a total of 46 for “often,” 125 for “some,” 381 for “rarely,” and 392 for “never.” For SN9: *How often friends make too many demands on you*, for P, there were 2,820 valid responses: a total of 96 for “often,” 349 for “some,” 1,117 for “rarely,” and 1,258 for “never.” For S, there were 945 valid responses: a total of 24 “for often,” 83 for “some,” 386 for “rarely,” and 452 for “never.” For item SN10: *How often your friends argue with you*, for P, there were 2,820 valid responses: 1,105 for “rarely,” 1,410 for “never.” For S, there were 945 valid responses: a total of 9 for “often,” 89 for “some,” 355 for “rarely,” and 492 for “never.”

Stigmatization. For stigmatization, there was of course only that one item. For item FB13: *Extent health problems cause embarrassment*, for P, there were 285 valid responses: a total of 8 for “a lot,” 20 for “some,” 24 for “a little,” and 233 for “a lot.” For S, there were 118 valid responses: a total of 2 for “a lot,” 6 for “some,” 5 for “a little,” and 105 for “not at all.”

Social support. For the variable social support, for item SN2: *Frequency rely on relatives who don’t live with you for serious problem*, for P, there were 2,817 valid responses: a total of 1,669 for “a lot,” 556 for “some,” 315 for “little,” 277 for “not at all.” For S, there were 944 valid responses: a total of 587 for “a lot,” 192 for “some,” 97 for “little,” and 68 for “not at all.” For item SN7: *How much can rely on friends when have serious problem*, for P, there were 2,809 valid responses: a total of 1,262 for “a lot,” 825 for “some,” 401 for “little,” and 321 for “not at all.” For S, there were 941 valid responses: a total of 471 for “a lot,” 275 for “some,” 125 for “little,” and 70 for “not at all.” For item SN14:

Easy to get close to and depend on others/no fear of abandon, for P, there were 3,103 valid responses: a total of 869 for “a lot,” 1,102 for “some,” 635 for “little,” and 497 for “not at all.” For S, there were 1,408 valid responses: a total of 559 for “a lot,” 486 for “some,” 221 for “little,” 142 for “not at all.” For item SN1:

Frequency talk on phone/get with relatives who don't live with you, for P, there were 2,819 valid responses: 577 for “most every day,” 843 for “a few times a week,” 696 for “a few times a month,” 289 for “once a month,” 414 for “less than once a month.” For S, there were 946 valid responses: a total of 170 for “most every day,” 251 for “a few times a week,” 260 for “a few times a month,” 111 for “once a month,” and 154 for “less than once a month.” For SN3, for P, there were 2,819 valid responses: a total of 1,259 for “a lot,” 760 for “some,” 445 for “little,” and 355 for “not at all.” For S, there were 943 valid responses: a total of 276 for “some,” 151 for “little,” and 96 for “not at all.” For item SN6, for P, there were 2,819 valid responses: 661 for “most every day,” 906 for “a few times a week,” 628 for “a few times a month,” 224 for “once a month,” and 400 for “less than once a month.” For S, there were 946 valid responses: a total of 197 for “most every day,” 293 for “a few times a week,” 227 for “a few times a month,” 89 for “once a month,” and 140 for “less than once a month.” For item SN8: *How much can you open up to friends and talk about worries*, for P, there were 2,817 valid responses: 1,293 for “a lot,” 853 for “some,” 403 for “little,” and 268 for “not at all.” For S, there were 942 valid responses: a total of 474 for “a lot,” 268 for “some,” 121 for “little,” and 79 for “not at all.”

Demographic variables. For the demographic variables, some split files also were obtained. For item WKSTAT3C: *Work Status 3 categories*, for P, there were 3,619 valid responses: a total of 2,411 for “employed,” 207 for “unemployed,” and 1,001 for “not in labor force.” For S, there were 1,586 valid responses: a total of 1,064 for “employed,” 205 for “unemployed,” 317 for “not in labor force.” For item MAR3CAT: *Marital Status – 3 categories*, for P, there were 3,644 valid responses, and for S there were 1,592 valid responses. For item ED4CAT: *Years of education – 4 categories*, for P, there were 3,644 valid responses, and for S, there were 1,592 valid responses. For item MR16A: *#times married*, for P, there were 2,252 valid responses, and for S there were 1,135 valid responses. For item AGE: *Age*, for P, there were 3,644 valid responses, and for S there were 1,592 valid responses. For item RANCEST: *Race/Ancestry*, for P there were 3,644 valid responses, and for S there were 1,592 valid responses. For item REGION: *Region of country*, for P there were 3,644 valid responses, and for S there were 1,592 valid response. For item SEX: *Sex*, for P there were 3,644 valid responses, and for S there were 1,592 valid responses. For item EM7_101: *Current employ situation: 1st mention*, for P, there were 2,953 valid responses, and for S there were 1,358 valid responses. For item HHINC: *Household income*, for P, there were 3,025 valid responses, and for S there were 996 valid responses. For item DA31B_101: *Religious preference: 1st mention*, for P, there were 3,103 valid responses, and for S there were 1,412 valid responses. For item DM19: *# marriages ended in divorce/annulment*, for P, there were 11 valid responses, and for S there were 4

valid responses. For item DM23: *# other living children including step/adopt/raised 5+ years*, for P, there were 516 valid responses, and for S there were 171 valid responses.

VITA

Melissa Sarah Coury grew up in Europe, Louisiana, and Washington State. Her favorite subject in high school was math. She completed a bachelor's degree with a major in psychology and a minor in Spanish. In 2006, she moved to Tennessee to begin graduate studies at the University of Tennessee. Melissa likes many things, such as dogs, reading, good friendships, AVEN, fiction writing, jogging, and Christianity, though not necessarily in that order. At the age of 16, she started considering the possibility of being a lifelong celibate, and in her 20s decided for sure that is the correct path for her. She finds it a little ironic, but interesting, to study a field such as child and family studies in graduate school.