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THE EFFECTS OF SEVERE MENTAL ILLNESS ON SIBLINGS

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Abstract

This phenomenological qualitative study examines the psychological, emotional, and social effects that severe mental illnesses have played on the lives of four well siblings. After conducting four interviews with well siblings, it became apparent that mental illness has a unique and significant impact on the lives of siblings in ways that are different from any other member of the family. Using phenomenological qualitative analysis, the following themes emerged: emotional reactions to living in a family affected by mental illness, need for education, lack of inclusion in the treatment process, and coping and advocacy. Based on experiences and descriptions of the sibling participants, it is clear mental health providers must begin to include siblings in the recovery process. Siblings are a crucial element of the family unit and they need to be treated as such; with their ability to make unique contributions to the treatment processes of their ill siblings, well siblings must be educated, included, and encouraged to discuss their own needs while helping their brothers or sisters in their own recovery.

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Chapter 1

Review of the Literature

In August 2010, my brother Mark was diagnosed with Paranoid Schizophrenia. I did not know then, nor do I fully comprehend now, how those two words would forever change my life.

Schizophrenia, at least from my understanding, is a disease that lulls one into a false sense of security. Someone could go weeks, months even, with no outwardly apparent symptoms, and then on one very unsuspecting day the disease could wreak havoc. This is how I understand my brother's illness to be, not a continuation of symptoms, but an illness marked by distinct memories and periods in time.

One recent memory that is forever etched in my mind took place on Thanksgiving evening, a time that one usually spends relaxing with the family and enjoying the afterglow of a great meal and a full stomach. Thanksgiving started the same way that it does every year. My mother's side of the family, 23 people in total, met at my aunt and uncle's house to eat dinner together. With football blaring on the TV, 8 screaming grandchildren under the age of 12, and 2 barking dogs, it was loud to say the least.

At the beginning of the day, Mark was fine; he seemed to be coping with the chaos and noise level really well. As time went on however, it became apparent to my immediate family that he was growing agitated. He began to isolate himself and often left the house for long periods of time. After dinner and cleanup were over, when the family was sitting and talking, Mark said that he needed to go home; he had reached his breaking point and could not stay any longer.

We walked to the car with bated breath, not wanting to say anything that would tip the delicate balance that Mark was resting on—the balance between a calm ride home and a symptom induced rage. Knowing that he needed space, my mother let Mark sit in the front passenger seat, while she sat in the back with my sister and me. For several minutes, everything was quiet. My mom, my sister, and I were quietly talking in the back seat when Mark shouted, "Stop kicking the back of my chair." No one was kicking the back of his chair. Following this, silence ensued. After a few minutes, when conversation had started again in the back seat, Mark asked, "What did you just say about me?" The conversation had nothing to do with him. His symptoms were coming out; he was having auditory hallucinations and paranoid delusions that usually precede a rage. Sure enough, a few minutes later, that is what happened.

*Mark turned in his seat and started screaming at us, an onslaught that lasted almost thirty minutes. At some point during that time, Mark blamed his illness on my mother, sister, and me saying, "You three b****es never stop talking. You never shut up. You are the reason that I hear f***ing voices in my head all the time. They won't ever stop. You f***ed me up because you won't ever stop talking. You are the reason that I'm sick and want to kill myself every day." He went on to say, "You better lock your doors tonight because I'm gonna bash your heads in when you're sleeping. That's fine if you send me to the hospital because I would rather be in the hospital than at home with you."*

Almost immediately after this Mark stopped talking. He turned the music up, faced forward, and did not say another thing to the family for the rest of the night. He sat calmly in the front seat while my sister and I were shaking in the back. With tears

running down both of our faces, I grabbed her hand and looked out the window. There was nothing else I could do.

That night, my mother had my father to comfort her. Mark saw his psychiatrist shortly afterwards. Jessie and I had no one. We supported each other like we knew how, but at the end of the night, we went to our own rooms alone, not knowing how to talk about what just happened. In a short thirty minutes our brother had blamed his entire illness on us, expressed that he was suicidal, and threatened to kill us, but we had no one to turn to.

Introduction

The above story does not exist in isolation. There are many individuals living with a severe mental illness and many siblings who are struggling to cope. As the mental health field is constantly in metamorphosis, it was only a few years ago that professionals believed that the family and family dynamics were to blame for an individual's illness. While this is no longer an accepted belief, it is one of the primary reasons that there is very little research to date on the effects that mental illnesses have on families. The research that does exist largely focuses on the viewpoints and experiences of parents (Lively, Friedrich, & Buckwalter, 1995). That is to say, previous research examines how having a son or daughter with a severe mental illness affects the everyday lives of parents. Researchers have failed to take siblings' perspectives into account and, as a result, siblings are left out of the recovery process.

With what little research has been done on the experiences of siblings, it is obvious that siblings experience many unique emotional, psychological, and social struggles that need to be addressed. These affects include, but are not limited to, intense grief, stress, distancing within the family, increased isolation, anger and resentment, family role changes, and shame.

Experiences of Siblings of People with Mental Illness

To begin, siblings frequently report experiencing a sense of never ending grief over the "loss" of their brothers or sisters (Lively et al., 1995). While the individual has not passed away, after the symptoms of mental illness strike, he or she is inarguably a different person. A sense of mourning exists for the loss of the sibling who was once known and loved. Siblings reported that they had to work to get to know their brothers or sisters again to reestablish the relationship that used to be extremely gratifying (Lively et al., 1995). On good days, siblings may see a glimmer of the brother or sister they used to know. On other days, they may feel like they are interacting with a complete stranger. There is no sense of closure.

Well siblings, sibling who do not have mental illness, also experience a drastic increase in stress and sadness. Many times, siblings have no experience with mental illness prior to their brother or sister's diagnosis. Therefore, well siblings often have no understanding of how to cope with their ill sibling's positive or negative symptoms (Lively et al., 1995). They might not even know what the symptoms of their sibling's illness are. This lack of knowledge and understanding is extremely stressful. Furthermore, as the ill sibling comes to terms with his/her mental illness, there is typically an increase of isolation. This isolation makes it even more difficult for a sibling to reestablish the bonds that are often reported lost after a diagnosis. Siblings may feel like their brothers or sisters are no longer even part of the family. Obviously, this sense of confusion and loss leads to much higher levels of stress and sadness.

After receiving a mental health diagnosis, the "ill sibling [becomes] the central focus of the family, depriving other members of time and attention" (Lively et al., 1995,

p. 231). Parents, perhaps due to feelings of guilt, often center attention and love around their ill child, the child they perceive as being more in need. Because of this, well siblings report having less time to spend with their parents; it seems therefore unsurprising that many well siblings report a sense of distancing from their parents and family unit in general (Lively et al., 1995).

With all of the stress and anxiety that stems from the existence of a mental illness, it seems logical that the well sibling would try to reach out to peers or friends for support, especially if he or she is not getting sufficient attention or concern at home. Unfortunately, the stigma related to mental illness is great, as society tends to shun people associated with mental illness. As a result, siblings often report feeling as if they cannot talk about the disease with anyone. Siblings, due to the sometimes unpredictable behavior of mental illness, report increased feelings of isolation (Lively et al., 1995). They feel as if they cannot invite friends or neighbors over to the house because they never know what the state of their home will be like. When the ill sibling is not emotionally stable, it is difficult to determine what situation one will encounter.

These feelings of grief, uncertainty, and sadness also lead to feelings of intense anger and resentment associated with the unfairness of life. Siblings ask themselves, "Why did this happen to me? Why did this happen to my family?" Siblings often report feelings of frustration stemming from communication difficulties with their sibling or from not getting the attention and care that they need in their home environment (Lively et al., 1995).

In addition to the many other emotions that well siblings carry with them each day, they are burdened with role confusion within the family. Specifically, siblings often

report experiencing "replacement child syndrome" (Marsh, Appleby, & Dickens, 1993).

As so many chaotic things are happening in the home environment, siblings want to spare

their parents from any additional grief by behaving badly or getting themselves into

trouble. Siblings feel like they need to be the "perfect" child. Thus, there is an extreme

amount of pressure on siblings to act responsibly and to "keep it together" when they

may feel like acting out. Siblings may not have previously felt the need to behave

perfectly, but following the diagnosis or symptomatic behaviors of their siblings they

experience this shift in family roles (Marsh et al., 1993).

Finally, and perhaps most importantly, siblings experience a great deal of shame

associated with their brother or sister's illnesses. Due to the stigma that society places on

people with mental illnesses, well siblings are ashamed to admit their brother or sister has

a mental illness, let alone discuss the illness and the implications it has on their lives.

This fact prevents siblings from getting the help that they need to cope with all of the

other aforementioned emotions and challenges (Marsh et al., 1993).

Needless to say, the mental illness of a sibling "is a cataclysmic event for young

family members that has a pervasive impact on their entire lives" (Marsh et al., 1993, p.

33). The illness affects virtually every aspect of siblings' lives, from their habits in

school to their socialization patterns to the amount of affection they may feel at home.

Thus, it is no surprise that many well siblings often report symptoms of a diagnosable

mental illness themselves. When siblings are involved in the recovery process, however,

it has been demonstrated that this pervasive impact can be changed for the better.

Siblings can emerge from the situation feeling empowered if, like parents, they get the

help they need (Marsh et al., 1993).

To further express the profound effects that mental illness has on well siblings, a thorough review of the preexisting literature was conducted. The literature, which is limited in nature, demonstrates the need for more studies to be conducted on this subject. The studies examined below just begin to show the varied effects that the mental illness of a sibling has on the lives of well siblings.

In one study, Lively et al. (1995) recruited 30 adults using membership lists from a local chapter of the National Alliance for the Mentally Ill (NAMI). During the study, participants were asked to complete an investigator-developed questionnaire and were interviewed for approximately one hour. Participants ranged in age from 22 to 52, and they lived in the same home as their ill sibling anywhere from 0-10 years. The 22 ill siblings ranged in age from 24-52. Many of the siblings became ill before they were 20 years old and had been ill for an average of 18 years. The majority of the siblings had been hospitalized at least six times (Lively et al., 1995).

Lively et al. (1995) found that although relationships of all kinds are affected by mental illness, the relationship most affected is that between the well sibling and the ill sibling. The following six main themes emerged to explain exactly how this relationship is affected: distancing in the relationship, grief associated with the relationship, anger and frustration related to the illness, the ill sibling viewed as broken or fragile, embarrassment and shame regarding the illness, and stress related to crisis. While Lively et al. identified themes, they did not discuss the themes in any detail; the study seems to lack the depth necessary to truly identify the affects of mental illness on siblings. Additionally, the study's sample size is relatively small, although that is typical in qualitative research, and not diverse, as supported by the fact that all participants reported being married, highly

educated, and employed at the time of the study. This study verifies the need for further investigation into the affects of mental illness on siblings.

In a follow up article by the same authors, Lively et al. (1995) wanted to assess the impact of illness behaviors and symptoms on siblings themselves, rather than exploring the relationship between the well sibling and ill sibling. Using the Impact of Illness Behaviors Scale and the same sample in the previous study, investigators determined that the most disturbing category of illness behaviors on siblings were negative symptoms and mood fluctuations. They also determined that the most commonly mentioned behaviors that affected the well siblings' lives were hallucinations and delusions, verbal or physical abuse, and social isolation (Lively et al., 1995).

Unfortunately, when delusions and hallucinations are really florid, siblings report a sense of chaos and anxiety related to their home environment. They do not understand how to respond to the irrational thinking. Additionally, physical and verbal abuse results in high level of stress for siblings; they are never able to tell when the next set of illness related symptoms will occur. Finally, social withdrawal affects siblings as they grow sadder the more their sibling isolates. The sibling relationship can deteriorate to the point that it is almost as if the ill sibling is no longer even a member of the family (Lively et al., 1995).

Based on this information, the investigators believe that siblings should be educated about how they can appropriately intervene when their siblings are symptomatic. For example, when their ill sibling disassociates from reality, they can use learned reality testing techniques to remedy the situation. In addition to these learned coping skills, Lively et al. (1995) believe siblings, along with other family members,

should be provided with an opportunity to discuss their emotions and reactions with other family members who may be experiencing the same thing. Like the previous study conducted by these investigators, the conclusions that the investigators draw lack detail; the stated affects on siblings are not discussed or analyzed thoroughly, which calls for further investigation. And while they suggest interventions, there was no investigation on the efficacy of these interventions.

In a related study, Lukens, Thorning, and Lohrer (2004) analyzed the needs and concerns of adult siblings who care for their siblings who have a severe mental illness. The researchers recruited 19 adult participants, all of whom lived in New York State and described themselves as being mentally well. The study sample included 16 White participants, 3 African Americans, and 1 Asian American. Sixteen participants were female and 3 were male. Participants ranged from 25-73 years old. Most of the participants reported that their sibling had been ill since childhood or early adolescence and all of the siblings were diagnosed with schizophrenia, schizoaffective disorder, bipolar disorder, or major depression. Of the ill siblings, 14 were male and 5 were female (Lukens et al., 2004)

The investigators used focus groups with the thought that they would be able to collect detailed personal information as well as group perspectives. They conducted five separate focus groups where each individual was asked to write down answers to one request: "Please list at least five ways, both negative and positive, that having a brother or sister with mental illness has affected your lives, both in the present and over time." These responses were then used to generate discussion and foster discussion. The

investigators then used grounded theory to code and analyze their data (Lukens et al., 2004).

Lukens et al. (2004) found that living with a sibling who has mental illness has the capacity to affect individuals in both personal and interpersonal spheres of their lives. On the personal level, siblings reported consistently negative emotions, including anger and guilt, mourning, fear, and anticipated burden. Participants felt angry at their siblings for depriving them of a "normal" life experience, but expressed extreme guilt over this as they knew that their siblings were struggling. The mourning felt was in response to the loss of the individual their sibling was prior to becoming ill. Fear was mentioned due to the unpredictability of the illness and not knowing how the illness would manifest itself in their siblings from one day to the next. There was also fear of becoming mentally ill themselves and fear of having children who have a mental illness. Finally, the feeling of anticipated burden was expressed because participants did not know whether they would be taking care of their sibling in the future and because they recognized the challenges that this would bring (Lukens et al., 2004).

On an interpersonal level, the sibling's mental illness affected the participants' relationships with their family, partners, and friends. In regards to their family lives, participants reported additional feelings of mourning and loss for innocence and "normal" childhood experiences they could not have. They expressed that they felt isolated and lonely. Participants also reported that there was an increase in secrecy surrounding the illness and role confusion as their parents were struggling to cope with their child's mental illness. In regards to relationships with others outside of the family, participants mentioned that they struggled with the stigma surrounding mental illness and

therefore had difficulties maintaining intimate relationships or close friendships. In both spheres, however, participants also said that they had good experiences too as they became more compassionate, patient, caring, and in some cases even grew closer in their bonds with family and friends (Lukens et al., 2004). This study was well designed and clearly demonstrated the needs and feelings of the well siblings. While the participant size was appropriate for qualitative research, it was not a demographically diverse group. Additionally, the authors advocated effectively for family oriented services like education for family members, involvement in the treatment process, and process groups for family members to speak about their experiences.

In another study, Lively, Friedrich, and Rubenstein (2004) aimed to analyze the impact of siblings' illness behaviors on specific aspects of well siblings' lives. In order to do this, the investigators developed the Friedrich-Lively Instrument for the Impact of Schizophrenia on Siblings (FLIISS). Participants were asked to respond to the close-ended questions on the FLIISS, which included demographic and illness information about the participant, family, and ill sibling. Additionally, the instrument analyzed primary stressors (sibling's disturbing behaviors, relationship with ill sibling, and caregiving responsibilities) and secondary stressors (relationships with friends and family and the effects on the school and work environment; Lively et al., 2004).

After recruitment was finished, there were 752 respondents. Seven hundred and sixteen (95%) of the respondents were White and 554 (74%) were female. The participants ranged in age from 18 to 79. The mean age of the participants was 20 when their siblings were diagnosed with Schizophrenia and they lived with their siblings from 0 to 7 or more years. The ill siblings ranged from 18 to 77 years old. The mean age of

onset was 20 and the siblings had been ill for an average of 20 years. The majority of the ill siblings had been hospitalized 5 or more times and several had been hospitalized 10 or more times (Lively et al., 2004).

After gathering their information, the investigators determined that there are two distinct types of illness-related behaviors that ill siblings portray: other directed behavior and self-directed behavior. Other directed behaviors include such things as hallucinations, delusions, disruption of household routine and verbal abuse, while self directed behaviors include things such as lack of personal hygiene, medication incompliance, social isolation, and a lack of motivation. The researchers discovered that stress levels for well siblings increased as their sibling exhibited more disturbing behaviors, specifically other directed behaviors. Lively et al. (2004) suggested, based on their study, that the majority of intervention programs should assist with decreasing the most disturbing behaviors of ill siblings, while simultaneously increasing the coping behaviors of well siblings.

It becomes apparent after examining the study that several limitations exist. To begin, the study sample is not diverse, as supported by the fact that the majority of participants were White and female. Additionally, the authors' primary suggestion for decreasing sibling stress was to change the illness behaviors exhibited by the ill sibling. This solution does not appropriately address the needs of well siblings. They recommend individualized attention to meet the specific concerns and needs of the well siblings, not an indirect solution aimed at their siblings. Moreover, due to the nature of severe mental illness, it would be much more difficult to control the behaviors of the ill siblings.

In a related study, Marsh et al. (1993) aimed to identify the experiences, coping resources, and needs of well siblings and children. Using the Siblings and Adult Children Network (SAC) they conducted two studies. The first survey consisted of both structured and open questions. The structured questions gathered demographic data and were used to assess coping resources and needs on a scale of 1-5. For the first study investigators recruited 60 participants between the ages of 21 and 67. Most were female and White. All of the participants had relatives diagnosed with a severe mental illness, primarily schizophrenia, and reported that they had lived with their relative for an average of 23 years (Marsh et al., 1993).

The second study consisted of structured questions that asked participants to identify and rate the frequency of their concern with 24 issues that emerged from the first survey on a scale of 1-5. They also asked whether participants had ever attended psychotherapy and whether or not they found it helpful. A total of 75 participants were involved in the second study, with the majority being White and female. Participants ranged from 21-77 years (Marsh et al., 1993).

The results provided investigators with data connected with seven themes: the impact of mental illness on childhood and adolescence, the legacy for adulthood, expressed concerns, the process of coping and adaptation, needs of siblings and children, mental health problems among siblings and children, and recommendations for other siblings and children and for professionals. Marsh et al. (1993) went on to describe many of the same concerns that other surveys have also reported including:

disruption of normal development; the experience of a powerful subjective and objective burden; distorted roles and relationships; impaired self esteem and

personal identity; personal mental health problems, especially depression and

anxiety; familial disruption and stress; social isolation and discomfort;

unsatisfactory peer relationships and academic performance; and a sense of

having grown up too quickly. (p. 19)

When researching the specific needs of siblings and children, the most compelling needs

that emerged were finding satisfactory services for their relative, working through their

own reactions to the illness, developing coping skills, and finding personal support

(Marsh et al., 1993).

 While Marsh et al. (1993) identified various themes affecting well siblings and

adult children, they did not differentiate the two groups. Thus, it becomes difficult to

determine what the specific affects of siblings and adult children are and how they may

be different from each other. Moreover, the sample of participants lacked diversity as the

majority of participants were White and female.

 In another study, Greenberg et al. (1997) examined the burden experienced by

well siblings as it related to symptomotology of the ill sibling and whether or not these

symptoms were viewed as being within the sibling's control. Researchers recruited 164

well siblings with a mean age of 45 years old. The majority of the participants were

female (70%) and married (84%). Five percent of the respondents lived with their ill

sibling at the time of the study, but those who did not had an average of 2.5 hours of

contact time each week. During the week prior to the interview, 63% of participants had

seen or spoken to their sibling, while 93% had done so during the past month (Greenberg

et al., 1997).

Participants were asked to complete the Wisconsin Family Burden and Services Questionnaire during the 90 minute telephone interview conducted by professional interviewers. The questionnaire consists of questions concerning their relative's current psychiatric symptoms and behaviors, their involvement in the sibling's care, their view on the amount of control that their siblings had over their symptoms, and their experience of subjective burden, like feelings of stigma, fears, and worries about their sibling's future care. Subjective burden was measured using a global assessment scale, as well as three other specific scales for stigma, fears, and worries about the future. Objective burden was measured using two different scales for amount of care and psychiatric symptoms (Greenberg et al., 1997).

Analysis of the results supported Greenberg et al.'s (1997) prediction that the burden of care increases for well siblings as their ill siblings experience more symptoms. Furthermore, when well siblings believe that their ill siblings are able to control their symptoms, subjective burden, stigma, fear, and worries about the future all increase. Additionally, researchers found that siblings who provided more care experienced higher levels of subjective burden than did siblings who provided less care (Greenly et al., 1997).

The primary flaw in this study is that it only analyzed a small number of the burdens that siblings face. While siblings do experience stigma, fears, and worries for the future, they also experience a variety of other feelings and stressors not mentioned in the study. Additionally, the study is flawed in that it states the first priority for siblings and families in general should be to provide medication management to the ill sibling in

order to stabilize psychiatric symptoms. While the ill sibling may indeed need medication management, the needs of well siblings cannot simply be neglected.

Need for the Study

A small number of studies exist that analyze the effects that sibling mental illnesses have on well siblings. Overall, these studies have found a relationship between a sibling with a mental illness and grief (Lively et al., 1995), stress (Lively et al., 1995), anger (Lukens, et al., 2994), guilt (Lukens et al., 2004), isolation (Lukens et al., 2004), and shame (Marsh et al., 1993). However, a majority of the studies lack detail and suggest solutions that do not actually meet the needs of siblings. Based on the findings, well siblings need to be given individualized attention and assistance based on their specific needs and experiences. They can no longer be treated in a secondary manner, with most of the attention focused on the ill sibling.

Based on the above evidence, it is apparent that well siblings need to be involved in the recovery process. They need to be informed of their ill siblings' diagnosis, of the symptoms associated with that diagnosis, and of the types of treatment their siblings will be receiving. Furthermore, it is crucial that well siblings are offered the emotional support they need. They need an open, stigma free space to discuss their experiences, feelings, worries, and anxieties. If the needs of well siblings were met earlier, "the adverse legacy for their adult lives might have been diminished" (Marsh et al., 1993, p. 21). By conducting a qualitative study exploring the effects of severe mental illnesses on siblings, I hope to demonstrate how imperative it is for siblings to get the necessary treatments and resources to allow them to be thriving and successful members of society in later life, despite facing the challenge of a sibling's mental illness.

During the study, a phenomenological qualitative approach was used to conduct four face-to-face interviews with individuals who have lived with a sibling who has a diagnosis of severe mental illness. Each interview lasted approximately forty-five minutes in length and discussed both the positive and negative effects the illness had on the participant's life.

The nature of this study, which is about an extremely intimate and sensitive topic, lends itself to qualitative methodology, as "the qualitative method…helps us to describe, interpret, and understand the meaning of family life and family relationships with as little disruption of the natural setting as possible" (Miller-Day, 2004, pp. 16-17). Because so little research and even information exists on the topic, it is necessary to gather the stories and experiences of individuals before a large scale study can be successfully conducted; the only way to truly hear an individual's story in detail is to sit down and listen. Conducting qualitative interviews is an effective way to competently and responsibly collect information on an ill researched topic.

As the qualitative method of research is an umbrella term for several specific types, I specifically conducted the study using phenomenological qualitative research methods. Phenomenology, as opposed to other types of qualitative research, focuses on the subjective experiences of individuals and aims to ultimately discover how someone interacts with the world around her or him. As this study directly involves the lived experiences of having a sibling with mental illness, a phenomenological approach seemed most fitting.

Chapter 2

Methodology

After examining the limited existing literature on the topic at hand, the effects of mental illness on siblings, a phenomenological qualitative approach seemed to be the most fitting for gathering data and analyzing the findings. The primary research question for this study was: "How does having a sibling with a mental illness affect your life?" The interview questions were based on my analysis of existing studies, my own experiences as a person who has a sibling with mental illness and as a person who knows and has worked with people with mental illness, as well as consultation with my thesis advisor. Specifically, the six open-ended interview questions were:

1.   What is it like having a sibling with a mental illness?

2.   How has it affected your life?

3.   How has it affected your family's life?

4.   What helped you to deal with your sibling's illness? What helped you to cope?

5.   Through your lived experiences, what advice can you give that would be helpful to families?

6.   What advice would be helpful for professionals?

Additional questions were used when necessary to clarify a participant's response.

Once an interview protocol was developed, participants were recruited through emails sent out to various Pennsylvania State University listservs, including the Rehabilitation and Human Services major listserv and the listserv for Active Minds, a student organization aimed to de-stigmatize mental illness on college campuses. In addition to emails, participants were recruited through social media websites, such as

Facebook, and through the use of snowball sampling, where my colleagues and study participants informed potential participants about the study. During the development of the study I met with my advisor several times to discuss potential biases and assumptions I might have that could affect how I conducted the study, and then I continued to consult with her throughout the study.

Four participants were recruited for the study. In order to qualify for the study, participants had to be 18 years of age or older, have a sibling with a severe mental illness, and not have a mental health diagnosis themselves. Of the four participants, one of them had a sibling diagnosed with Paranoid Schizophrenia, while the other three siblings had diagnosis of Bipolar Disorder, one of whom also had Borderline Personality Disorder. Once participants were screened, they sat for an interview that lasted approximately forty-five minutes. The interview was recorded using an audio recorder and then I transcribed it into a word processor using Dragon Naturally Speaking software.

Data Analysis

Data analysis began with immersion, or getting a sense of the big picture (Cohen, Zahn, & Steeves, 2000). I independently read each participant's entire transcript twice to get a sense of the overall experiences of all of the participants. After that I began reducing the data (Cohen et al.; Cresswell, 1998; Moustakas, 1994) by identifying general themes that connected to the broad, consistent experiences of being a sibling of a person with mental illness. Once these broad areas of experience were identified, I reread the transcripts to verify that the broad themes held up, as well as to begin noting experiences that exemplified each theme.

At this point I began thematic analysis (Cohen et al., 2000) of the broader themes by reviewing the transcripts again, identifying experiences that spoke to the list of themes that emerged from previous readings. I moved back and forth between the data and emerging themes (Polkinghorne, 1989) to define the themes and indentify exemplars, or direct quotations, from participants that seemed to capture the essence of each theme (Cohen et al., 2000). Many of these are cited below in the Findings. For each theme, I then finalized the description or definition of each theme as I understood it and included exemplary quotes to provide context for each theme. I established trustworthiness by consulting with my advisor throughout the course of the study, and by revisiting the transcripts as I analyzed the transcripts. I also added rich text by using exemplary quotes from participants.

Chapter 3

Findings and Discussion

After conducting a thorough analysis of the interview transcripts, it became apparent that while each sibling and family has a different story, four common themes emerged to describe the experience of being a sibling of a person with a severe mental illness. The first theme emerged as emotional reactions to living in a family affected by mental illness, and included subthemes of anger and stress. Need for education and lack of inclusion in the treatment process, the next two themes, emerged as issues that would have made living with the illness easier and as suggestions for professionals in the field. Finally, a fourth theme of lack of coping and advocacy skills emerged. Each theme is discussed below, as well as implications for professionals, families, and siblings.

Overview of Themes that Emerged

Emotional Responses to Living in a Family Affected by Mental Illness

The first theme to emerge related to the depth of emotions siblings felt in response to the effects their sibling's mental illness have on them and the family as a whole. As the effects of mental illness are varied and numerous, the emotional responses felt by siblings are also many. The two main feelings that emerged were anger and stress.

Anger. Unfortunately, anger is an all too common sentiment among siblings of individuals with mental illness. Anger, while it is often reported as stemming from a specific family member or specific occurrence, also stems from the fact that mental illness exists in the family in general. Siblings reported a sense of injustice over the fact that mental illness affected their family, rather than another family.

In addition, siblings feel anger towards their ill siblings for causing the pain that they feel, and anger towards their parents for neglecting to understand their needs. One

sibling reported thinking, "Wait a minute, I'm doing everything right—my family, my behavior is good, I get straight As—and she is the one getting all of the attention." She later went on to supplement that with, "I think anger and resentment in terms of either you're getting all of the attention no matter what I do…"

Stress. Time and time again throughout the interview process, siblings mentioned that their households were incredibly stressed because of the active symptoms of their siblings, the general unpredictability of mental illness, and conflict between family members. This same sibling quoted above finished her thought by saying, "…or I feel this enormous amount of pressure to be successful because I was the only other child, so I'm kinda like my parent's 'only hope,'" which gives insight into the other common emotion siblings often face- stress.

Stress was also complicated by stigma that families faced. Several siblings reported a sense of secrecy about their sibling's illness, which furthered the stress that they felt, demonstrated by this sibling's experience:

> I remember having that sit down with my mom, you know, "We don't tell other
> people what happens in this house and we don't tell about those experiences," so I
> think there was a lot of expectation to look very good on the outside, to do really
> well, again, a lot of that pressure falling to me to do really well and not embarrass
> the family and little discussion ever of what was really happening.

As a result of the stressed households, siblings feel that it is up to them to keep the family moving forward. They feel a sense responsibility to care for their family members and to be the perfect child, since the rest of the family unit was so disrupted. That feeling

of responsibility is another complicated layer of stress that siblings living with a sister or brother with mental illness face.

Need for Education

Each of the participants interviewed, when describing their experiences with a sibling's mental illness, stated that education about the illness would have drastically reduced the stress and anger that they felt every day. Well siblings reported a sense of confusion associated with their ill sibling's mental illness since many of them had no previous experience with the symptoms or implications of mental illness prior to their siblings becoming ill. Participants mentioned that they would have liked professionals, whether hospital staff, counselors, psychologist, psychiatrists, or other professionals, to have given them information on their sibling's disorder, and in some cases even to explain what was happening. Exemplifying this, one sibling said it would have been beneficial, "If somebody would have told me what was wrong with him or how to deal with him, you know what I mean? Like it was sort of like 'Dave's sick' and that was really the end of it. It's not like, 'What should we do? What should we not do? What's gonna help him? What's gonna hurt him?'"

Additionally, siblings mentioned that lack of education promoted stigma, which played a large role in their experiences. In each interview, participants reported that others around them did not understand the fact that their siblings had a disease. Rather, participants said that neighbors, friends, and even other family members thought that the ill sibling was only being defiant or behaving badly. These viewpoints increased the isolation felt by well siblings as no one could truly understand what it was they were experiencing. One sibling said, "It's very difficult because I would find growing up that a

lot of people wouldn't understand what it's like having him, so I guess I felt very alone. My best friend growing up thought that we were all nuts because like 'Why can't anybody keep this kid in line?'" This participant described not only her feelings of isolation, but stigma and lack of understanding promoted by a lack of education.

Inclusion as Part of Treatment

In addition to the need for education, well siblings unanimously reported that they wanted to be included as part of their brother or sister's treatment process. They expressed that it would have been profoundly helpful if professionals would have even asked, "How are you?" One sibling summed up these huge feelings with, "You can't treat one member of the family without treating everyone. And just [for professionals] to be aware that these things are happening and it has such a profound effect on everyone involved. And just to make sure that everyone involved is getting the help that they need." Yet another sibling said, "I think as professionals, it's really important to recognize that the person that you are working with is part of a bigger puzzle, which is their family." Being included as part of the treatment process would not only have allowed well siblings to help their siblings with mental illness, it would have allowed them to receive the help they needed in adapting to the effects of the illness on themselves and the family.

Lack of Coping and Advocacy Skills

If well siblings had this education and inclusion, it would have made the coping process much easier. Unfortunately, another common theme among the participants was lack of positive coping mechanisms and an inability to advocate for their siblings or themselves. Participants reported time and time again that they did not have very healthy

coping mechanisms; rather, they used repression and avoidance to deal with a very difficult and confusing situation. Several of the well siblings reported that they ultimately sought help through counseling and eventually learned to cope with their sibling's illness by educating themselves about the disorders. If these strategies would have been implemented sooner, the well siblings would not have gone through as much anguish and uncertainty.

Learning to advocate was another powerful experience for participants. In their own ways, through their experiences, participants ultimately learned to advocate for themselves and their siblings. Whether it was through independently seeking therapeutic resources or through an eventual job in the mental health field, each of the siblings now fights to end stigma and shame associated with mental illness. It is almost certain that if the siblings were to get the help that they needed earlier, they would have been in a better position to advocate even sooner, thereby reducing the stigma associated with mental illness and increasing the chances that others living with mental health issues will get the help that they need.

<p align="center">**Connection to Existing Literature**</p>

While several studies acknowledge that negative effects of mental illness on siblings exist, specifically anger and stress, few studies discuss interventions to adequately reduce those effects. In each interview of this study, information and inclusion in the treatment process emerged as the two best strategies to help siblings cope. However, this was not the case in all other research studies.

Some authors discussed indirect interventions to help the well siblings cope, mainly by treating the ill sibling's symptoms; some of these treatments include

medication managements and psychiatric rehabilitation (Greenberg et al., 1997). After conducting these interviews, however, it became apparent that well siblings need their own specific interventions to learn to live and cope with their siblings' illnesses. That is to say, it is not enough to simply reduce the disturbing behaviors of the ill siblings; rather, well siblings must be give adequate information and included in the treatment process.

Only one study, among the few that exist, discussed the importance of these two interventions for well siblings. Lukens et al. (2004) discussed the numerous effects that mental illness has on a sibling's personal and interpersonal spheres in life. In response to the varied effects, the investigators determined that the best interventions included education for family members, involvement in the treatment process, and processing groups for families to communicate with others going through similar situations. These are the exact interventions that siblings in the current study reported as being crucial to coping and overcoming the negative implications of their siblings' illnesses.

Implications for Professionals, Families, and Siblings

The affects that mental illnesses have on families, specifically siblings, are undeniable; whether it is increased feelings of stress, anger, resentment, loneliness, or sadness, siblings must live with a wide variety of distressing experiences. But these experiences can be minimized or eliminated with specific interventions.

Professionals in the field must understand that when one family member is living with a mental illness, the entire family must be treated. Well siblings must be asked about their feelings, experiences, and specific needs. Participants expressed that even being asked, "How are you?" would have been extremely helpful. Additionally, professionals need to understand that well siblings and other family members need education about

their sibling's specific disorders. This education reduces the stress and confusion associated with a new diagnosis, new symptoms, and new behaviors of their siblings.

Families, like professionals, have to understand that siblings must be included in the treatment process. Siblings are a large piece of the puzzle that is a family, and without their involvement in treatment everyone suffers. Furthermore, families must understand that while the ill sibling needs help and support, well siblings also need that; although well siblings may not be struggling with a mental illness, they are struggling in their own ways and these struggles need to be addressed.

Finally, siblings need to recognize that they are an extremely crucial piece of the puzzle. Again, just because they are not suffering from a mental illness does not mean they are not suffering. Well siblings need to advocate for themselves and ask for what they need. By advocating for their own needs, siblings will begin to get the treatment and the attention that they so rightfully deserve.

In summary, it is the combined responsibility of professionals, families, and siblings to ensure that well siblings are educated and included in the treatment process. Through these two interventions, the disturbing and painful effects that previously defined a sibling's experience will be a piece of the past. It will take the cooperation of many individuals, but we must constantly remind ourselves of the significance of well siblings and their role in the family unit. When we advocate and implement these interventions, will we begin to see a necessary change in the mental health system.

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