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ABSTRACT

The purpose of this study is to examine the emotional and psychological effects well siblings encounter when a brother or sister is diagnosed with a major mental illness. Qualitative, exploratory interviews were conducted in person and audio-taped with 10 volunteers who were recruited from the National Alliance of Mental Illness (NAMI). Questions were aimed at developing a broader understanding of the feelings and experiences that may be unique to this vulnerable population.

Major findings were consistent with previous research demonstrating reactions which are associated with the sudden rupture in a sibling relationship due to mental illness. In particular survivor guilt was a common characteristic described in multiple different examples. Other responses of guilt, sadness, grief, loss, shame and stigma were also highly prevalent. Personal accounts reveal that well siblings share many of the same feelings regardless of age or circumstances. The study concluded that experiences were overwhelmingly negative and well siblings also lack sufficient support. Suggestions for future research are discussed.

THE IMPACT OF SIBLING MENTAL ILLNESS ON THE WELL SIBLING

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master in Social Work.

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2012

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This thesis is for the countless families whose lives are profoundly affected by mental illness. I wish to thank all of the siblings who so willingly and generously participated in this study. It was their compassion and desire for change that made the project possible.

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CHAPTER I

Introduction

When a sibling is diagnosed with a major mental illness such as schizophrenia or bi-polar disorder, it has a profound effect on the family. The sibling relationship is unique in that it is likely to be the longest bond shared with another person over the course of a lifetime (Cicirelli, 1991). A rupture of this bond due to psychiatric illness impacts the nature of the sibling dyad in a number of ways. While previous research has focused on the effects of mental illness on the parents and the ill sibling, less is known about the consequences of such a trauma on the “well sibling.” The purpose of this study is to capture the psychological and emotional experiences of the well sibling in order to broaden our understanding of their personal challenges and internal processes. The primary question this study intends to answer is: *What is the experience of the “well sibling” when a sibling is diagnosed with major mental illness?*

Serious psychotic illnesses such as schizophrenia and bipolar I disorder greatly impact one’s level of functioning when the illness is ongoing and chronic. The same is true for other types of disabilities. Studies have shown that there appear to be differences between siblings of adults with mental illness and siblings of adults with other disabilities. Studies such as Taylor et al., (2008) measured differences in life course outcomes between siblings of adults with intellectual deficits versus siblings of adults with mental illness. Results demonstrated that the negative psychological responses of adults with a mentally ill sibling were far more severe. Further differentiating adults with mentally ill siblings from other groups is important in distinguishing their uniqueness. Learning more about their particular reactions could be valuable to clinicians working with well siblings, as well as offer important insight into this relatively

unknown group. Through qualitative interviewing, these dynamics could be understood more clearly, and help shed light on clinical interventions and healing.

Some research has studied the well siblings' role of caretaker, and the implications of the financial (and other) burdens involved. In addition, studies such as Greenberg, Kim, & Greenley (1997) have examined the stress levels of well siblings. However, these studies have not focused in detail on emotional factors. Studies have also examined effects on well siblings' career choices and personal relationships; yet scant research is available about the multitude of psychological or emotional impacts they face as a result of having a mentally ill sibling. Existing research has found feelings of grief, loss, emotional adjustment and neglect to be common among well siblings (Abrams, 2009). These and other issues are significant in gaining a deeper knowledge of their experience. Lack of research in this area suggests that the well sibling's experience is marginalized and ignored.

In a focus group study by Lukens, Thorning and Lohrer (2004), they cite Friedrich et al. (1999) as saying, "To date, few investigators have used qualitative approaches, particularly in-depth interviewing techniques, to study the relationships between adult siblings when one or more is affected by mental illness" (p.490). This exemplifies the need for more qualitative and exploratory research to capture distinctive patterns and possible themes. Another recurring emotional feature which has surfaced in studies on adults of siblings with mental illness is guilt. The multifaceted nature of guilt and other complicated emotions influence people's lives in unknown ways. Adding to that are social attitudes towards mental illness which increase isolation and shame. To reinforce these dilemmas and the need for increased focus in this area, Madeleine Abrams (2009) describes the challenges of adults with mentally ill siblings and eloquently writes: "the sibling relationship, however, has been insufficiently explored both in the

literature and in clinical practice. And yet, the ill siblings long for a relationship with their well siblings, and well siblings suffer, often in silence” (p. 307).

CHAPTER II

Literature Review

Historically, well siblings have not been an integral part of the research around severe mental illness in the context of a family. Parents and the identified patient have been the primary focus, despite the obvious and important connection that siblings have always shared. While Freud placed quite a bit of emphasis on the sibling relationship, it was not until the late 1970's that siblings of mentally ill individuals began to be viewed as having more importance in literature. Up until that time they had mainly been researched in terms of etiology and their own risk of developing schizophrenia or other psychiatric illnesses (Judge, 1994). Parents of schizophrenics were often examined and highly criticized for their own pathology and personality traits, which were seen as contributing to the onset of a child's illness (Blasko, 2008). An excerpt from the results of one such study in 1963 examining family pathology of 17 schizophrenic patients demonstrates the trend which existed to find parents at fault:

More male than female patients came from families where one went along with the behavior of the more disturbed spouse and had passive, ineffectual fathers and disturbed, engulfing mothers. The parents of female schizophrenics were typically in opposition to each other, with a paranoid, seductive father and a cold mother (Fleck, Lidz, & Cornelison, 1963).

Terms such as "disturbed, passive, ineffectual, engulfing and cold" are vague and not descriptive enough in their meaning to reveal anything of importance about personality traits today, nor do they lend any credence in determining maladaptive parenting styles.

Towards the end of the 1960's research shifted towards family burdens of caretaking (Blasko, 2008) and it was generally accepted that parents were no longer to blame (Dixon, 1997). Researchers noticed that well siblings often did not succumb to mental illness and in many cases

were highly functional (Judge, 1994). Twin studies have also helped shed light on the complex predictors of illness, as it is not unusual for one identical twin to present with the illness but not the other (Canavan, 2000). As more neurological and scientific advances have been made incorporating genetic predispositions, environmental influences, and other potential factors as causes, research has broadened.

As parents age, well siblings often assume the roles of caretaking. Consequently, they have gained somewhat more significance and interest in learning about their experiences. Many of the burdens they face have come to light, which has in turn led to discoveries about their emotional well being. Although well siblings have mainly been disregarded in the past, more recent studies have revealed that they likely share commonalities which are strikingly prevalent (Lukens et al., 2004; Stålberg, Ekerwald, & Hultman, 2004; Abrams, 2009). It also appears that they may differ from other groups of well siblings who have brothers or sisters with varying disabilities. This does not seem surprising given the severity of mental illness, its overwhelming effect on families, and the longevity and intimacy of sibling relations.

Siblings share common genes, experiences, and environments. They also share a connection with each other that is unique from other family members. Cicirelli (1991) who has done extensive research on siblings notes that closeness and rivalry are the most commonly researched dynamics among them. Based upon in depth studies on sibling connections he concludes that most adults feel either “close” or “very close” to their siblings (p. 295). Additionally, it has been determined that closeness increases throughout the life span. It is now widely accepted in literature that most elder people have at least one sibling and remain in contact with them almost until the end of their lives. Rivalry is more complex and appears to fluctuate throughout different age categories. Gold (1989) was able to distinguish 5 categories of

sibling connections: intimate, congenial, loyal, hostile, and apathetic. Follow up studies found that most sibling connections fell into one of the first 3 categories; however, these have also been criticized for over generalizing and not taking racial and cultural variables into enough account (Cicirelli 1991).

The closeness experienced between siblings is explained by Cicirelli (1991) using attachment theory. In psychology attachment typically refers to parent child relationships. It is most generally described as “an emotional or affectional bond between two people,” and is thought to be evolutionary in nature and function as an adaptive and survival mechanism (p. 305). Based on Bowlby’s (1979) discovery and theoretical formulations, Cicirelli (1991) maintains that the theory also serves as a basis for sibling attachment. He states, “Such attachment extends to siblings in childhood and continues to adulthood and old age” (p. 305). In general attachment takes on protective qualities as the relationship matures, eventually requiring action to preserve the attachment figure and avoid any potential loss. Like parental attachment, it is through the process of identification with the sibling that the bond between them is maintained (Cicirelli, 1991).

Other theoretical underpinnings have been used to describe the power of sibling relations. In a study by Cicirelli (1980) on adult sibling relationships across the lifespan, he writes about Walter Toman’s (1976) “duplication theorem” (p. 459), which attempts to explain how childhood sibling relationships dictate the course of their adult lives. Toman (1976) theorized that the more similarities a marital partner shared with one’s sibling, the greater the likelihood of having a successful marriage. For example an older sister being married to a man who is the youngest sibling of his family would make for a conflict free marriage, because they are both assuming the same roles they had as siblings. Toman (1976) presented clinical data to support

his hypothesis, although Cicirelli (1980) notes that “there is little supporting evidence” (p. 459). Never the less, this theory could be useful when observing well siblings. Some research has shown that adults of mentally ill siblings have lower marriage rates. If early sibling relationships do help to determine life course outcomes, they may have significant impacts on partnerships, marriages and other areas of life. Given this data and what we know about how attachment can shape our destiny in determining future relationships and personality styles, a rupture in this bond would have the potential for dramatic influence on a sibling.

Disruption in sibling attachment can occur in a number of ways, namely illness, disability or death. Disabilities range vastly and may be physical or mental in nature. A disability transpiring at a later age requires more of an adjustment for the sibling and the family (Seltzer et al., 1997), whereas when one is born with a disability sibling attachment is not abruptly severed. In the case of mental disabilities, they appear to have different effects on well siblings depending on the type and severity of the illness or handicap. For example, studies comparing well siblings of autistic and Down syndrome individuals found both groups to be psycho socially well adjusted (Kaminsky & Dewey, 2002). However, studies of adults with mentally ill siblings present a much different picture.

A study by Taylor, Greenberg, Seltzer, & Floyd (2008) compared the well siblings of adults with mild intellectual deficits (ID) and well siblings of adults with mental illness (MI) to a norm group. They selected their sample from the Wisconsin Longitudinal Study, which followed sibling pairs over the life span from ages 18 to 64. The data obtained by Taylor et al., (2008) was taken from phone interviews and a self administered questionnaire sent to participants. Mental illnesses consisted almost entirely of depression and anxiety disorders. Intellectual deficits were measured by IQ scores from high school. Researchers measured levels

of psychological distress, well being, and personality characteristics among all groups. Psychological distress was measured in terms of depression; well being was measured using 6 categories (“self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth”); personality was measured using a Big 5 inventory scale (p. 909). Quantitative analysis of the data found that “siblings of adults with MI reported more psychological distress, less psychological well being, and less adaptive personality characteristics compared with the norm, particularly for siblings of men with MI” (p. 905). Moreover, the MI group was significantly more likely to experience a depressive episode. The ID group did not differ from the norm in any of those same variables. They were found to have more overall contact with their siblings than the norm group, while the MI group had less overall contact with their disabled siblings than the norm group. Reasons for this are discussed later.

One surprising result of the Taylor et al., (2008) study was that siblings of men with MI had less psychological well being, less agreeableness and higher neuroticism than the norm. Siblings of women with MI did not. This difference among genders alerted researchers to an important finding. It helped to rule out the theory that well siblings may experience more psychological distress and less well being due to entirely genetic factors. Differences among adults of brothers versus sisters pointed to symptoms being the result of experience, and not organic. Although results leave open the possibility that some genetic factors could exist, the gender discrepancy suggests that reactive effects must be at play.

The authors offer one explanation for the gender difference and cite Thorup et al., (2007) as saying that men with MI often have more severe symptoms than women which could in turn affect their siblings. This seems like a rather simplified rationale and further research on gender would be useful. Despite this important observation, one drawback of the study was that

psychological distress was interpreted only as levels of depression. Other emotional issues were not touched upon such as sadness, grief, remorse, guilt, shame or stigma. Another limitation of the study was its failure to include more major mental illnesses (i.e. schizophrenia) which would logically appear to have an even greater impact on the psyche of well siblings.

Interestingly, the Taylor et al., (2008) study supports findings from other previous studies which did focus on major mental illness. For example, Seltzer et al., (1997) contrasted siblings of adults with mental retardation (including Down Syndrome) to siblings of adults with either schizophrenia (72%) or bipolar disorder (17%) using a quantitative approach (the remaining had major depression or other diagnoses). They observed psychological well being, closeness, frequency of contact, and level of impact on the sibling's life. Data was collected using a self administered questionnaire and tests were given measuring well being. The study was attempting to establish (in part) whether or not the *type* of disability makes a difference in the well sibling's experience. It did. The researchers also noted 3 very important differences in family experiences between the two groups: "the timing of the diagnosis in the family life course, the predictability of the course of the disability, and the level of soci-et al stigma and support for the disability" (p. 395).

Results of Seltzer et al., (1997) showed that in all the areas of the well siblings' life which were examined (including careers and romantic relationships), adults with a MR sibling felt more strongly impacted in a positive way by the relationship than the adults with a MI sibling. The *kind* of impact described by the MI group was substantially more negative than the MR group. Most of the adults with a MR sibling felt it was a positive experience, while over half of the adults with a MI sibling described it as a negative experience. Follow up tests showed that this was likely due to the timing of the diagnosis and an ability to adjust to the relationship

over time. Mental retardation usually surfaces early, whereas mental illness typically occurs during the late teens or early 20's and is often sudden.

Another finding of Seltzer et al., (2007) revealed that a greater level of closeness among adults and their MR siblings predicted better psychological well being. Conversely, more emotional distance among adults with a MI sibling predicted better psychological well being. One additional finding was that the siblings of adults with MI responded differently to behavioral problems than the siblings of MR adults. The MI group showed less well being when their sibling displayed more behavioral problems, whereas the MR group was not affected at all. The researchers speculated that this may be related to a sibling's level of understanding. The MR group scored higher in sympathy and understanding towards their sibling than the MI group, suggesting they see the disability as the cause of behavioral issues. The MI group may feel more responsibility, and in turn, experience higher levels of stress.

As with Taylor et al., (2008), distancing amongst adults and their MI siblings was also evident in the Seltzer et al., (1997) study. Researchers postulated that the siblings of adults with major MI distanced themselves from their siblings as a coping mechanism to control the impact it had over their lives (Seltzer et al., 1997). They also suggested that this dynamic may be a contributing factor to the variances in socioeconomic status between MI individuals and their siblings. Certainly, the sudden and later onset of mental illness would impact one's level of grief and loss.

Taken together, both Seltzer et al., (1997) and Taylor et al., (2008) point to a different symptomatology in well siblings of adults with MI. However, the Seltzer study also did not include specific emotional factors such as grief, guilt, shame, etc. in their measurement of psychological well-being. The majority of participants were white, which undoubtedly limited

cultural and racial differences. In addition, while both studies were able to aptly measure certain characteristics, quantitative methods may not have allowed for more detailed or descriptive experiences to emerge.

Using a qualitative approach, Lukens, Thorning and Lohrer (2004) studied well siblings of individuals with major mental illness, specifically schizophrenia, schizoaffective disorder, bipolar disorder and major depression. They recruited 16 female and 3 male adult well siblings as volunteers who each participated in 1 of 5 focus groups over the course of 9 months as they discussed their experiences. Some drawbacks were the unequal ratio of women to men, and the majority of white participants. Despite these discrepancies, results demonstrated that “all the siblings consistently described a complex set of negative emotions, including anger and guilt, mourning and loss, fear, and anticipated (or future) burden” (p. 492). The study found the siblings’ reactions were distinctly different from those of their parents. Another shared response was a fear that they could become mentally ill themselves. Loss of boundaries and role confusion were common, including a feeling of having to grow up too fast and assume parental roles. Emotional neglect was also prevalent, which is consistent with other studies as well (Blasko, 2008; Abrams, 2009).

In reference to guilt expressed by the siblings, results of the Lukens et al., (2004) study stated: “Others referred to survivor’s guilt, feeling guilty about not being crazy (p. 495).” This particular statement is the authors’ only reference to “survivor guilt,” which is a loose description at best, especially given the overwhelming guilt reactions of participants. Guilt in general is described in other contexts mainly as a tendency to feel non deserving of happiness or self fulfillment over the course of their lives, given the extent of their sibling’s suffering. For example, questions emerged such as “How could I have fun if my brother is in the hospital?”

“How could I have fun when my parents are devastated?” “How could I go and do something that is good for me when I know what he’s going through?” (p. 492). These questions can all be inferred as meeting criteria for survivor’s guilt, which is important to distinguish, especially in terms of treatment and intervention. An elaboration on these feelings would be helpful in determining other kinds of guilt associated with well siblings such as a sense of fault or responsibility, remorse, and guilt commonly associated with grief.

Survival guilt is an emotion that has often been studied in relation to people who experience or witness the death of a friend, relative or loved one. However it can also be felt as a reaction to another type of significant loss such as major mental illness in a family (Abrams, 2009). Khouzam & Kissmeyer (1997) define survivor guilt as “guilt experienced by trauma victims related to surviving the fate of one’s fellows,” and is not exclusive to death or dying (p. 694). Their case study of one war veteran examined the treatment of major depression and post traumatic stress disorder (PTSD) with an anti-depressant medication. While the major depressive symptoms subsided after use of the anti-depressant, the patient’s survivor guilt became more prominent and distressing. It was eventually resolved through a spiritual experience and connection with God. Yet despite the resolution of the survivor guilt, the patient’s PTSD symptoms of nightmares, hyper vigilance, etc. persisted suggesting that survivor guilt may be “a distinct symptom of PTSD” requiring specific and separate interventions (p. 694).

The guilt described by well siblings has similar features to survivor guilt in veterans, and further research is necessary to understand the process. For example, an existential crisis exists with both veterans and well siblings about the “randomness of life,” as one struggles to find personal meaning in a tragic event. For treatment of PTSD in veterans, Harmand, Ashlock &

Miller (1993) describe the importance of integrating the meaning of past events into one's sense of being. Like Khouzam & Kissmeyer (1997), they also draw a connection to spirituality:

“Existential therapy asserts that being and meaning are intertwined in an individual's life.

Accordingly, one cannot live a life of emotional wellness if the messages (events) of one's life are incomprehensible or, in a lesser sense, seem unclear as to their significance” (p. 286).

Traumatic events often shatter meaning as those effected struggle to find some kind of answer.

As well siblings witness a crisis such as psychosis and sudden loss of identity in their sibling, meaning inevitably becomes questioned. Survival guilt has an association with meaning and presents a dilemma with this group as well.

Other reactions of well siblings are characterized by grief. Previous research has noted that the grief experienced in response to a family member succumbing to mental illness is similar to that of a death (Stein and Wemmerus, 2001). In a qualitative study by Riebschleger (1991), 21 (11 female and 9 male) well siblings were interviewed via telephone and in person. All had a sibling with chronic mental illness (schizophrenia, bipolar affective disorders and one organically impaired individual). They were asked a series of questions covering 8 issues including emotional reactions from the time of onset, perceived effect on their lives, experiences within the mental health system, and reactions from friends, family or outsiders.

Results of the study concluded that “siblings experience the mental illness of their brother or sister as a personal trauma that elicits many negative emotional experiences consistent with grief and loss.” Other emotional responses were interpreted as phases of the grief and loss: denial, anger, bargaining, depression, relief/respice, and acceptance. Five of these stages were initially introduced by Kubler-Ross (1969) as emotional phases people undergo when faced with death. The exception of relief/respice was found in Riebschleger's (1991) study as an additional

process that well siblings described. Siblings moved through all 6 stages, but not in any particular order and often fluctuating. They also expressed that these symptoms were brought on as result of their siblings' illness and by inconsistencies in the mental health system.

Although Riebschleger's (1991) study had a fairly equal gender ratio, the interviews were not audio taped. This compromised the reliability of results, and limited the findings (and was acknowledged in their discussion). Another limitation of the study was the interviews were not all conducted in person which could have further omitted important observable data such as emotional responses, affect, evasiveness, etc. However, is it important to say that this research has been acknowledged as one of the few well sibling studies using qualitative methods and producing valuable and insightful data, demonstrating the need for further in-depth interviewing techniques (Lukens et. al., 2004).

Physical disabilities should also be considered when comparing well siblings' experiences. Dew, Balandin, & Llewellyn (2008) performed an extensive literature review on the psychosocial impact of well siblings having a brother or sister with a lifelong physical disability. Their review included research from 1970 to 2008. In all, they found 21 empirical studies, only 4 of which addressed adult sibling relationships. Clearly there is a gap in the literature on these adult siblings and how they are impacted by childhood experiences.

One the 4 adult studies found that well siblings of people with physical disabilities reported positive results including: "a greater understanding of people; more tolerance and compassion towards people in general; a heightened awareness of the consequences of prejudice; an appreciation of their own good health and intelligence; and a feeling that the experience had resulted in closer family ties"(Grossman 1972). However, they also reported a sense of guilt, shame, and a feeling of being defective themselves. Grossman's (1972) study included both

intellectual disabilities and Cerebral palsy. A second study by Burton & Parks (1994) found positive results such as increased flexibility, responsibility and tolerance. They also concluded that well siblings had significantly higher levels of internal locus of control than a norm group, and possibly greater psychological strength. Disabilities in this study ranged in type and severity. The other two adult studies focused on the sibling relationship, and not on the well sibling.

Existing studies on well siblings have used methodologies such as clinical interviewing, quantitative longitudinal studies, and focus group studies. However, qualitative research remains limited. Lukens, Throning & Lohrer (2004), cite Friedrich et al. (1999) as saying, “To date, few investigators have used qualitative approaches, particularly in-depth interviewing techniques, to study the relationships between adult siblings when one or more is affected by mental illness” (p.490). Moreover, while existing research has uncovered similar features among this particular group of siblings, there remains a gap in delineating and identifying specific reactions which could prove to be unique. It exemplifies the need for more qualitative and exploratory methods to capture their individual experiences and identify possible themes. It would also open the door to examining cross cultural differences in the future and determining which reactions are universal versus culturally, racially or ethnically dependent. Differences among gender should also be further analyzed.

According to the National Institute of Mental Health (1993) schizophrenia affects approximately 1.1% of adults over the age of 18 in the United States in a given year, and approximately 2.6% are affected by bipolar disorder. Additionally, the US Census Bureau (2001) reports that approximately 79% of children live with at least one sibling. These numbers indicate the vast amount of well siblings who are most likely impacted. Existing research

indicates that adults of siblings with major mental illness experience a cluster of symptoms and life experiences which are serious and complex. More comprehensive studies are needed to broaden our understanding of this vulnerable population.

CHAPTER III

Methodology

Sample

The purpose of this study is to capture the psychological and emotional experiences of the well sibling in order to broaden our understanding of their personal challenges and internal processes. The methodology is a qualitative, interview based study. A random sample of 12 - 15 adults consisting of men and women will be interviewed individually during an in person, audiotaped session. The sample of adults should be over the age of 30 and have a sibling with a chronic mental illness of either schizophrenia or bipolar disorder (or a variation of such as schizoaffective disorder). A nonprobability sampling method will be used to select participants based on availability, for the purpose of convenience and practicality. Names will remain anonymous and not be matched up with interviews. Participants will not know about each other and all interviews will be held at separate times. The primary question this study intends to answer is: *What is the experience of the “well sibling” when a sibling is diagnosed with major mental illness?*

Recruitment

Recruitment will begin following approval from the Human Subjects Review Board of the Smith College School for Social Work (see Appendix A). Participants will be recruited on a volunteer basis. I plan to post an advertisement on the “list serve” computer network system of the Alameda County Psychological Association (see Appendix B). This organization is a local affiliate of the American Psychological Association. I have been in touch with a psychologist from the association and have received verbal permission to submit a posting. Their online system is a resource for psychologists of the ACPA to post questions, advertisements, and share

information with other members for purposes of networking, research and collaboration. The members of the ACPA are all licensed psychologists who have regular access to patients and family members associated with mental illness. It is common practice to use the network for information sharing, questions, and research purposes such as recruiting participants. Because their network system is a main feature of being a member of the association, there is a high response rate to posts and research requests. Their website is <http://www.alamedapsych.org/>.

Another method of recruitment will be from the National Association of Mental Illness (NAMI), which I have been in contact with in regards to the proposed study. NAMI's San Francisco office is the headquarters for the California Bay Area. They hold weekly "family to family" support group meetings for family members associated with a mentally ill member. The San Francisco office has offered to post flyers in the form of an advertisement and distribute them to group members who may be willing to participate in the study (see Appendix B). I am responsible for making the flyers in accordance with the HSRB rules. In addition, NAMI has offered to post the advertisement on their Facebook page with information about the study for interested volunteers. NAMI serves a wide range of people who have or are affected by mental illness, and have responded positively to my request for assistance in recruiting participants. They have numerous other local offices throughout the Bay Area which also hold support groups and other services. If necessary, flyers could be distributed to these offices as well.

Volunteers will contact me directly for screening. Recruitment criteria for participation is as follows: being age 25 years or older, having a sibling diagnosed with major mental illness, diagnosis must have occurred at least 5 years ago, and participants must not have a mental illness. Any affiliations with local agencies will also need to be determined. Once participants qualify for interviewing, a meeting time will be arranged at a convenient location.

Measures

For the proposed study, the 12 - 15 participants will be interviewed by me, the researcher. Qualitative data will be obtained through standardized, mostly open-ended interview questions (see Appendix C). The wording and sequencing of the questions will be precise in nature. To control for bias, all interview questions will be the same and asked in the same order. A cross sectional, exploratory design will allow for possible themes to emerge among participants' responses. Responses will be unstructured, and participants will not be limited to their response times. As this study attempts to explore the emotional and psychological experiences of well siblings, several questions will aim to gather information in this area.

Interview questions will begin by asking participants basic demographic questions such as the type of diagnosis their sibling has, the age of onset, age difference between the siblings, length of time they have lived with the diagnosis, and family or life circumstances surrounding the diagnosis. Questions will focus on their emotional and psychological experiences as well siblings, with particular attention to grief, loss, guilt, shame, stigma, and how they feel their lives have been impacted. Descriptive interviews will also explore their adult relationships, career choices, and how these have been influenced by having an ill sibling. Questions will also investigate well siblings' changing roles within the family system in response to the sibling rupture, and if they perceive their experience as overlooked or ignored. The study will attempt to choose a diverse sample of participants in order to examine possible cultural and socioeconomic differences.

Depending on participants' responses, interview questions may probe further. For example, if a participant states they had feelings of guilt, the interviewer will ask them to

describe these feelings in more detail. Additional questions will ask more specifically about their adult lives and if they feel their experience has had an effect on their relationships, careers, or any other aspects.

Data Analysis

Demographic data will be collected for all participants. The most relevant demographic information for this study is gender, age, ethnicity and socioeconomic status. The sample will be as diverse as possible with the aim of having a near equal ratio of men and women. These demographics are factors which could affect the results and highlight differences among participants. One hypothesis of the study is that similarities of emotional responses will be evident in most or all of participants regardless of demographics. Demographic data will be analyzed by breaking groups into categories and comparing responses.

The initial step in analyzing recorded data will be done through a process of open coding. Answers to each question will be transcribed so that all responses are organized to correspond with each question. For example, each question will list the responses of each participant. A list will be kept of each response. Through detailed observations of the responses, the data will then be categorized according to content, including specific words, phrases and possible themes that emerge. The categories will depend on the similarities or differences of responses. As each person's experience is subjective, the data will be further broken down into subheadings and hierarchies to capture each person's unique experience. The data will then be analyzed for comparisons. Words which are used most often will be counted, as well as any phrases or themes having the same or similar meanings. These code categories will be further developed as the qualitative data is examined.

Following the coding of data, the next step will be to identify possible patterns and relationships among responses. Using a grounded theory approach, observations of possible commonalities that emerge will inform a conclusion or possible theory about the experience of well siblings. This process will begin by comparing participants' responses for similarities or differences, and then identifying relationships between them. Frequency, magnitude and structure will be noted. As patterns become more obvious, data will be sorted according to what is relevant. The categories will then be condensed to reflect the pertinent themes and responses. The remaining materials will be used to inform the results of the study and form a conclusion.

The data analyzed should answer questions about well siblings' psychological and emotional experiences to having a mentally ill sibling. Answers should explain how they have personally been affected and the impact over their lives. Questions will attempt to capture a timeline from their initial responses at the time of diagnosis to how they feel today. The interviews are expected to uncover similarities in well siblings' emotional experiences which have not yet been understood or investigated thoroughly.

Storage

To ensure confidentiality, participants signed consent forms will remain separate from their results and placed in an envelope (see Appendix D). Codes in the form of numbers will be assigned to participants instead of using their names, so that the interviews will be anonymous. It will be the researcher's responsibility not to divulge any names or use any identifiable information. The tapes will be transcribed and analyzed by the researcher to further protect the participant's privacy. Research advisors will have access to the data once anonymity has been established. Any presentations or publications of the study will be explained in terms of the

group as a whole, rather than individual accounts. Any quotes or comments will be disguised so as to not reveal the personal identity of the participant. After the completion of the study, all materials will be kept in a secure location until they can later be destroyed. This is in accordance with federal regulations.

CHAPTER IV

Findings

This chapter contains the findings of interviews conducted with 10 well siblings who have a brother or a sister with mental illness. All interviews were conducted in the same format, and questions were asked in the same order. Some interviews asked additional follow up questions in an attempt to capture more detailed and accurate information, or to clarify a participant's response. The purpose of this study was to gain a deeper perspective of the experience of well siblings and determine possible commonalities or themes. The data from these interviews was gathered using a grounded theory approach. It begins with demographic data followed by responses to the interview questions.

Demographic Data

The study was comprised of 10 participants: 9 women and one man (n=10). Despite an effort to create a diverse sample through advertising, the majority of volunteers were women. All female participants identified as Caucasian, and the one male participant identified as Japanese/ Mexican American. All participants were born and raised in the United States, with the exception of the male participant who was born in the U.S. and grew up in Tokyo, Japan and Mountain View, CA until the age of 17. During this time he lived for several years in each country. All participants were English speaking. Each participant had a brother or sister diagnosed with a major mental illness (8=schizophrenia, 1=schizoaffective disorder, 1=bipolar NOS). The degree, course of illness, situational factors, and levels of functionality of their siblings varied. Ages among women were as follows: 28, 33, 34, 38, 46, 50, 53, 56, and 57. The male participant was 20 years of age.

One unexpected finding which appeared to be age related was in participants 50 years and over, who stated that mental illness was either not discussed in their families or was of a secretive nature. There were no leading questions geared at eliciting this specific information, yet it was revealed throughout questioning. They were not asked the impact that this had, however all responded

affirmatively to experiencing shame and/or stigma. They also did not say why their families (parents) had not discussed it openly. The participants identified the sex of their mentally ill sibling, their diagnosis, and how many years apart they are in age. The information is as follows:

Table 1:

Sibling order, Sex, Family Size and Age of Diagnosis

PARTICIPANT	DIAGNOSIS OF SIBLING AGE OF DIAGNOSIS	SEX/BIRTH ORDER	# OF SIBS IN FAMILY
20 year old male	Paranoid schizophrenia Diagnosed: age 17	Brother, 4 yrs older	2
28 year old female	Paranoid Schizophrenia Diagnosed: age 27	Brother, 20 months older	2
33 year old female	Schizophrenia Diagnosed: age 23	Brother, 9 yrs younger	2
34 year old female	Schizoaffective disorder Diagnosed: age 24	Brother, 3 ½ yrs younger	4
38 year old female	Bipolar NOS Diagnosed: age 21	Sister, 4 yrs older	2
46 year old female	Schizophrenia Diagnosed: age 19	Brother, 1 yr younger	2
50 year old female	Schizophrenia Diagnosed: age 20	Sister, 5 yrs older	5
53 year old female	Paranoid Schizophrenia Diagnosed: age 20	Brother, 2 yrs younger	5
56 year old female	Schizophrenia Diagnosed: age 18	Brother, 3 yrs older	3
57 year old female	Schizophrenia Diagnosed: age 15	Brother, 5 yrs older	4

It should be noted that while participants were asked to state the actual age of an official diagnosis of their sibling, in all cases there were factors or precipitating events leading up to the diagnosis. It is also important to clarify that the sibling with bi-polar disorder was reported to be at a higher level of functioning than other siblings. This means she had been able to work at different points in her life and psychosis was not chronic but sporadic.

Parents' Reaction to Diagnosis

This question asked: "What was your parents' reaction to the diagnosis?" The question was aimed at trying to understand how this may have impacted the siblings' experience and in what ways. Parents' responses to diagnosis can affect the amount of caretaking a sibling provides, as well as their attitudes, beliefs, outlook, support, and course of action. There was a wide range of responses. In some cases mothers reacted differently to fathers. For example, four participants said their parents had taken an active role in learning and educating themselves about the illness, while participating in care. In 3 of these 4 cases the mothers took a much more active role than the fathers and sustained a deeper level of involvement. Two of these mothers were described as not giving up. It was not asked or explained why the fathers in these cases had less involvement as the mothers.

A fifth participant was unsure of her parents' reactions, because it was not discussed within the family. The sixth participant said her parents had a sense of guilt, and it was a time during the 70's. She stated, "It was something the mother did or something, so they really struggled with it." The 7th participant speculated that her mother had also felt guilty. Three out of the 10 participants specifically stated denial as a primary reaction. The male participant stated his father "is very organic and all that, he was like you don't need the medication." His mother felt differently and was more proactive with care; however both parents had "a lack of understanding." As a follow up question, this participant was asked about possible cultural differences since his father was in Japan and mother from Mexico. He responded:

“if you’re diagnosed with something you should take the medication, even in Japan. It was just my dad. He was like just eat vegetables, stay healthy and it will go away.”

Another participant described her parents’ denial as “complex, not wanting to believe it.” She also stated they had thought her brother may be “demon possessed,” and felt “like it was his own fault because he had chosen to play extensive amounts of video games over the last couple of years and bailed out of school so it was his own choice that this was how things had turned out.” She added that later her mother joined NAMI and became more educated and was a strong support person. This was similar to the third participant who stated “total denial” was her parents’ response. She clarified that it was “denial that this was a mental disease.” Her father had also felt ashamed of the diagnosis.

Closeness of Sibling Relationship Prior to Diagnosis

This question asked: “Did you have a close relationship with your sibling prior to the diagnosis?” The level of closeness between siblings before and after diagnosis was asked in order to ascertain the effects the illness may have had on the relationship. Additionally this question seeks to establish the nature of the siblings’ relationship prior to any rupture that may have occurred as a result of illness. Given whether or not there was a change, it could also help to determine the emotional impact or consequences the well sibling may have experienced as a result. Eight out of 10 participants stated they *did* have a close relationship with their sibling prior to diagnosis. Two participants did not, one due to family dynamics and the other because she moved away from home at 16 and said she did not have a lot in common with her brother.

No participants gave specific feelings in regards to being close to their siblings; however, most gave examples of childhood times they spent together to demonstrate the closeness. Some just gave very brief answers. A few people mentioned a severing in the relationship at some point due to their sibling’s illness. For example, one woman stated:

Yeah, then I was friends with his friends so it was kind of typical, we got a long really well because I was the younger sister by a few years, and he had the really cool cars, I remember that, a little red Porsche and you know stuff like that. But it was short lived.

Another participant described a rupture in the relationship when his brother was sent to juvenile hall for 2 years. One woman described her sister as “my best friend, but then as teenagers we drifted apart, I think the disease started to manifest fairly early on.”

Primary Reactions and Feelings around Diagnosis

This question asked: “What would you say were the primary emotional reactions and feelings you experienced around the time of diagnosis and the realization of mental illness?” The question sought to gain a sense of the well siblings’ emotional experience in response to the realization that their brother or sister had a mental illness. It seeks to understand how this may have changed their lives or impacted them in different ways. All participants described what their experience was like during this time. Some used specific emotions, while others used examples of what was transpiring in their lives or their sibling’s lives. Some participants gave elaborate answers to the question while others gave more brief responses. Feelings ranged from “grief, sadness, denial, guilt, devastation, loss, fear and anxiety, confusion, shame, resentment, and disbelief or shock.” One person stated denial as their primary reaction. Another stated fear of not seeing his brother again due to incarceration as his primary reaction. Of all the emotions described, grief and sadness and loss were the most common. Seven out of 10 participants named “sadness” as a reaction in their responses. The remaining 3 participants implied sadness while describing the loss but did not name it specifically. One of these three was the participant who had a sister with bipolar NOS. She said that while her reactions have changed over time, she suffered from depression and anxiety as a result of her sister’s illness and the stress it caused on the family. In all cases, there was an intensity portrayed in the answers. Two people said it was like experiencing a death. Both examples of that are as follows:

It was as if he had died. It was severe grief, a sense of guilt that he was the one diagnosed, but the rest of us weren't, and why did he pull the short straw on that? A sense of responsibility... I had one of those light bulb moments when he was catatonic for a few days before I took him into the hospital and I sat down with him. He was lying in bed and he was looking up at me but he was none responsive. I told him that things were not adding up, he thought the FBI was trying to poison him, etc. I suggested that we go to the hospital and that his dreams of becoming a cop or joining the military would never come to be. That if he was pretending, he needed to stop immediately because it wasn't funny. If he couldn't make the decision to go to the hospital that I would and that I would be there with him through every step of this for the rest of his life if that's what needed to happen.

Second example of describing a death:

Disbelief or shock. Just grief, I've had to grieve, I still grieve. We've all gotten therapists to help deal with the emotions... yeah I think grief is the number one. And tremendous sadness, it's like his body's still here but he's not. You know it's like he lives in a completely different reality and he's unreachable. There's a barrier between me and him and that's his disease and it's really frustrating. It's the loss of my brother as I've known him. Like this person is no longer here. Like a death but worse because there's hope and then you teeter and you go back and forth, and it's exhausting. Like there's no closure. I'm not saying that I want my brother to die.

Other participants described many different emotional states and reactions such as the following:

I think I felt a sense of guilt, wondering if I had done something or if... I think it was very confusing and I was very sad about it. I didn't quite understand it, but he was now in the system. And I felt a sense of relief too because there was something versus this is just a defiant young man who gets violent and angry and who is causing me a lot of strife in my life. I think for me the sadness was a loss of potential. He was a great kid, he was an attractive young man, athletic,

had friends, he had been chosen to be one of the 10 students used for the models of pictures of the year book, and so it was sort of this recognition that his life is very different. I think the other thing... the confusion was sort of a cover for shame. I already came from a very dysfunctional family, there was alcoholism, so we already had weird family dynamics so just was one more layer of like what the hell do we do now?

Another response with complex feelings:

Very devastating for me. The challenges in my life just grew drastically and even physically I lost 15 lbs which is a lot. I think I felt a real sadness all the time. It's hard to even come to grips with the word schizophrenia. I felt like I was doing things on the surface.

One participant describing sadness and anxiety:

Initially of course I was very sad. I felt like my mom could be doing more, but I don't know if she knew how...there was a period of time when I didn't see him, I didn't know where he was for 6 years. I was very worried, I was sad and consumed with it and I wanted to help him and I wanted everything to work great and I wanted my mom to come and help. And my step dad you know he didn't really understand a lot about mental illness. But finally I got everybody together again. I probably did too much but then you kind of have to.

A description of sadness, anger and resentment in one participant:

Really sad, sad to know that all of the hopes that my mother had, all of the optimism that she had that he would you know somehow straighten out probably would never be realized, and remember I was 10 years old at the time. A real sense of loss on my own part knowing that he would now, as he had been all along but now even more so would become the sole focus of my parents' attention. Anger that I almost didn't matter anymore. Tremendous resentment. I felt invisible.

One participant did not name any emotion but described a loss:

Well see it was like he was almost sent away, so I didn't have a relationship with him anymore, I mean I'd visit him. I kind of just went with the flow. I didn't know any other way to be. As I got older I could definitely see the loss, I lost my brother.

Finally, the participant who had a sister with bi-polar disorder said she grieved the "loss of her childhood." She also stated: a lot of the grieving I have done has been around just the weight of having to carry sanity for my whole family."

Worries or Fears about Self

This question asked: "Did you have any worries or fears concerning yourself around the time of diagnosis or afterwards? If so what were they?" Some research has found that well siblings may fear mental illness in themselves or their offspring as a result of their sibling's diagnosis. This question was aimed at gaining insight into specific fears they may have concerning themselves. Responses were mostly brief, and interpretations of the question seemed to range. Three out of 10 participants did not name any fears concerning themselves. One participant described being afraid of her brother who had a tendency to be violent. Two participants said they were worried about passing the illness onto their children. One of them also worried about herself developing a mental illness. Her description of this fear is as follows:

Yes I worry about myself and my children. For myself whenever I am tired or stressed and I happened to be taking a shower at that time, I will have weird noises in the sound of the water running. I've talked to my sister about it and she says she's had similar experiences and after I found out that my brother had mental illness I've always been suspect of this and wondering if this was an opportunity that I needed to keep strong control over my brain because otherwise I could end of going down the same path as him. And I know that it's probably normal. I also have strong worries about my children, I have a 10 year old, 7 year old, 6 year old and a 2 year old. The 2 year old is a boy the other ones are girls, and I have a stronger worry for the boy because the mental disease seems to run more strongly in the males in my family.

Two participants said they worried about themselves succumbing to stress over the situation: one thought she may have “a breakdown,” the other was in treatment for alcoholism and worried that she may drink again as a result of stress. The remaining two participants cited concerns that they could also become mentally ill.

Grief or Sadness

This question asked: “Did you experience any grief or sadness and can you describe what it was like?” The question appeared somewhat redundant in the series of questions asked, given that grief and sadness were mentioned frequently in response to the previous question asking about emotional reactions. Given this, most responses were brief. However, 9 out of 10 participants answered “yes” to the question, citing different examples. The remaining participant did not remember grief or sadness, but rather denial, fear and a “sense of moving on.” All spoke about grief in different ways. One poignant and articulate example outlines many facets of this participant’s experience which was a similar voice to others:

It was a loss, the knowledge that he would never be the person that I knew before, he would always be somebody different. The incredible sense of responsibility that I did not know how this was going to play out but I needed to make sure I help him in some way, that he was now a child of mine. I guess I felt very maternally about the situation... but just incredible grief. And every time he goes into an episode that grief returns. My sister and I have cried together, and a sense of how unfair it is, because mental illness is not a disease from which one recovers so it’s pretty bad.

Other participants when describing grief or sadness used similar examples of situations, crises, or how they felt as a result of the circumstances.

Guilt or Powerlessness over Fate of the Sibling

This question asked: “Did you or do you ever feel a sense of guilt or powerlessness over the fate of your sibling? If so please give example.” This study is interested in capturing any feelings of guilt in well siblings not only to make more sense of their experience, but particularly to explore the possibility of survivor guilt or other types of guilt. This question also appeared somewhat redundant to previous questions which evoked responses involving guilt and powerlessness, yet was necessary in trying to determine one’s level of personal guilt, especially if it was not mentioned in a previous answer. In establishing the possibility of survivor guilt in well siblings, this question was aimed at eliciting any feelings that might suggest guilt for having a healthy functioning life (while their sibling could not) or guilt for not being mentally ill. Previous research identified different aspects of guilt including that of survival guilt, therefore this question sought to explore it further.

In a previous question asking about the level of closeness among siblings, one participant responded saying she wondered if she had contributed to her brother’s illness in some way. This exemplifies one aspect of guilt. Another participant questioned why her brother had succumbed to illness and not her. This signifies guilt on a different level. Other examples portrayed people’s sense of guilt for different reasons. All responses were critical in developing a deeper understanding of the experience.

Responses were more heavily related to guilt than powerlessness, although three participants said they felt powerless but not guilty. Their reasons for feeling powerless varied depending on the individual (and examples were given in each case), but they did not differ in that all 3 felt helpless to change circumstances that had been created due to their siblings’ illness. However, one of the 3 who said they did *not* feel guilty later eluded to possible feelings of guilt when asked a follow up question. For example:

Not guilt but I feel not happy. But if I’m doing something and I don’t want to do it I just think about my brother and that he won’t be able to do it so I have to... so if it’s like work or

something, like if I don't really want to go to work, I'll think about my brother, and then I'll like push myself.

While this participant said he did not feel guilty, his answer may be contradictory. Another of the participants who responded "no" to feeling guilty over having a functional life (during a follow up question), said it was because she would "not allow" herself to feel that way. Therefore 2 of the 3 answers responding negatively to guilt are considered ambiguous. The third stated "I don't think so" to the question.

The remaining 7 participants said they felt guilty *and* powerless, and cited examples of each. With regards to guilt, all 7 explained in their own words how they felt guilty for having a normal and functional life while their sibling cannot. This was a recurring theme which would sometimes be explained in different ways (and in some cases was asked as a follow up question for verification and clarification). All 7 examples from the responses are as follows:

Example #1:

I feel guilty now that I don't have more interaction with him. That I can go for periods of time and he's not uppermost in my mind. I think the hardest thing is he is aware he's mentally ill. He'll often say "so do you still live in SF?" And I'll say yes, and he'll say "do you still have an apartment," and I'll say yeah, and "are you still living by yourself," yeah, and then he'll say "you know I've been thinking I'd like to get an apartment too." And it just breaks my heart because it's realizing his limitations.

Example #2:

The guilt, just sometimes I feel I should be doing more... there are times when I don't call her, yeah I do actually call her at least once or twice a week, but sometimes I think I should probably check in with her and so sometimes I feel guilty for not doing more. I guess a little bit I think sometimes, yeah around things like I have a job, I have more money than she does, I have a home, so those kinds of things.

Example #3:

Oh all the time I feel guilt. He may never be like me and it's sad for me that he doesn't have anybody in his life like a girlfriend or boyfriend or stuff like that. I mean I have friends I have a boyfriend, school, I mean I have things that are normal. It makes you feel kind of sad. A lot of times I feel angry, just how did this happen? Like why my family, why my brother?

Example #4:

I'm well and he's not? There is that. Definitely. I wish I could have taken some of his burdens and I wish I could get well for him. But the powerlessness is really challenging. I can't get well for my brother, so that's when you go to Alanon and gel with your powerlessness and turn it over.

Example #5:

She's tried to make me feel guilty and I think I did probably more in my 20's feel a sense of guilt, and I still feel like there are ways in which I hold back from succeeding on my own, there are ways in which I refrain from pursuing certain dreams because it would just be... like I'm just not allowed to be that successful.

Example #6:

I would say both, I think guilt as in anything we could have done differently. Like is it a reaction to him being totally stressed out about my family, or was I not there enough for him. When it first happened I thought it was our fault, my parents or whatever me... not that there was any trauma but every family I think has their stresses. And powerlessness...there's just nothing you can do a lot of the time, I wonder if I had a million dollars could I fix it? You really can't fix it.. so it is powerless. Over the last year I barely socialized with my friends, I just felt like I couldn't have fun. Like it just isn't right. He was in the hospital, he was sick, it just didn't feel right to me to be having any fun or be social so really last year was totally focused on him.

Example #7:

Yes quite a substantial amount of both. Guilt that he was genetically chosen for this experience. Guilt that I'm not caring for him and I'm not more involved than I am. Guilt that I don't call him more than I do or participate in a greater degree in his care and well being. Powerlessness because of the vast inefficiencies that exist in the mental health care system. And constantly trying to advocate for him and feeling very emotionally engaged in that, very stressed, very angry, very overwhelmed especially during an episode that there are so many barriers to him receiving quality care. Finding out about the torture that he experiences not just from his disease but because of the quality of care that he receives.

Three of these 7 also stated they felt guilty for not having more of a relationship or being more involved in their sibling's life.

Other examples of guilt were also cited. For example, one woman felt guilty for not letting her sister out of the hospital when she was ill. The same woman also felt powerless over her sister's illness by not being able to influence her decision to take medication, etc. This was also the case with another participant who could not control his brother's decision to take medication. He added that he felt guilty for not "pushing the issue" because his brother was later incarcerated. Similarly, one woman felt powerless over not being able to control her sister's symptoms of paranoia, especially when her sister was paranoid about her. Two people said they felt powerless over the mental health system and its lack of help.

Feeling Alone in the Experience as a Well Sibling

This question asked: "Have you felt alone in your experience as a "well sibling" and if so how?" Seven out of ten responses to this question answered an emphatic "yes." In 6 out of the 7 answers the feeling of aloneness was reported to be due to lack of understanding from the outside world, including friends and relatives. This left people with the inability to talk to others or seek understanding from

others. One person out of the 7 acknowledged the same lack of understanding from others but said her primary feeling of aloneness was as a caretaker because others in her family had not done enough and the responsibility had fallen on her. A second person out of the 7 also stated lack of understanding but said she felt “like an only child now,” due to the loss of her brother who was missing and presumed to be somewhere in Mexico at the time of the interview. Out of the remaining 3 responses one person answered “no,” another stated “in some ways” (citing examples), and one person answered: “no, I feel jealous sometimes when I see my friends with their siblings.”

Sibling Relationship since Diagnosis

This question asked: “Has the relationship with you and your sibling changed since diagnosis? If so, how?” Asking about the sibling relationship and level of closeness since diagnosis and leading up the present day was important to ascertain the effects of any rupture between siblings due to illness. Additionally it helped to provide insight into how the relationship has impacted the well sibling over time, and understand why they are closer or not closer as a result of mental illness. A strain on the relationship may have other implications to the well sibling. The following is a chart with the level of closeness before and after diagnosis. Six out of ten participants reported having a close relationship with their sibling prior to diagnosis. All six reported a more distant relationship now as a result of their sibling’s illness. Two participants reported being close prior to illness and are closer now. Two participants did not have a close relationship with their sibling prior to diagnosis; one feels “much closer” now and the other remains distant. See Table 2 on the next page

Table 2

Sibling Relationships Prior to and After Diagnosis

CLOSENESS PRIOR TO DIAGNOSIS	CLOSENESS SINCE DIAGNOSIS
Yes	More distant
Yes	More distant
Yes	More distant
Yes	More distant
Yes	More distant
Yes	More distant
Yes	Closer
Yes	Closer
No	Closer
No	Unchanged/Distant

Shame and Stigma

This question asked: “Do you feel that shame or stigma have personally affected you? If so, how?” The question elicited a range of responses because it was asking about two different separate issues. This was problematic in the questioning because participants answered (in most cases) without clarifying whether they were referring to shame or stigma and by giving examples. Ten out of ten participants responded “yes” to the question. Below is a chart outlining details and specific feelings:

Table 3

Reasons for Shame or Stigma

SHAME OR STIGMA	REASONS
Yes	Being excluded and ostracized from activities growing up due to brother's illness. Not able to talk about it. Lack of understanding from others. Fear of people assuming similarities or sameness (discrimination).
Yes	Lack of understanding from others. Not able to talk about it. Fear of judgment from others. Fear of people assuming similarities or sameness (discrimination).
Yes	Not able to discuss it with others; lack of understanding from others.
Yes	Not able to discuss it with others; fear of judgment and people assuming similarities or likeness (discrimination). Fear of "being painted with the same brush." Lack of understanding from others.
Yes	Not able to discuss with others; lack of understanding from others; fear of judgment.
Yes	Not able to talk about it; fear of judgment.
Yes	Not able to talk about it.
Yes	Feelings of shame; lack of understanding from others.
Yes	Shame and embarrassment; fear of judgment from others; lack of understanding from others. Fear of people assuming similarities or sameness (discrimination).
No to shame, yes to stigma	Lack of understanding or help from others (more so in the past than now).

In almost all cases, participants said they would not discuss their situation with others due to lack of understanding, or fear of judgment or discrimination. Some said they could not talk about it as if it was simply not an option. For example, one participant stated:

Yeah like I'll try and avoid that as much as possible. Like if somebody asks me if I have a brother and what they're doing I'll just say he's in Japan. And then if they ask what's he doing I'll just say I don't know.

One woman did not disclose her brother's illness in medical records for fear that it "could bias the health care professionals from providing quality care for myself or my children." Another woman was excluded from girl scouts while growing up due to her brother's condition and said she experienced other discrimination. She felt angry about it and gave the following example:

Developmentally it was all over me. I was excluded from things, I was told that I was somehow infectious, I was told that I for instance was not allowed to hold an office in my girl scout group because people thought that like my brother I would abuse other kids.

In a follow up question she stated:

I have no happy memories; it was constant chaos and tension. I mean I don't feel any shame about saying it, but the fact is why say it? Nobody's going to understand what I'm talking about anyway. My partner of 27 years doesn't understand it.

At some point in the interview, participants specifically referenced difficulty at work. Examples are as follows:

Example #1:

So when your mom gets cancer you can tell your coworkers my mom has cancer and you get sympathy and you have support. I find myself loath to say my brother is schizophrenic because people don't know how to respond. They don't understand and they think oh my God this reflects on your family, you're airing your dirty laundry to me, I'm incredibly uncomfortable. It's so awful and unnecessary.

Example #2:

I think some of it is the ridiculous fear of what their judgment would be and will I be painted with the same brush? And sometimes it isn't about the shame it's about how much I'm willing to expose. I tend to be a private person. It's so misunderstood... fear of judgment and fear of misunderstanding.

Example #3:

Like recently my mom stopped by my work because she had gotten a call from my dad about my sister and that was very hard for me, for her to interrupt my work day to talk about my sister's mental illness is like... I think there was some shame there, this is not the place. My sister had a job for a branch for the city of government that I wanted to get a job at later. She thinks she was fired because she had a mental illness but that's not the reason they gave because they're not allowed to give that reason, so I did feel like going in there I had to prove I wasn't my sister, that they wouldn't hire me if they felt like I had the same issues around stability that she did.

Other participants also described fear of discrimination using different examples.

Necessary Support for Coping

This question asked: “Do you feel you have had the necessary support in your ability to cope, understand, and come to terms with your sibling’s illness and resolve any other personal issues that may have occurred?” The question was aimed at determining levels of support for well siblings as well as the ways in which they have or have not had access to help in coming to terms with their sibling’s illness or dealing with any other factors that may have affected them. Five out of 10 participants stated they had no support whatsoever in the beginning stages of their sibling’s illness. *All* participants stated that they had to seek help on their own, and it was not offered to them in any way. They all said they found help once they did their own research and found ways to seek help on their own. Some mentioned their families had been a source of strength and support. Nine out of 10 participants stated they had seen therapists due to the effects they had experienced having a brother or sister with mental illness. All nine said therapy had been helpful in this regard.

Another common response was the lack of support from the mental health system including doctors. Examples of this are as follows:

Example #1:

In the beginning absolutely not. There was nothing offered to me except a 5 minute conversation with a psychiatrist that was working on my brother’s case to say “hey, we’ve diagnosed him with schizophrenia and this is where we’re at.” No family support of family education was offered to me at that time, no information was given to me regarding an organization that I could contact to give me any kind of family support, nothing, absolutely nothing. It was no different than going to the doctor and getting diagnosed with a cold except that it was tremendously more weighty. It was not until a year later that my brother nearly died. He had been hospitalized and discharged 8 times in a period of 2 months. He had lost 80 lbs, did not know his own name, was not willing to dress, and at some point somebody broke HIPPA laws and gave me a call and said “hey, I’ve got

your information, I see this on the file and I just want you to know that if someone doesn't participate in his care he is going to die." At that point I ramped up. It was another whole experience of grief, but at that point it was ok, this is for real. I need to be participating all the time with what's going on. And at that point I found NAMI... marginal support. Now I feel there's a much greater level of support but still lacking. Especially when he's in an episode it would be really nice to have a better social connection, a better medical team that I could interface with and feel like I was able to participate in his care.

Example #2:

The first hospital he was in it was like a teaching hospital and he was there for 5 months or something and every month it's like a new amateur Dr. who just got their degree but they don't know anything about it. So in every single one he has to get to know them again, and then they leave, so that was not good support. I think you have to be a very strong advocate and call the doctors. No one's going to come to you and help you out. So it's just really hard to get information and to have that support.

Example #3:

Some of the drugs require blood testing and the system wouldn't pay for it. There was resistance to do it and they keep cutting back benefits.

Example #4:

I find it interesting, I'm really curious about it, but you know with his situation certainly don't know how to help it, so... I don't think the system is helping it. I kind of just go along with it. Probably nobody said "it's a brain disorder." I think I had to learn things on my own rather than it being told to me. Because I don't think they really understood, I don't think my mom understood so I don't think she could tell me clearly.

Issues of support varied depending on the individual; however, many of the frustrations were the same. The mental health system, available resources, and having to do one's own searching were the most commonly expressed concerns. All participants conveyed the lack of assistance offered for educational resources and support services. Lack of support from the outside community in general was implicit in all the interviews at some point during questioning.

Summary

This chapter presented the findings of 15 interview questions including follow up questions which were asked to a total of 10 participants who identified themselves as well siblings. Some questions prompted an overlapping of responses, mostly involving emotional reactions. In most cases answers were very similar, and varied according to specific examples or events. The most unanimous response was in regards to shame or stigma in which case every participant stated they had experienced one or the other in some form. Sadness and loss appeared as the most significant emotional reactions experienced, in combination with other feelings. There were no positive reactions mentioned in response to this particular question. Finally, feelings associated with guilt, especially those related to survivor's guilt, were also supported by the majority of participants.

CHAPTER V

Discussion

This study attempts to broaden the understanding of the experience of well siblings through qualitative interviewing. Previous literature has touched upon some of the burdens they face involving caretaking and some of the psychological stresses they encounter. Less research has focused in detail on the emotional experiences of well siblings to determine more specific reactions which may be unique to this population. The findings of the 10 interviews conducted are discussed in this chapter. They suggest that well siblings do have similar features which are shared among them. Areas for future research and clinical implications will also be reviewed.

Demographics

An important item to note is the majority of female participants. The one male participant called at the suggestion of his mother. All were volunteers responded to an advertisement in the NAMI monthly newsletter. It is not clear why they were mostly women. One can speculate that women tend to take on more of a caretaking role. Many of the participants had multiple siblings, yet they had either shared or been more involved in their siblings' care than the other siblings. This may have to do with level of closeness to their sibling, age, or gender. NAMI as an organization has both men and women members, so should not be a factor. It could also be speculated that women have more of a tendency to reach out for help than men do. It is well known that more women attend therapy than men for example. Therefore women may be more likely to participate in research of this kind. It is also difficult to interpret any gender differences in experience given the unequal ratio of women to men. Broadening the scope of agencies for advertising and reaching out to other non-agency populations would be helpful for future recruitment.

Age of participants varied, which was helpful in capturing differences in experience. Several (n=3) participants had a sibling who was diagnosed within the last 3 years. This may have a potential effect on their experience since time could change their responses. An interesting theme that emerged was in participants over the age of 50. All 4 stated that their families had either not discussed the illness with them or treated it as secretive. This would fit with the time period of the 1950's when mental illness was tremendously misunderstood and stigmatized. The impact this had over them is difficult to determine, however there was a positive correlation with these participants and shame and/or stigma. A few noted that it was typical of the time period and were understanding that their parents probably had little information themselves. One could theorize that parents either did not have enough knowledge of the disease to discuss the issue openly, or were consumed with their own grief and not able to focus on the well sibling. In all cases, the experience had not been positive. There did not appear to be any other themes or similarities that suggested age was a factor in other findings.

Eight out of ten participants had a mentally ill brother as a sibling; two had a sister who was mentally ill. This also presented an unequal ratio; therefore it is difficult to ascertain if there are differences in experience given the gender of the ill sibling. The unequal ratios limited the findings of this study. However, almost all siblings had the diagnosis of schizophrenia. This added to the reliability of findings and provided a common variable among most participants. Finally, the small sample size is not large enough to generalize to a larger population. More research with a larger and more diverse sample size would be helpful. A stratified sampling method would be beneficial in order to achieve this.

Emotional and Psychological Factors

There appeared to be some overlap in the responses to questions. This was mostly in regards to the questions asking about emotional reactions. For example, this particular question was more general and elicited feelings of sadness, guilt and a loss among most participants. Two other questions specifically asked about sadness and guilt. Here the responses provided more information, but some answers overlapped with previous ones. Sadness was expressed among all participants, which indicates that a loss has been experienced. Two participants described the experience as “a death.” This would also signify the level of intensity that the sadness was felt. Grief was expressed along with sadness in most cases, although only named specifically in a few. Responses suggested that participants went through a period of mourning the loss of their sibling, combined with other emotional reactions which are common with grief or loss such as fear and anxiety, confusion, and guilt. It is critical to note that while the losses were in some cases described differently, all participants identified some form of sadness or loss. This would inevitably impact their experience. It also supports other studies which have identified well siblings who have a brother or sister with mental illness as experiencing more severe negative psychological reactions than siblings who have a brother or sister with a different disability. This would be a logical conclusion given that mental illness usually appears suddenly versus disabilities which one is born with.

Another interesting finding was that the diagnosis of the sibling did not seem to make a difference in the emotional reactions experienced. Although most people had a sibling with some form of schizophrenia, the two outliers having bi-polar NOS and schizoaffective disorder described similar feelings of loss. The woman with a bi-polar sibling felt her loss had been “of her childhood.” This did differ slightly in that her feeling of loss was not of her sister. She

reported fear and anxiety as an emotional reaction and said she suffered from depression periodically throughout her life. It is possible the depression was not related. However, this participant had the highest functioning sibling of the group. It is interesting to note that while she did not experience other descriptions of grief, she described a sadness and loss of her own childhood. This would suggest that diagnosis may not make a significant difference in one's emotional experience. More follow up studies would be needed to determine this.

Sibling Connections

The level of closeness between siblings is important in determining any rupture in the relationship and the impact it may have. Level of closeness was not measured in any way, but was a subjective interpretation of the participants. In 8 out of 10 cases, well siblings had a close relationship with their brother or sister prior to diagnosis. Six out of 10 of these became more distant after the illness presented itself. Therefore it is not surprising that they also experienced emotional feelings of sadness, loss, grief and other feelings since the illness would have created a rupture in the relationship. This happens due to personality changes, institutionalization, sibling dynamics, and many other factors that mental illness creates. One could speculate that the feelings of sadness, loss and grieving were not only due to loss of their sibling as they knew them, but also in response to a loss of the relationship and severing of the bond between them.

In the 3 out of 10 cases reporting that well siblings felt closer after the diagnosis, one can speculate as to why they differed from the 6 who reported feeling more distant. One of the 3 said her sibling was only diagnosed a year ago with schizophrenia. Therefore it may not be enough time to determine the level of closeness post diagnosis. In the second case, the participant had remained involved in her brother's life, and continued to worry about his well being. However, her brother had always exhibited "other issues," namely ADHD and substance abuse. It may be

that their relationship did not change as significantly as with other participants because her brother had preexisting symptoms and the rupture was not as sudden or intense. It may also be that due to medication and care it was possible to have a relationship with him where it wasn't before. Conversely, it may also suggest that siblings react differently. More research would be necessary to determine this. The third participant lives in a different state than her brother and sees him infrequently. Though she stated their relationship is closer now, it is difficult to determine the level of closeness and the degree of change from what it was before.

There were only 2 cases where participants did not feel close to their sibling prior to diagnosis (one was the last case mentioned). In one instance the siblings later became closer while the other pair remained unchanged. Interestingly in both cases, despite not being close to their siblings prior to the diagnosis, their emotional reactions, including loss, sadness, and grief, were no less significant than any other participant (with the exception of guilt which was not present in the woman who remained distant from her brother). This correlation suggests that being close to one's sibling prior to diagnosis may not be necessary to experience the same emotional impact. Because degree of closeness or emotional states were not measured, it is difficult to ascertain in what way they may affect one another. Being more specific with questioning would be helpful in defining closeness. The question did not ask specifically about closeness but asked how the relationship had changed. This was probably too general of a question and should be asked differently.

Guilt

This study was particularly interested in exploring the possibility of survivor guilt among well siblings. This could be an important psychological determination in assessing symptoms. While guilt is a complex emotion and is often experienced in different ways, there was a

consistency among the participants to suggest that survivor guilt is very much a feature of their experience. In fact, it was one of the questions which elicited the most consistent responses. Seven out of ten participants not only described feeling guilty, but specifically discussed the feeling of guilt over being “normal” or having a functional life while their sibling could not. It is important to say that in some cases a follow up question was asked as clarification to an answer, which may have led to more specific information in this area. Additionally, guilt is often associated with a feeling of powerlessness, and there was overlap in the responses. At times the two feelings were interchangeable. The feelings of guilt described in general confirm previous research and suggests that guilt is a significant feature of well siblings. It appears that this study succeeded in highlighting and delineating survival guilt as a feature of well siblings.

The male participant somewhat contradicted himself and answered “no” to feeling guilty, yet gave a clear example of how he thinks of his brother (who is incarcerated) for motivation when he doesn’t feel like doing something. One could speculate that he is referring to guilt when he says thinking of his brother gives him the “push” to keep going. It is also important to note that this participant was from an Asian culture (his sibling was in Japan), and this was not the only response which seemed contradictory. One possible explanation for this is a cultural issue may exist whereby he is reluctant to disclose any negative feelings or weaknesses (yet follows up by describing them). The young age of the participant may also be a factor as he may not be fully aware of his emotional state. However, given the ambiguity of his answer he was not counted as feeling guilty, therefore 7 out of 10 participants said they felt guilty.

Another important finding is in regards to the other 2 participants who stated they did not feel guilty. Both had not communicated or seen their brother in multiple years. A relationship no longer existed between the siblings in either case. Both were over the age of 50. While they

had described feelings of loss and sadness earlier on in life, their current feelings appeared more emotionally distant and disconnected when talking about their sibling. This is not to say that the experience had not had a profound impact on them, but a correlation existed between lack of guilt and lack of closeness for a substantial period of time. And yet all other feelings involving sadness and loss were present. It may be possible that they experienced guilt at one time but either no longer remember the feeling or have moved beyond it. Or it may be that guilt is not present unless an emotional bond exists. This suggests that more exploration in this area is necessary to determine if there may be association between guilt experienced and level of closeness.

With respect to survivor guilt, all 7 examples represented some form of regret that participants out-performed their sibling in one way or another. The examples were different, and the intensity of responses varied as did the impact it had over their lives. However, all can be inferred as having a sense of guilt for either the illness and/or a change in the relationship. Answers varied from “not being there enough” to feeling guilty that their sibling was “genetically chosen for this experience.” One woman described feeling guilty for not thinking about her brother enough. Another wondered if she might have contributed to her brother’s illness in some way. These responses are also common reactions after someone has died. This is further reinforcement that mental illness in a sibling can be like experiencing a death, which would in turn make survival guilt a logical response. Regardless of the examples given by participants, all 7 could be interpreted as meeting criteria for survivor’s guilt. The level of suffering that people who experience survivor guilt go through is well known, and often it is the result of trauma. Researching this feature in more detail is crucial to understanding the

experience of well siblings. Results suggest that this is most likely a common feature among them.

A correlation also existed between guilt and the last interview question: “do you feel you’ve had the necessary support in your ability to cope, understand and come to terms with your sibling’s illness and resolve any other personal issues that may have occurred?” All participants who reported feeling guilty also said they had to seek support by themselves. An interpretation could be made that because the majority of attention is given to the ill sibling in crisis (and in some cases parents), when confronted with such an overwhelming sense of guilt, well siblings may feel they are not deserving of help (since their sibling is suffering and the focus is on them). However, all but one participant had sought therapy on their own and all found it helpful, which may refute this theory. It is interesting that almost every participant had entered therapy and found it helpful. Although coincidence is a possibility, it is unlikely. This finding alone may be indicative of the hardship they face. Certainly it demonstrates the need for understanding from a mental health professional. It should be noted again that participants who volunteered were all associated with NAMI. For this reason it may be that they were more likely to seek support in general, or had the means to do so. Not every well sibling in the general population has this capability given the cost of therapy. They also may not have access to services. Future studies should also incorporate more of the general population and include people from different socio economic backgrounds.

Shame and/or Stigma

Shame and stigma are ever present on society with regards to mental illness. This was echoed by each and every participant. Answers to the question overlapped with another question asking about feelings of aloneness. In both questions participants gave similar examples and

sometimes did not distinguish between the two. Both questions elicited answers stating that there was a lack of understanding from the outside world. It may also be likely that this additional pain leads to a “feeling of being different,” which would contribute to the emotional stress of well siblings. For this reason it may be that people interpreted both questions very similarly, because feelings of aloneness and shame or stigma may be understood in some ways as inseparable. This indicates that there was not enough clarity between shame and stigma in the questioning. For future interviews it would be more beneficial to ask separate questions about each to capture the differences between them. One way of achieving this would be to ask about any experiences one has had in which they have been impacted by stigma. Since shame is more of an internal process, asking participants if they have ever encountered feelings of shame would also be helpful.

This question also elicited the most overwhelming response compared to other questions, in that all participants answered affirmatively. This suggests that well siblings face a great deal of shame or stigma on a regular basis. It also indicates that there is a level of secrecy they live with, which is the knowledge of their ill sibling. This is not by choice but out of fear. Most participants stated a lack of understanding from others as a main source of shame and/or stigma. This prevented them with discussing the situation with outsiders. Each example was a painful example of society’s misunderstanding of mental illness. It would make sense that one could not help but feel different from “the norm” when treated in this manner by society. It clearly has an impact on well siblings and would be another factor that may set them apart from siblings who have brothers or sisters with physical disabilities.

Support

While the issue of support has been discussed in other sections demonstrating more overlap amongst questions, participants had been forced to seek support on their own. Lack of support came from many different areas of their lives, and was not specific to mental health services. Support was missing from most aspects of their lives. This included (in some cases but not all) family support. As previously stated participants over 50 had little family support in understanding and coping with the illness, but others also echoed this feeling. Lack of support also came from friends and spouses, mostly due to lack of understanding. Support was missing from places of employment, communities, and society in general. More than one participant said that NAMI had been helpful but did not have groups or services specific to siblings. Some participants have reached a point in their lives where they are able to cope with their circumstances, and have found the necessary support to come to terms with their sibling's illness. However, others are in the beginning stages and still finding their way.

There was a substantial amount of anger from some about the mental health system. Just the very fact that no support or educational services were offered could in itself induce a sense of shame in people. For example, one woman saw her brother's diagnosis of schizophrenia typed on his discharge papers, but was offered no verbal explanation, access to educational or support services to help in understanding what it meant. This type of neglect from the mental health system contributes to an already present sense of shame. There was also a sense of anger in regards to lack of support from society. People displayed resentment when describing the rejection they received from their communities. They also had a tendency to give up. As one woman stated: "I mean I don't feel any shame about saying it, but the fact is why say it? Nobody's going to understand what I'm talking about anyway." This was the attitude of most

participants, who felt strongly that they would not be understood and figured there was no point in trying. In cases of work related issues, it was not worth the risk.

Conclusion

Findings show that responses to most questions are overwhelmingly negative. Many of the examples given do not describe positive experiences. In all cases, a pain and frustration is described which reveals the suffering one endures when faced with such a challenge. There tended to be a feeling of overshadowing within families whereby the well sibling was left feeling alone in their experience. It is possible that parents felt alone as well, and did not know how to fill this void. Or perhaps they were consumed with their own grief and could only focus on the ill sibling. It seems they were very much alone in their experience overall: seeking help on their own; struggling with difficult feelings; not being able to share information and fearing judgment from others.

Although most responses were negative, this was partly due to the interview questions which did not ask participants if they had experienced any positive feelings or outcomes. It may be that due the nature of questioning this information was not elicited. However, some questions were general enough to provide the opportunity for positive responses. Taken together, the answers underscore the likelihood that well siblings undergo their own trauma as they cope with the devastation and powerlessness over having a sibling succumb to mental illness, without the outside resources in place for coping. One way to improve findings in this area would have been to ask if there had been any positive feelings or experiences. Future research would be helpful in making this comparison, and determining what, if any, positive aspects exist.

Another way to improve upon questioning would be to ask more specific questions in relation to guilt and sadness. A survey asking detailed questions about their experience would be

one way to capture or confirm such feelings. With the issue of survival guilt, a separate study asking questions about this alone would help to delineate it from other feelings. Because many questions and answers overlapped in this study, it presented more of a challenge in finding recurring patterns and themes, although many responses supported each other and were indisputable.

The results of this study confirm previous research suggesting that well siblings suffer their own set of symptoms and stresses. More research with this vulnerable group is needed to help counteract the oppression they experience. As their parents age, they will assume caretaking roles and will also serve as advocates for the mental health community. It is not generally understood that they themselves have experienced a trauma. Attention needs to be focused in this area so that support and educational services are more available. This study used a sample from one mental health organization, which most likely limited the findings. All participants were also from middle class backgrounds which is not a reflection of the general population. Future studies should examine well siblings using larger and more diverse samples.

There are various approaches for future study. For example, comparing adults of mentally ill siblings to adults of physically disabled siblings would be important to note any emotional differences, while expanding on the limited research in this particular area. Additionally, using more comparison groups to examine differences in well siblings with other mental illnesses would be of interest. For example, one interesting finding of this study was the overwhelming number of siblings who had a diagnosis of schizophrenia. This may be indicative of more severe symptoms in those with mental illness which in turn impacts well siblings. It may have other meanings as well and should be explored further. Finally, studies which focus on survivor guilt in more detail to recognize the impacts or possible limitations it may have over

the lives of well siblings is important in developing a deeper understanding of this shared characteristic. It could also help to develop interventions which would facilitate the healing process.

I, who am also a well sibling, can relate to each interview and identify with many of the responses. Many participants were eager to know about others like them who share many of the same issues. Some asked if they could contact other participants. They were comforted to know they are not alone. Each person volunteered to participate in the study simply “for the cause.” This study succeeded in identifying areas of common ground among well siblings. While each person comes with their own set of circumstances, many of the feelings and experiences are the same. With more research and attention given to this overlooked population, more help could be given to improve the overall well being of well siblings who do not deserve to suffer in silence.

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Appendix A



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February 15, 2012

Lisa Frierson

Dear Lisa,

You did a very nice job on the revisions and your response was very professional. Your project is hereby approved by the Human Subjects Review Committee.

Please note the following requirements:

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

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

In addition, these requirements may also be applicable:

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

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

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

Best of luck, with what I think is a very important research question critical to many families in the U.S. (including my own).

Sincerely,

A handwritten signature in black ink that reads 'David L. Burton'.

David L. Burton, M.S.W., Ph.D.
Chair, Human Subjects Review Committee

CC: Diana Fuery, Research Advisor

Appendix B

ADVERTISEMENT FOR RESEARCH STUDY

Do you have a sibling with a major mental illness?

I am looking for volunteers to participate in an interview describing their personal experience of having a brother or sister with a major mental illness (schizophrenia, bipolar I disorder or schizoaffective disorder). The study is to gather information and learn more about the possible impacts of mental illness on siblings. Interviews will be audio taped and restricted to one hour, and held in a convenient location. This study is part of a thesis requirement for a social work masters program. The information gathered will be confidential and anonymous, and used strictly for research purposes. Volunteers should be over the age of 25. Your participation is greatly appreciated. For questions or to sign up, please contact Lisa at **(personal information deleted by Laura H. Wyman, 11/30/12)**

Thank you!

Appendix C

INTERVIEW QUESTIONS

“Thank you again for participating in this study. First I’m going to ask you some general questions about your background such as where you grew up, and other demographic information. Then I will ask some questions surrounding the diagnosis of your sibling, followed by questions about your experience leading up to the present day.”

- 1) Where were you born and raised?
- 2) How many siblings in total are there in your family?
- 3) What is the age difference between you and your sibling with mental illness? Are you older or younger?
- 4) How old were you and your sibling when the diagnosis occurred?
- 5) What is the diagnosis of your sibling?
- 6) What was your parents’ reaction to the diagnosis?
- 7) Did you have a close relationship with your sibling prior to the diagnosis?

(“Now I am going to ask you some questions about how you felt when you learned of your sibling’s diagnosis”).

- 8) What would you say were the primary emotional reactions and feelings you experienced around the time of diagnosis and realization of mental illness?
- 9) Did you have any worries or fears concerning yourself around the time of diagnosis or afterwards? If so what were they?
- 10) Did you experience any grief or sadness and can you describe what it was like?
- 11) Did you or do you ever feel a sense of guilt or powerlessness over the fate of your sibling? If so please give examples.

(“Now I am going to ask you few questions about your experience within the context of family, friends and society overall”).

- 12) Have you felt alone in your experience as a “well sibling,” and if so how?
(“Now I will ask some questions about your present day experience”).
- 13) Has the relationship with you and your sibling changed since diagnosis? If so, how?
- 14) Do you feel that shame or stigma have personally affected you? If so, how?
- 15) Do you feel you have had the necessary support in your ability to cope, understand and come to terms with your sibling’s illness and resolve any other personal issues that may have occurred?

Appendix D

INFORMED CONSENT

Dear Participant,

I, Lisa Frierson am a graduate student at the Smith College School for Social Work. I am conducting a research study in order to learn more about the personal experiences of siblings who have a brother or sister living with a major mental illness. The information gathered will be used for research purposes only as part of a MSW thesis requirement, and may be presented or published. This study seeks to gain a more in depth understanding about this particular group.

Your sibling must have been diagnosed with schizophrenia, bi-polar I disorder or schizoaffective disorder at least 5 years ago. You will be asked to partake in an audio taped interview lasting approximately 1 hour. Questions will begin with basic background information, followed by questions surrounding the diagnosis including emotional and psychological reactions and experiences. You are not required to answer any questions or go into any details if you choose not to. I will transcribe the data and sign a confidentiality pledge not to release any personal or identifying information about you.

The risks to participants include possible emotional reactions which may arise due to sensitive questions asked by the interviewer. Some questions may trigger certain feelings or emotions which could be difficult. A referral source will be provided with contact information for local support networks. The benefits of participating include the potential that this unique and important population will be understood more thoroughly so that advances in therapy can be made. Compensation will not be provided for participating in the study.

Confidentiality will be maintained by using anonymous coding during the transcription process, so that participants' names will not be matched up with specific responses. I will be the only transcriber and have sole access to the data. In the event of publications or presentations, data will be presented as a whole and any quotes or other illustrations will be disguised. All data will be kept in a secure location for a period of 3 years and required by Federal Guidelines, and any electronic data will be protected. If the materials are needed beyond the 3 year period, they will continue to be kept in a secure location and destroyed when no longer needed.

Participation in this study is voluntary, and you may withdraw at any time during the data collection process or refuse to answer any questions. In such an event all materials collected will be destroyed immediately. Once data is gathered and coded anonymously, it is too late to withdraw. You are encouraged to call me or with any additional questions or concerns about the study. You may also contact the Chair of the Smith College School for Social Work Human Subjects Review Committee to answer any questions about rights or any other aspects of the study. A copy of this form should be kept for your records. Contact information is as follows:

Lisa Frierson (researcher): **(personal information deleted by Laura H. Wyman, 11/30/12)**

Chair of the Smith College School for Social Work Human Subjects Review Committee: (413) 585-7974

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Signature

Date

Thank you for your participation in this study.