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Sarah A. Quish
Sibling's Perspectives: The
Impacts of Having a Sibling
Who Suffers from an Eating
Disorder

ABSTRACT

The purpose of this qualitative study was to explore sibling's perspectives on growing up with a sibling who suffers from an eating disorder. The study particularly examined sibling's reactions and responses to the discovery and progression of his or her sibling's eating disorder. An analysis of the literature revealed a lack of research on the experience of having a sibling who suffers from an eating disorder. This review of literature also brought forth the alarming prevalence and life-threatening nature of eating disorders.

Ten siblings participated in semi-structured interviews which asked them to talk about their experiences of having a sibling with an eating disorder. The findings from these ten interviews revealed a range of powerful emotional reactions to the sibling's illness including feelings of anger, frustration, guilt, sadness, and fear. Findings also demonstrated sibling's withdrawal and helping behaviors towards his or her sibling and the use of coping mechanisms as escape behaviors from the stress of their sibling's eating disorder. Participants reported high levels of stress and tension in their family environment while their sibling was ill. Recommendations by participants to mental health clinicians reveal the crucial need for both education and emotional support for siblings of individuals suffering from eating disorders.

SIBLING'S PERSPECTIVES: THE IMPACTS OF HAVING A SIBLING WHO
SUFFERS FROM AN EATING DISORDER

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

Sarah A. Quish

Smith College School for Social Work
Northampton, MA 01063

2010

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	ii
TABLE OF CONTENTS.....	iii
LIST OF TABLES.....	iv
CHAPTER	
I INTRODUCTION.....	1
II LITERATURE REVIEW.....	4
III METHODOLOGY.....	16
IV FINDINGS.....	22
V DISCUSSION.....	41
REFERENCES.....	53
APPENDICES	
Appendix A: Human Subjects Review Committee Approval Letter.....	57
Appendix B: Informed Consent Form.....	58
Appendix C: Screening Questions.....	60
Appendix D: Recruitment Flier.....	61
Appendix E: Preliminary Demographic Questions.....	62
Appendix F: Interview Guide.....	63
Appendix G: Recruitment Email.....	65

LIST OF TABLES

1.	Table 1 – Age and Gender.....	23
2.	Table 2 – Time Line and Status of Sibling’s Eating Disorder	25

CHAPTER I

INTRODUCTION

Eating disorders such as anorexia and bulimia nervosa are serious and complex psychiatric illnesses that stem from a combination of emotional, social, and familial issues. As many as 10 million females and 1 million males in the United States are struggling through a life and death battle with eating disorders such as anorexia and bulimia (Hoek, 1995). Anorexia, itself, has the highest mortality rate of all psychiatric illnesses (Harris & Barraclough, 1998) with the American Psychiatric Association (1993) finding that 18-20% of individuals with this devastating disease die within 20 years of onset. Consequently, treatment for persons with eating disorders can be intensive and long-term. Eating disorders occur most frequently in adolescence and young adulthood (Pawluck & Gorey, 1998) while the sufferer is often living with and cared for by family members (Treasure et al., 2001). Given age of onset, severity, persistence, and mortality of eating disorders, a need for an increased understanding of the impacts of these life-threatening illnesses on sibling's well-being is essential. From the perspective of family systems theory, due to interdependence within family systems, that which affects one member of the family affects other members psychologically, physically, and socially (Kinsella et al., 1996). Most of the research on family members of persons with eating disorders explores the perspectives of parents whose child is suffering from mental illness (Riebschleger, 1991). With more studies examining parent-child relationships, sibling relationships, in the context of eating disorders, are largely neglected in the literature

(Moser, Jones, Zaorski, & Mirsalimi, 2005; Dimitropoulos, Klopfer, Lazar & Schacter, 2009). Siblings of persons with eating disorders appear to be a forgotten group.

A limited number of recent studies on serious mental illness and siblings bring forth implications for how eating disorders such as anorexia and bulimia may impact siblings emotionally. Researchers have found consistent patterns of negative emotions among siblings who have cared for their siblings who suffer from mental illnesses. These researchers have also found both constructive and destructive methods of escape by siblings to distance themselves from the adverse effects of their brother or sister's illness. These findings imply that siblings of persons with eating disorders may have unique needs due to their experiences with their sibling's illness. Although these past studies examine the emotional impacts and coping mechanisms experienced by siblings of individuals with general mental illness, research is lacking the exploration of the emotional impacts of having a sibling with a serious eating disorder from the perspective of the sibling.

This gap in the research on siblings has led to my research question, what are sibling's perspectives on having a brother or sister who suffers from an eating disorder? I am curious to know more about how siblings are impacted by the experience of growing up with a sibling with an eating disorder in their own words. In this study, I will explore more specifically sibling's responses and reactions in the face of their brother's or sister's illness. This exploratory research is valuable for clinicians who work with siblings and families affected by eating disorders. My hope is that sibling's narratives in this study will give clinicians a richer understanding of what it is like to grow up with a sibling suffering from an eating disorder. In the next section, I will examine the relevant

literature on this topic of siblings and the impacts of having a brother or sister who struggles with mental illness.

CHAPTER II

LITERATURE REVIEW

This literature review is a brief introduction to research focusing on the severity of eating disorders; the theory behind the interconnectedness of siblings; and the effects of having a sibling with a mental illness. This literature will also highlight the lack of research studies that examine the specific effects of having a sibling with an eating disorder from the perspective of the sibling.

Eating Disorders

Eating Disorders are characterized by severe disturbances in eating behavior. According to the DSM-IV-TR, eating disorders can be classified into three diagnoses: anorexia nervosa, bulimia nervosa, and eating disorder not otherwise specified (ED-NOS). Although the text of the DSM-IV-TR allows specific diagnosis, often patients exhibit a mixture of symptoms of both anorexia and bulimia. Symptoms of anorexia include severe disruption in eating behavior often concurring with rigorous weight control techniques and unhealthy weight loss. In patients diagnosed with bulimia, symptoms include repeated episodes of binge eating followed by “recurrent use of inappropriate compensatory behaviors to prevent weight gain” (DSM-IV-TR, 2000, p. 590) such as self-induced vomiting; misuse of laxatives, diuretics, enemas, or other medications; fasting; or excessive exercise. Eating disorders are complex conditions with no single cause; they appear to arise out of a mixture of complex interwoven factors

(psychological, interpersonal, social and biological) which are expressed through a restriction and/or purging of food.

Research findings serve to reinforce the overwhelming prevalence and severity of eating disorders. Anorexia nervosa, itself, ranks as the third most common chronic illness in adolescents behind obesity and asthma (Misra, 2004, p. 1574). Furthermore, anorexia nervosa has the highest premature mortality rate of any psychiatric disorder (Harris et al., 1998, p.11) with the American Psychiatric Association (1993) finding that 5-10% of persons with anorexia die within 10 years of onset and 18-20% of individuals with this devastating disease die within 20 years of onset. The mortality rate among people with anorexia is about 12 times higher than the annual death rate due to all causes of death among females ages 15-24 in the general population (Sullivan, 1995, p. 1073). Worse still, individuals with anorexia have the highest rate of suicide of any psychological illness. A longitudinal research study conducted by Keel et al. (2003) found that persons diagnosed with anorexia are 56 more times likely than their peers to take their lives. For those sufferers who receive treatment for eating disorders, treatment can be extensive, long-term, and ineffective. Eating disorders occur mainly in adolescence (Pawluck & Gorey, 1998) while the sufferer is often living with and cared for by family members (Treasure et al., 2001). The limited body of research regarding caregivers of persons with anorexia indicates that these caregivers experience high levels of distress as result of their care-giving role which is made worse by significant levels of shame and self-blame (Treasure et al., 2001). Siblings are recognized as a major source of support for individuals with eating disorders; however, studies on family members of persons with eating disorders neglect to examine the impacts on siblings. Given the age

of onset, seriousness, persistence, and mortality of eating disorders, a need for an increased knowledge of the impacts on sibling's wellbeing is critical. Particularly concerning is that recent research provides evidence of substantial genetic influences on eating disorders which suggests siblings of sufferers are at a higher risk for developing an eating disorder themselves (Klump, Suisman, Iacono, & Burt, 2009; Kortegeard, Hoerder, Joergensen, Gillberg, Kyvik, 2001). Both twin and adoption studies demonstrate that a genetic predisposition plays a role in the emergence of eating disorders and thus, biological siblings of sufferers have a much higher risk than controls of developing an eating disorder (Bulik, Sullivan, Wade & Kendler, 2000; Klump, Suisman, Iacono, & Burt, 2009).

Theory and Sibling Relationships

The significance of sibling relationships on psychological development has largely been ignored in psychotherapy literature (Blessing, 2007). Some authors attribute this to the individually focused psychoanalytic theory which overlooks relationships with others. However, even more relationally based theories do not place much weight on the sibling relationship, focusing most of the attention on the parent-child relationship (Moser et al., 2005). Blessing (2007) asserts that "siblings have always been part of the clinical picture, but without an adequate theoretical hook on which to hang their significance" (p. 37). The theoretical lens has been trained to focus much more on parental figures.

With an absence of attention on sibling relationships in theories, recent studies looking at the impact of mental illness on sibling relationships have relied on systems

theory as a framework (Kinsella, Anderson, & Anderson, 1996; Lukens, Thorning & Lohrer, 2004; Riebschleger, 1991). In this study, family systems theory will be used as a foundation for exploration. Family systems theory offers a general basis for exploring sibling relationships and the effects siblings have on each other. From the perspective of family systems theory, what affects one member of the family affects other members psychologically, physically, and socially. The effects on each other are due to the interactions between members of the family and their interdependence on each other. One family member may be affected by a mental disorder but due to the interdependence within the family system, every member is affected by the illness in some way (Kinsella et al., 1996). Jane Ogden (2003) explains that in family systems theory approach, “Causality is seen as a circular rather than linear process, as the eating disorder not only develops within the context of a particular set of family relationships but also becomes a part of these relationships” (p. 208). Family systems theory, thus, would suggest that the disease of eating disorders would significantly affect the sibling (Caldwell & Pichert, 1985). From this theoretical perspective, sibling relationships would be just affected by the illness as the parent-child relationship and recent studies from other severe chronic mental disorders suggest just this: siblings are as affected as parents and consequently, siblings are often regarded as “secondary victims” of mental illness (Barak & Solomon, 2005).

Early systems theory explanations of patients with eating disorders proposed models of “psychosomatic” or “anorexigenic” (Minuchin, Rosman, & Baker, 1978) families where specific family patterns or dysfunctions led to the development and persistence of eating disorders (Cook-Darzens, Doyen, Falissard, & Mouren, 2005, p.

223-224). Family systems theorists in the 1980's described the "anorexic family as being typically fused, rigid, and dedicated to self-sacrifice and group loyalty" (Cook-Darzens et al., 2005, p. 224; Minuchin, Rosman, & Baker, 1978). This concept of the "anorexic family," consumed with specific patterned behaviors, has been challenged by researchers who may agree that the presence of anorexia within a family cannot be based on over-generalized family patterns. Despite challenges to this early family systems conceptualization of anorexia within a family, the relationships between the individual with the eating disorder and family interactions should not be ignored. The basic tenets of family systems theory which focus on the interdependence and interconnectedness of family members offer a strong foundation for exploring the effects of having a sibling with a serious eating disorder.

Siblings and Mental Illness

Relevant literature on severe or chronic mental illness and siblings brings forth implications for how eating disorders may impact siblings emotionally. Research studies have shown that chronic childhood illness can have a harmful impact on the emotional health and behavior of well-siblings (Honey et al., 2006). Studies have looked into the emotional responses of siblings who have a brother or sister affected by chronic mental illness. These studies have uncovered a full spectrum of emotional responses from siblings towards their brother's or sister's mental illness. In a qualitative study by Riebschleger (1991), twenty siblings reported experiences of grief and loss in interviews examining their current and historical experiences as siblings of persons with mental illness. In this experience of grief and loss, a frequent emotional pattern was to travel

circularly through the four emotions of anger, bargaining, depression, and relief. Using focus groups, Lukens et al. (2004) also found a consistent pattern of negative emotions among siblings who care for their mentally ill sibling including anger, guilt, loss, fear, and anticipated burden. Feelings of guilt, in siblings of persons who have been hospitalized for “mental disturbances,” were a steady theme which emerged spontaneously during interviews in a mixed-method study conducted by Deal and MacLean (1995). Furthermore, feelings of guilt and sorrow over being healthy in relation to their sibling with chronic mental illness were consistently found in a qualitative study by Stalberg, Ekerwald, and Hultman (2004). Researchers also found high levels of physiological anxiety, worry, and withdrawal in well-siblings (Deal & MacLean, 1995, p.279). Although these studies point out sibling’s negative emotional aspects to their sibling’s mental illness, positive aspects of the sibling care-giving experience described by siblings include increased empathy and emotional responsiveness to others (Greenberg, Greenley, & Benedict, 1994; Lukens, et al., 2004).

With the emotional impacts of having a sibling with mental illness in mind, Taylor et al. (2008) and Kinsella et al. (1996), have investigated coping mechanisms utilized by well-siblings. In a qualitative study, Kinsella found that siblings of persons with severe mental illness used both “constructive and destructive methods of escape” to distance themselves from the adverse effects of their sibling’s illness. The pattern of sibling’s coping, by psychologically distancing themselves from their brother or sister with mental illness, was also found in a longitudinal, descriptive study by Taylor et al. (2008). Other coping mechanisms used by siblings in the study conducted by Kinsella et al. (1996) included seeking support from others, objectifying the illness, acquiring

information, and self isolation. Furthermore, a study conducted by Friedrich et al. (2008) also identified coping strategies used by siblings of persons with schizophrenia. This study found three major coping mechanisms used by siblings; these included: educational resources to help manage their sibling's illness, recognition that their sibling was not at fault for their illness, and acceptance of the unavoidable cost of the illness to the family.

A study completed by Barak and Solomon (2005) which assessed the impact of schizophrenia on non-schizophrenic siblings found that the quality of the sibling relationship deteriorated with time and that the non-affected siblings described a more distant relationship with their parents than normal controls with their own siblings and parents. Research on siblings of individuals with schizophrenia has also revealed that siblings report that the demanding behaviors associated with their sibling's illness inflict significant subjective burden and severely disrupt their household routines (Friedrich, Lively, & Buckwalter, 1999). These studies recommend that siblings of those who suffer from mental illness receive more professional attention with more education about their sibling's illness.

Each of these studies gives adult well-sibling's perspectives on the impacts of having a brother or sister with a variety of serious mental illnesses. Honey and Halse (2006) narrowed their study to focus on siblings of persons with anorexia nervosa, rather than on mental illness in general. Their qualitative study, which include 24 parents, found that anorexia in the family "had a negative emotional impact on siblings that required additional parental attention, such as taking siblings to therapists. . . addressing siblings' eating issues, managing siblings' feelings of neglect and resentment against parents and the daughter with anorexia" (p. 55-56). Although this study is from parent's

perspectives, it brings forth significant implications of the profound emotional effects of growing up with a sister with anorexia. The study highlights the importance of gaining a clearer picture of the struggles siblings endure, through their own perspectives, while living with a person with anorexia. Further exploration must examine the experience of siblings through their own eyes.

A new study by Dimitropoulos, Klopfer, Lazar, and Schacter (2009) moved beyond previous studies by being the only published study which directly explores the insights and experiences of 12 sibling caregivers of persons with chronic anorexia nervosa (p.362). This study focused on sibling's perspectives of their relationship with their sibling prior to the illness and the impact of the course of anorexia on the sibling and the sibling relationship. Siblings described a profound sense of "helplessness and powerlessness in mobilizing their affected sibling to recognize the seriousness of the eating disorder" (p. 357). Siblings universally reported that the emaciated appearance of their sibling, the binge-purge succession, and the restrictive eating as behaviors elicited the most negative emotions including anger, anguish and fear (p.357). Similar to Taylor et al. (2008) and Kinsella et al. (1996), this study explored coping strategies used by non-affected siblings. Dimitropoulos et al. (2009) found that siblings coped by externalizing the illness (separating the illness from their sibling) and creating distance between their ill-sibling when they felt overwhelmed. A limitation of this study is that it only looked at siblings of chronic anorexia developed in early adolescence and cannot be generalized to siblings of individuals whom developed anorexia later in life. Self-selected bias also occurred in the study as siblings were chosen based on their perception of being a "caregiver." This study suggests the importance of future research exploring sibling's

experiences in response to a range of eating disorders; most significantly, this study asserts that future studies need to include multiple siblings from the same family to provide information into varying perspectives about the illness within the family and the differing roles siblings adopt. Thus, in this study, I will, to the extent possible, include siblings of the same family to explore their varied perspectives on their sibling's illness. Dimitropoulos et al. (2009) study was also limited in the fact that the participants were all female; this limitation suggests the importance of conducting future studies with both male and female participants.

Familial Factors

In addition to this research which emphasizes the impacts on the emotional well-being of sibling's of persons with eating disorders, research by Dimitropoulos et al. (2009) has also brought forth sibling's perspectives of their familial environment while their sibling was ill. During interviews, siblings of sufferers reported a profound denial of the eating disorder on part of their parents and a minimization of the siblings' concerns by parents about their sisters' eating disorder symptoms. Additionally, inconsistent familial responses to the sibling suffering with anorexia were a prominent theme which emerged. According to participants, these inconsistent responses among family members elicited conflict among family members. Sibling's also described enabling behaviors of their sibling's illness by parents and a sense that their parents elicited their help to assist their ill-sibling. Based on these findings, researchers suggest that clinicians provide a space for siblings to discuss and express their feelings about the way their family is managing their sibling's illness (Dimitropoulos et al., 2009, p. 361).

Limitations

Limitations of several of the studies on siblings of persons with mental illness, lays in their small sample size and design. Small and purposive samples are a pattern throughout the literature on siblings of persons with mental illness (Blessing, 2007; Dimitropoulos et al., 2009; Riebschleger, 1991). These studies are generally qualitative studies which often limits sample size due to the volume of data collected. The lack of diversity of the samples used in these studies is also limiting and future research will need to explore the effects of mental illness on a more ethnically diverse population of siblings (Lukens et al., 2004; Taylor et al., 2008). Due to the small sample size and lack of diversity among the sample, results of the studies are limited in generalizability. With these methodological concerns evident in the review of literature, future studies will need to incorporate a larger and more ethnically diverse sample.

Implications

Despite the limitations of recent research on siblings of persons with mental illness, these studies bring forth important implications for families and treatment providers. Studies affirm that clinicians, who are treating families with a child suffering from an eating disorder, would benefit from an increased understanding of the impact of this illness on siblings. Moser et al. (2005) asserts that a lack of awareness by clinicians of the unique influences of the sibling relationship, “can lead to inaccurate understanding of one’s client, stalemates in treatment, and therapeutic failures” (p.268). Furthermore, having a clearer picture of the emotional and psychological impacts on siblings can help

clinicians assist and empathize with parents in families with eating disorders (Honey & Halse, 2006).

According to theorists, clinicians must be aware of the emotional support needed for siblings who are growing up with a sibling suffering from an eating disorder:

“Clearly, siblings need emotional support and validation if they are to move beyond feelings of anger and guilt . . . Siblings and others need services that both support the person with illness and create space and validation for their own needs, concerns, and personal development” (Lukens et al., 2004, p.498). Along with the importance of validation for siblings of their feelings towards their ill-sibling, all sibling participants in the study conducted by Dimitropoulos et al. (2009) shared a crucial need for education about their sibling’s eating disorder:

All sibling participants recommended that professionals provide non-affected siblings with educational information about the eating disorder. Siblings suggested that dissemination of educational information must be accompanied by an opportunity for discussion and exploration of how the information specifically applies to them and their sibling with anorexia (p.360).

With this education, siblings unanimously shared that clinicians need to make every attempt to explain to siblings that they are not at fault for their sibling’s eating disorder and they are not responsible for their sibling’s recovery. Sibling relationships have long been placed on the back-burner and more research into these relationships, especially in the face of serious mental illness, can only further our understanding of how to effectively help these individuals and their families.

Summary

Eating disorders are severe and persistent diseases; often unique in their outward visibility, they are a cry for help in the face of painful emotions including pervasive feelings of loneliness. Siblings who grow up and live with a brother or sister with an eating disorder are not free from the effects of the sometimes life and death struggles their ill-sibling faces. Looking at the emotional impacts of having a sibling with an eating disorder can provide profound insight into sibling's own struggles in response to the illness. Parents, siblings, and treatment providers can benefit from an increased awareness into the experiences of siblings, placing into perspective the fears and challenges siblings may face while living with and or caring for an ill-sibling. Treatment providers, who are using family therapy to assist families with a child suffering from an eating disorder, would also benefit from an exploration into the effects of eating disorders on the "secondary victims," siblings.

CHAPTER III

METHODOLOGY

The purpose of this study was to explore the question: what are sibling's perspectives on growing up with a brother or sister who suffers from an eating disorder? This study particularly looked at sibling's perceptions of their reactions and feelings towards their sibling's illness. The study also specifically looked at sibling's perceptions of their family's response to their sibling's eating disorder. A qualitative, exploratory study was used to examine this research question since a lack of literature on this topic calls for a more in-depth examination. Detailed, semi-structured interviews of adult siblings of persons with eating disorders were used to explore their perceptions of having a sibling who is facing these life-threatening illnesses. My objective was to obtain detailed, narrative data of sibling's experiences by using this semi-structured open-ended questioning. My hope is that the findings of these interviews will help educate others on the impacts of growing up with a sibling with disordered eating including the unique needs of this population.

Sample

A purposive, non-probability method of sample selection was used in this study. To have qualified for this study, participants must have been: a) over the age of 18 years and b) had a biological brother or sister who suffered from an eating disorder. All eating disorder subtypes outlined in the DSM-IV were eligible for this study including

Anorexia, Bulimia, and ED-NOS. ED-NOS was included as a diagnosis in this study because often persons with life-threatening eating disorders do not exactly meet specific parameters for anorexia or bulimia. Often those diagnosed with ED-NOS have anorexia or bulimia or both, but do not fit the diagnosis due to technicalities. An attempt was made to include multiple siblings from the same family as participants in order to glean differing perspectives siblings have within the same family. I interviewed 10 siblings for this study whom met the inclusion criteria. Although my desired sample size was 12, through rigorous recruitment methods I was able to find and interview 10 participants, including two sibling pairs, who met the criteria for this study. These 10 participants ranged in ages from 19 to 38 years old. The sample consisted of 4 male participants, two of whom were siblings of the same family, and 6 female participants, two of whom were siblings from the same family. Each of these participants took part in a 45-to-60 minute interview where they were asked both demographic questions and a series of open-ended questions regarding their experiences of having a sibling who suffers from an eating disorder. I made it a priority to include both male and female siblings in this study. I also tried to have a sample that was more ethnically diverse since previous studies, looking into siblings of individuals with mental illness, used samples which were homogenous and lacking in diversity; past study samples have consisted of primarily Caucasian females.

I located and recruited participants for this study through the use of the snowballing technique. I contacted clinicians, with their own practices, who specialize in the treatment of eating disorders and informed them of the study I was conducting. I then consulted with them as to how I may be able to find my sample. I asked them if they

knew of anyone who may be interested in participating in the study and asked them if they would be willing to distribute a flier regarding participation in the study (see Flier in Appendix D). I had several private practice clinicians offer to post a flier in their office. The flyer contained contact information for which interested clients could email or call me regarding participation. Two of these clinicians who I contacted offered to participate in the study themselves as siblings of persons with serious eating disorders.

As part of the snowball sampling technique, I also contacted a few survivors of eating disorders whom I met at local events for mental health clinicians and trainees. I called these survivors to see if they had any ideas on finding participants. These survivors offered to help me and forwarded an informative recruitment email that I created to people within their social network regarding my study (see Recruitment Email Appendix G). One of these survivors posted information about participation in the study on her online blog. The method of survivors sending emails to members of their social network was the most successful recruitment method for this particular study.

Data Collection

I began data collection after the Human Subjects Review Committee granted approval of my research study (See Appendix A). I contacted eating disorder survivors, private practice clinicians, and dieticians specializing in the treatment of eating disorders over the phone. I found their contact information through an informational website by MEDA (Multi-disciplinary Eating Disorder Association) which lists clinician's contact information by state. I contacted clinicians in both Connecticut and Massachusetts, described my study to them, and asked for their help finding participants. Several

clinicians asked for a flier to post outside their offices. I delivered these fliers to clinicians through the mail and in-person.

Interested participants contacted me through email or phone regarding their desire to help me with my study. I then called these participants to see if they met the inclusion criteria for the study. During this screening phone call, I confirmed that they were an adult biological sibling of someone who suffers from an eating disorder. I also answered any questions they had about participation. All ten of the participants screened met inclusion criteria. Two of the participants were within nearby geographical locations and agreed to do the interview in-person at a public location. For these in-person interviews, two copies of the informed consent form were brought to the meeting, one of which was signed by the participant prior to the interview and the other copy was given to them for their records (See Informed Consent Form Appendix B). For the remaining eight participants who were unable to meet face-to-face, a phone interview was conducted. Prior to the interview, phone participants were sent two copies of the informed consent through the mail with a stamped return envelope. Once I received the signed copy from the participant, we set up a time to complete the interview. Interview times and dates were scheduled at the convenience of the study participants.

In-depth, semi-structured interviews of adult siblings of persons suffering from an eating disorder were employed to explore their perspectives of their sibling's illness including their emotional reactions and responses. These interviews were conducted using an interview guide approach as the qualitative measurement instrument. Questions were created by the researcher after an extensive review of past literature on siblings of individuals suffering from mental illness. The interview guide listed in outline form the

open-ended questions and more specific topics that need to be covered during the interview (See Interview Guide in Appendix F). Before starting the interview, I began by going over the informed consent form and asking participants if they have any questions about the interview procedure. I then began the first part of the interview with a series of questions that collect demographic data. The demographic information collected consisted of the age, gender, and ethnicity of the participant and his or her sibling. The demographic data also consisted of questions regarding how many siblings participants had, whether they lived with their sibling while they suffered with disordered eating, and whether the parents were in the home while their sibling was ill. These demographic questions provided vital contextual information that helped the researcher to examine the individual-in-context. In the next part of the interview, I asked questions, outlined in the interview guide, focused on their perceptions of growing up with a sibling who suffers from disordered eating. The interview began with broader questions regarding how they learned about their sibling's illness and what it was like living with their sibling while they were suffering with an eating disorder. Subsequent questions were more narrowly focused on sibling's feelings about their sibling's illness and how these feelings shifted over time. Questions also focused on siblings' responses to their brother's or sister's illness including helping behaviors or withdrawal behaviors. Due to the flexible method, the interview guide was adapted in the beginning of the data collection process; an additional question was added focusing on what siblings would want mental health clinicians to know about their experience growing up with a sibling who suffers from disordered eating. Participation in the entire interview process ranged from 45 minutes to an hour.

Data Analysis

The interviews carried out in this study were audio recorded. During these interviews, I also wrote down any themes that seemed to be emerging in the participant's narratives. After each interview, I recorded my reflections about participant body language (in the in-person interviews) and how I felt the interview proceeded. The audio-recorded interviews were then transcribed verbatim, by me, into a written format. Thematic analysis was used as the method to analyze the data gathered in these interviews and to present my findings. Using this type of analysis, I created a coding system for common themes uncovered in the interviews. I began the analysis by arranging quotes by interview question and then looking for themes within each question. In this thematic analysis, attention was placed on similarities, differences and variations among individual participants and in the sample as a whole. Possible researcher bias in interpreting the data was monitored by meeting and discussing with my research advisor during the coding process.

CHAPTER IV

FINDINGS

This chapter presents the findings of interviews with 10 participants who are siblings of individuals suffering from eating disorders. Aware of the increasing prevalence and life threatening nature of eating disorders coupled with the lack of research on siblings has inspired this research topic. Furthermore, the implications of limited research on siblings of persons suffering from a broad range of serious mental illnesses have inspired the researcher to explore the question: What are sibling's perspectives on growing up with a sibling who suffers from an eating disorder? The findings of the 10 semi-structured interviews exploring siblings' perceptions of their sibling's illness are presented below in six sections; findings were divided into six major areas based on the recollections of participants. The first section looks at the demographics of participants which gives information about the sibling-in-context. The next five sections explore siblings' perspectives on: their discovery of the eating disorder; their emotional responses to the illness; their behavioral responses to their sibling; family dynamics while their sibling was ill; and recommendations for mental health professionals.

I. Demographics

Age and Gender

The ages of the ten participants ranged from 20 to 38 years with an average participant age of 26 years. Participants' siblings, who they identify as suffering with an eating disorder, ranged in age from 17 years to 45 years of age at the time of the interview. Six of the participants identified as female and four participants identified as male. All ten of the participants reported that their sibling identified as female. Two female participants were from the same family and two male participants were from the same family.

Table 1 - Age and Gender

Participant	Participant Age	gender	Age of sibling with ED
1	21	F	17
2	23	F	17
3	36	M	34
4	28	F	27
5	38	F	45
6	25	F	26
7	22	M	18
8	20	F	30
9	21	M	18
10	26	M	30
Average	26		26.2

Race and Ethnic Background

All participants identified themselves as Caucasian. In terms of ethnicity, three participants identified themselves as Irish, two participants identified as of Scottish

decent, two as Scandinavian, one of German decent and one participant identified as Jewish.

Birth Order

Two participants identified themselves as the oldest child of their biological family. Three participants identified as the youngest child and five participants described themselves as being the middle child of their family. Six of the participants identified their younger sibling as struggling with an eating disorder. Four of the participants described their older sibling as suffering from an eating disorder.

Family

All participants described their parents as being physically present while their sibling began suffering from an eating disorder. One participant reported that her parents were separating at the time that her sibling showed symptoms of an eating disorder; she states that while separating her parents lived in the same house until the divorce was finalized a couple years later.

How Long Ago Disordered Eating Was Noticed

Participants were asked how long ago they noticed their sibling's disordered eating habits. The table below highlights the wide range of responses (see Table 2). In terms of how long ago participants noticed their sibling's eating disorder symptoms, one participant noticed the symptoms within the past year. Three participants noticed symptoms 3 years ago, one 9 years ago, one 10 years ago, one 12 years ago, two 15 years ago, and one 19 years ago. Eight of the participants described their sibling as actively

suffering from an eating disorder. Two of these participants stated that their sibling was in recovery.

Table 2 - Time line and Status of Sibling's Eating Disorder

	Age of Partic.(yrs)	Age of ill-Sib	Status of ED	How long ago noticed Sib's ED (yrs)
1	21	17	Active	1
2	23	17	Active	3
3	36	34	Active	15
4	28	27	In Recovery	10
5	38	45	In Recovery	19
6	25	26	Active	9
7	22	18	Active	2.5
8	20	30	Active	15
9	21	18	Active	3
10	26	30	Active	12
Average	26	26.2		9

II. Discovery of Sibling's Illness

Participants were asked how they first learned that their sibling was suffering from an eating disorder. Participants described three major areas where they first noticed changes with their sibling. These areas included witnessing their sibling's changes in eating behaviors, physical changes, and emotional changes.

Changes in Eating Behaviors

Six participants reported that they first discovered their sibling was suffering from an eating disorder by witnessing changes in their sibling's eating habits. These six participants stated that they saw their sibling restricting their food intake. Three of these participants described scenarios where their sibling was refusing to eat meals and would

make excuses for not eating with the family including that they “were not feeling well” or “had already eaten.” Three participants stated that they witnessed their sibling exercising excessively. One participant said that he noticed his sibling had a problem when he found vomit outside his house.

Physical Changes

Five participants stated that while noticing shifts in their sibling’s eating behavior they also learned that their sibling was suffering from an eating disorder by witnessing their sibling’s striking physical changes. These five participants stated that they noticed their sibling’s weight loss and physical appearance of thinness. Two siblings stated that their sibling’s initial weight loss was commended by their family members and peers; they describe their sibling receiving initial positive feedback from peers about their weight change. One participant states “My sibling started to lose weight slowly initially and then of course people were giving her positive feedback. She looked thinner and didn’t look sick yet– eventually however I noticed her looking more emaciated and then a lot more fixated on food when we would go out.” Four of these participants stressed how striking and drastic the weight loss became. One participant stated “Every time I saw her it would take my breath away. . . I would see the bones, the baggy clothing some days, depression, hair falling out, dull looking skin, strange behavior – so many things that screamed this isn’t right, this isn’t normal.”

Emotional Changes

Four participants identified distinct emotional changes in their sibling. Three of these participants stated that they experienced their sibling as increasingly angry. Three participants described their sibling as withdrawing and isolating themselves from family and friends.

Three participants said that they first noticed that their sibling had a problem through witnessing increased strife and tension between their sibling and their parents. One participant described “I remember that my parents would find throw up outside and they would confront my sister about it . . .and I remember a lot of secretness and they were yelling back and forth at one point and that’s the first time I really ever got to know about my sister’s eating disorder.”

Three participants, two of whom were from the same family, reported that after noticing their sibling’s weight loss, they learned about their sibling’s eating disorder from their parents. These participants stated that their parents pulled them aside, without their sibling sufferer present, and told them of that their sibling had an eating disorder.

III. Emotional Responses Towards Sibling’s Illness

Initial Feelings in Response to Sibling’s Illness

Participants described a range of feelings in response to seeing their sibling suffering from an eating disorder. Anger, frustration, jealousy, guilt, sadness, pain, and hopelessness were the most common feelings described by participants. The most common emotion that participants described in response to their sibling’s illness was

anger. Six participants stated that they initially felt anger towards their sibling for her eating disorder. Participants' anger was described in response to seeing their sibling's behaviors towards food including the compulsive restricting, purging, and binging. For example, one participant stated: "When I first saw her restricting, I didn't really know what eating disorders were and I remember being angry at that time." Similarly another participant whose sibling suffered from bulimia stated: "I would always get really angry because she would always eat my food that I would save that I would like and I would get really mad at her. . .you couldn't really talk to her about it because she would not want to hear about it." This anger was often described by participants as a response to their sibling's denial of her unhealthy behaviors towards food. When asked how a participant felt when she learned about her sibling's eating disorder, she stated:

"I was very angry for a chunk of time, once she was in treatment I was better about it but for that period of time that she was denying she had a problem, I was very very angry. I stopped coming home from school; I wouldn't speak to her and felt as though she was trying to flaunt this lifestyle when really that was not what was going on. She was miserable and I couldn't let my guard down."

One participant described her feelings of anger as emerging out of experiencing her caregivers be consumed with her sister's eating disorder. She describes: "My sister took so much of the family's attention and emotion during those years. It was all about her, all the time. So much maintenance and support to get her through the day."

Similar to anger, the next most common feeling brought up by participants was frustration. While anger is a strong feeling of displeasure or hostility that can be expressed physically, frustration is defined as "a deep chronic sense or state of insecurity and dissatisfaction arising from unresolved problems" (Merriam-Webster, 2010). For four participants, frustration was the emotion they described as most present for them in

their experiences with their sibling's illness. One participant explained his feelings in response to learning about his sibling's eating disorder:

“First I would see a cup outside filled with throw up and you know there is a problem but you don't really know exactly and you don't know what to do. I was just really frustrated about it and then I would yell at her for eating my food. Her sneaking around and in the middle of the night trying to steal food and waste it. . . cause she didn't really consume any of it. So that really frustrated me so I tried not to deal with it and . . . tried not to think about it.”

Another participant described similar feelings of frustration in response to his sister's behaviors towards food. He asserted: “It was very hard living in the house. She was always on the edge towards everyone around food or anything. If a crumb hit the floor, she would freak out. It was very frustrating for me. I did the best that I could . . . to help her.”

Feelings of guilt were present for the four participants who were older siblings. Three of these participants reported feeling a sense of guilt for being naturally thinner than their siblings as children. For example, one older sister stated that she felt responsible for her sibling's eating disorder because of her own weight loss: “I felt a sense of responsibility for her eating disorder on my shoulders in a way that she saw me lose weight and that made her want to lose weight and made her feel like she was the heavier child in our family.” Similarly another older sibling stated:

“I spent a lot of time crying over it because I felt guilty for her [eating disorder]. . . I think I masked the underlying guilt I had with anger. Instead of taking it on me, I would take it out on her saying “how could you do this” . . . instead of ‘look what I did, when I was in the mirror saying do I look fat, do I look fat.’ That was so wrong to do that in front of my sister, I was so self-absorbed, and it had a huge impact on the way my sister viewed herself.”

Both of these female participants clearly blame themselves for their younger sibling's struggles with body image and disordered eating based on their own behaviors when they

were younger. A male participant also described feeling guilty for causing his younger sister's eating disorder. When asked how he felt, he asserted: "a guilty feeling – you start to blame yourself or you will question yourself – if you were the cause of the eating disorder." The testimonies of these older siblings clearly convey how they questioned and blamed themselves for their sibling's illness.

Three female participants shared that they felt jealousy towards their sibling while they were suffering from an eating disorder. These three participants shared that they also suffered from some disordered eating habits and felt competitive with their sibling's weight loss. One sibling stated: "Seeing my younger sibling have an eating disorder and lose all that weight, it made me jealous and I know that I'm not supposed to want that but part of me does want that. . . I was having these unattractive emotions and saying to myself: 'you should not be jealous of someone else's disease – that's not right.'" Another participant stated: "I had struggled with my own weight, but had never developed an eating disorder. But I think a part of me was jealous that my sister was getting so thin and she seemed to have so much self-control."

Two siblings from the same family described their feelings as sadness. One of these participants stated "I felt more sad for her cause there was nothing I could really do about it." For this participant, sadness was coupled with a feeling of hopelessness regarding his sibling's eating disorder. Furthermore, two siblings used the word "painful" to describe their experiences seeing their sibling suffer with an eating disorder. One sibling stated "I remember thinking this was very hard to watch – someone who has been so pretty, had such a great sense of humor, had all these great qualities – just to see her in such a state was so painful . . .and you just knew that she was isolating and living

in this place that was in the basement. So it was very painful to see her in that state.”

The pain of experiencing a distinct shift in their sibling’s personality was also identified by another participant. She described:

“It was really hard watching how much she changed, when you do not eat, you are a bitch, you are angry, you are volatile, don’t want to talk about anything. It’s incredible how much her personality shifted. She would come home for family events; she was completely closed off, not engaging with the family. She was miserable and did not talk to anyone. . .I was very hurt to have lost my little sister who would joke together, inside jokes together, we loved movies together – and I lost all of that.”

Changes in Feelings Overtime

Most of the participants described their feelings towards their sibling’s illness as changing overtime. Two participants emphasized that their feelings shifted from anger and frustration towards realizing that they were powerless over their sibling’s illness. One sibling stated “I have definitely taken a step back and only intervened as it affects my life, realizing that I am powerless over that eating disorder. I have come to the realization that it is a very powerful disease that you can only help so much. That she is really responsible for herself, getting professional help and dealing with it.” Another participant also shared this shift in thinking: “I don’t enjoy seeing her sick but at the same time . . .I can’t do anything. She has to want . . . get better . . .it has to come from within herself. That’s the way I look at it and now understand it.” Another sibling described a shift from frustration towards more of an understanding of their sibling’s disease. This participant said:

“Now it is more understanding the disorder and knowing that she suffers from a disease that is not good. I guess when we were younger, we never thought about it as a disease. It was more of something she wanted to do and she can get over it

but that has changed. I have learned that it is going to take time and it involves patience. She needs to work on it and go to therapy.”

These participants seem to find some catharsis in placing the treatment of the eating disorder in their sibling’s hands.

Another sibling summed up the shifting of emotions that occurred towards her sibling during the years that she suffered from disordered eating. She explained: “My feelings towards my sister have gone through stages from just being devastated and shocked to anger and despair to thinking she was going to die and not knowing what to do.” Two other participants also shared these feelings of fear that their sibling could die from their eating disorder. One sibling stated: “The more I started noticing it the more I realized how sick she was. And I was really worried she would be hospitalized or if not that she might die. . .The biggest challenge was this fear I carried that she was never going to get better.”

Attitude Towards Food Affected by Sibling’s Eating Disorder

In addition to exploring participant’s feelings towards their sibling, participants were also asked about their attitudes and feelings towards food. Participants were asked the question: What was food like for you after you discovered your sibling’s eating disorder? Seven participants reported changes in their eating habits after experiencing their sibling’s behaviors around food. Two siblings reported restricting their food consumption in response to seeing their sibling do such behaviors; one of these participants reported feeling competitive with their sibling and the other participant reported feelings of jealousy towards her sibling. Of the remaining participants who

reported changes in their attitude towards food, one stated that she developed a hyperawareness towards food especially when she was eating near her sibling. She stated: “The biggest issue was eating because if I was eating less or more intuitively, I was always aware of how it might be affecting her.” Another participant reported overeating because she was so determined not to be like her sister and persons who suffered from eating disorders. She stated: “I overate a little bit because I was so determined to not become like that and I think there was a part of me that didn’t want to have to watch calories or think about it the way she thought about it.” Interestingly, one male participant described maintaining a sense of connection to his withdrawn sibling by “mimicking” her obsession with food. He recalled:

“She distance herself so much and in retrospect, I think in a way that I connected with her is that I took on some of the qualities of an eating disorder. I don’t know if I had one or not but I mimicked it. We shared that in common – that obsession with food and body image and at that point – fat free was the crazy – that was the method that she used and I picked it up as well. We would talk about the latest fat free foods or go on binges together with fat free foods.”

Another male participant described being unable to eat in their home because of his sister’s severe phobia towards certain foods and her fixation on restricting food. This participant reported eating out daily or eating at friend’s house to avoid his sister’s angry outbursts at him while he ate. Thus, for these seven participants, they noticed a clear change in their eating habits prompted by experiencing their sibling’s struggles with food.

IV. Behavioral Responses to Sibling

When asked how participants responded to their sibling while they were ill, participants offered varied answers including withdrawing from their sibling, trying to engage their sibling, and confronting their sibling. Two participants distinctly described withdrawing from their sibling. This included physically removing themselves from their sibling's environment and also mentally trying to avoid thinking about their sibling's illness. A participant explained how he responded to his sibling: "I just dealt with it in a selfish way. I don't want to think about it. I try not to think about it. So I put it on the backburner and tried not to be around it because if you are not around it, it is not happening. . .So you just detach away from what's going on and your family and your house."

Seven participants reported helping behaviors in response to their sibling. Two of these participants described trying to maintain a positive outlook with their sibling and guide her away from negative thinking. Four participants stated that they tried to increase their communication with their sibling when they were struggling with this illness. Communication in the form of calling their sibling to check-in on a daily basis and see how they were feeling was a common response by participants who were physically out of the house at that time. For siblings living in the house at the time, they described initiating conversation to see how their sibling was feeling.

One participant described responding to his sibling's illness by trying to assert control over her life through monitoring her behaviors. He stated: "By asserting control I mean that I watched everything that she ate or didn't eat, monitored her physical activity

and exercise. Monitoring not so much her weight but the clothes she was wearing, how she was acting and feeling, trying totally to have an understanding where she was at day to day or hour to hour at that point.”

V. Family Environment

Experience Living with Sibling

When participants were asked the question: “What was it like living in the house at the time?” most participants described the high levels of tension within their family. Seven participants directly used the words: tension, strife, stress, fighting and devastation, to describe their family environment while living with their sibling while she was ill. One participant asserted: “When I was living in the house with my sister, it was very chaotic. It was very stressful. People were in and out and it was just a stressful environment. . . I think mental health clinicians should know just how stressful - the tension and the stress that floats in the air and in the house.” Another participant recalled his experience of living in the house at the time his sibling was sick:

“Living in the house, it was devastating on the family, stress on the family. We took it upon ourselves to try and fix the problem through subtle help or more forceful measures, through trying to force her to eat. Everyone went through manners of trying to fix the problem but it just consumes the entire family and its all you think of: ‘how can we get her better, is she going to be okay, did I cause this, what caused this, who caused this?’”

Thus, for most participants, they experienced their family environment as highly stressful while their sibling was sick.

Perception of Parental Responses to their Child's Eating Disorder

Participants were asked their perspectives on their parent's responses to their sibling's eating disorder. Three participants described their parents as initially not addressing their sibling's struggles. Two of these participants stated that their parents seemed to keep their sibling's illness as "secretive." These two participants shared that their parents would not talk about what was going on with their child and were not willing to ask for professional help. One of these participants recalled his parent's lack of action towards his sister's eating disorder. He stated: "My parents tried to make everything be like on the outside it is okay and we will deal with it within the family type of manner. We will deal with it between us and not ask for help because we couldn't do that – so it was almost neglect there." When asking about how he felt about his parent's response to the illness he went on say: "Looking back on it now – I think how dumb and stupid we all were and how ridiculous it was when we found throw up outside or how we did not seek help from someone." These participants described a real awareness on the part of their parents of their sibling's problem, yet these participants believed that their parents initially did not take the action needed to help their sibling. One of these participants said that she felt her parents were aware of her sister's eating disorder; however, they did not know how to approach her sister. She recalled: "My parents were aware but they did not know how to approach it. I remember my mom reading about eating disorder when my oldest sister was young and I guess she never knew how to approach her about it." When asked how this response by her parents made her feel, the participant shared: "I was angry at my parents. I did not know what to do either but I felt like it was more their place to say something to my sister rather than me."

Seven participants reported that their mothers were supportive of their sibling and tried to get help for them. Four participants stated that their father reacted to their sibling with more negative emotions like anger, frustration, and control. One participant stated that his father would often “lose it” in front of his sibling. Another participant stated that his “father used more anger and showed his frustration through anger. My mother would go between anger and trying to get every piece of help possible for my sister. It took awhile to realize that it is not something that you can just punish or yell away. That it requires a hell of a lot of help. They stepped up and got the help which I think saved her life.” For this participant there was a shift of realization on his parent’s part of the seriousness of the illness and the importance of getting professional help. Two participants from the same family described their father making a shift as well in his mindset. They reported that their father was very “strict” about food growing up and would often “rebuke” his children for the type or amount of food they were eating. They both went on to say that their father now, years later, recognizes his role in contributing to his daughter’s struggles with food.

Perception of Sibling Responses

Participants were questioned about how their other brothers and sisters responded to their sibling who was suffering from an eating disorder. Then they were asked how they felt about their sibling’s response. Two participants described their older female siblings as being in denial about their sibling’s eating disorder and unsupportive in helping their sibling. Both of these participants stated that they were angry and frustrated at this older sibling for not taking an active role in trying to help his or her sister. One

participant stated: “My older sister was in denial about my younger sister’s eating disorder and she never really talked about it. With her, I am annoyed and still annoyed with how she dealt with it.” Similarly participant stated: “I remember just being frustrated and angry towards my older sister who was so hard on my younger sister for her eating disorder. In contrast, three female participants stated that they could empathize with their male sibling’s response to their sister’s eating disorder. One participant stated that she experienced sadness for her brother who struggled with witnessing his sister’s eating disorder.

Coping Mechanisms Utilized By Siblings

Four participants reported unhealthy ways of trying to escape from thinking about their sibling’s eating disorder. Two participants stated that they used alcohol as an escape and one shared that he began to drink to excess. One of these participants stated that she coped with her overwhelming emotions associated with witnessing her sister’s illness by self-harm behaviors such as cutting and restricting her own diet. Another participant reported abusing a prescription medication to suppress her own appetite as an “escape” mechanism for her during the time period that her sister was very sick. Three participants stated that leaving for college and leaving the home where their sibling resided helped them cope with the experience of seeing their sibling suffer with an eating disorder.

In terms of more healthy ways of coping, three participants described the importance for them of educating themselves about eating disorders. One stated that she channeled her energy at college into eating disorder prevention involvement on her

campus. Two of these participants went on to become mental health clinicians specializing in the treatment of eating disorders. Two other participants shared that they immersed themselves in sports as their coping mechanism for the stresses related to their sibling's eating disorder. Three participants credited their relationship with close friends as helping them take their mind off of their sibling's illness.

VI. Advice for Mental Health Clinicians

Four participants emphasized the importance of family therapy for all family members; they stressed the importance of participation in family therapy by not only the parents, but older and younger siblings as well. One participant stressed: "Mental health clinicians need to realize that not only the person with the disorder is affected but the whole family and this must be taken into consideration and family therapy is critical." Another participant stated: "the family therapy piece is really important and getting siblings involved in it is so important. I think that my sister could have really benefitted from family sessions with all of my siblings and not just my parents." Three participants stressed the need for education for the family members on eating disorders. Two of these participants emphasized that siblings often do not understand what their sibling is experiencing and the severity of the illness. One participant stated:

"I don't think a lot of people understand; I don't think the siblings understand. As a mental health clinician you know the severity of what is going on and you have to assume that the family and siblings don't know the significance of what is happening. They know what is going on but not significance so you have to explain that to them. I think that's what was going on with us. We really didn't understand the significance of it. We didn't take time to research or seek help."

This participant then went on to say:

“It’s a real problem and its worse than any other disease like alcoholism. Our siblings are slowly killing themselves so it’s almost like suicide, but ten times worse. You have to explain that to the family in a constructive way. I feel like it’s almost like a good way to explain it. A good way to explain it is that it’s almost like committing suicide for like 15 years instead of it taking 5 seconds, 15 years. It’s extremely painful to see someone go through that who is your sibling.”

This participant brings forth the question of how mental health clinicians should best address and educate these siblings about the seriousness of their brother’s or sister’s eating disorder. Another participant also commented on the importance of education for siblings. She stated: “It would be helpful to have the siblings participate in some of the therapy because when the person suffering is going into treatment, they are with their siblings a lot. So it may be good to teach them about what their sibling is going through and how to be of help.” This participant spoke further on her concerns about her younger siblings and what they internalize from witnessing their sibling’s eating disorder. She continued to say: “I was old enough that it didn’t affect my attitude towards food as much but for younger people it might. The younger siblings may look at older sibling’s behaviors as a healthy way to lose weight and may not realize how dangerous it is. So I think some type of training for younger siblings may be good.” This participant emphasizes her concern that without guidance her younger sibling’s may imitate her older sister’s behaviors towards food and weight loss.

CHAPTER V

DISCUSSION

This study explored sibling's perspectives on growing up with a sibling who suffers from an eating disorder. The ten participants interviewed shared their reactions and feelings towards their sibling as they witnessed the changes that ensued as their sibling battled an eating disorder. They shared how they responded to their sibling's illness and how they took care of themselves while their sibling was ill. Siblings were able to open up about their family dynamics, while their sibling's disordered eating habits emerged and worsened. Prominent themes emerged in these semi-structured interviews with participants. Some of this study's findings support previous research on siblings of persons with eating disorders and other serious mental illnesses. This chapter will review major findings and discuss them in relationship to the existing literature. Specifically, this chapter will review findings on participants' discovery of the illness; their feelings in response to their sibling; their behaviors towards their sibling; their perceptions of their family dynamics in response to their sibling's eating disorder; and their recommendations to mental health professionals.

Discovery Process

Participants discovered that their sibling was struggling with an eating disorder by first noticing changes in eating behavior including skipping meals, restricting food intake, and vomiting after eating. According to participants, these changes in eating behaviors

were accompanied by striking physical changes and emotional changes. Two participants described their sibling receiving positive feedback about their initial weight loss from family and friends which was upsetting for these participants. Participants noticed emotional changes in their sibling including isolation, withdrawal, and increased anger.

Emotional Response to Sibling's Illness

During the discovery process, participants reported experiencing a range of negative emotions; the most prominent emotions being anger, frustration, and guilt. These emotions were described in response to siblings' unhealthy eating behaviors, unhealthy body image, and drastic changes in their siblings' personalities. These emotions of anger, guilt, and frustration support findings in a study conducted by Lukens et al. (2004) on siblings of persons with mental illness. Furthermore, participant's descriptions of the type of experiences which triggered feelings of anger reinforces findings in a study by Dimitropoulos et al. (2009) which reported that sibling's anger was elicited from the emaciated appearance of their sibling, the binge-purge cycle, and the restrictive eating behaviors. Dimitropoulos et al. (2009) also found that the denial of the seriousness of the eating disorder and concealment of the eating symptoms significantly interfered with sibling's ability to maintain an emotional connection with their affected sibling (p. 357). Reinforcing these findings, strong feelings of anger in this present study were often described by participants towards their sibling as a reaction to their sibling's hiding and denial of their unhealthy eating habits.

The feelings of guilt reported by siblings in this study were particularly interesting. Guilt has been found in previous studies (Deal & McLean, 1995; Stalberg,

Ekerwald & Hultman, 2004) exploring perceptions of siblings of persons with severe mental illness; the guilt in these studies was found in response to being healthy in relation to their sibling. In this present study, there was clearly a link between guilty feelings and birth order. All participants who reported feelings of guilt were older siblings. They blamed themselves for their own struggles with weight or body image which they believed their younger sibling internalized, leading to their disordered body image and eating habits. These strong feelings of self-blame by participants indicate the importance for mental health professionals to explore feelings of guilt with siblings and to educate siblings that they are not to blame for their sibling's eating disorder. Luken's et al. (2004) asserted in their study that for siblings to move beyond feelings of guilt and anger, then emotional support and validation are essential. Thus, these findings of guilt clearly have implications for mental health clinicians working with siblings of eating disorder sufferers to have an awareness of possible feelings of self-blame and to provide a supportive intervention.

Most siblings described shifts in their feelings towards their sibling overtime. For some participants they reported feelings of powerlessness over their sibling's illness which was also a finding by Dimitropoulos et al. (2009). For these participants, with their recognition of their powerlessness over their sibling's disease, came a cathartic feeling that the responsibility of their sibling's well-being was no longer in their hands. They described recognizing that they were not the vehicles of change for their sibling and were more aware of their sibling's responsibility in receiving treatment for their eating disorder. One participant described his shift in thinking to more of an understanding that his sibling suffered from a disease and that her behaviors were not of a volitional nature

where she could easily stop. This participant was able to externalize the disease from his sibling and see the disease as both serious and separate from his sibling. This process of externalization was consistent with reports by siblings of individuals with severe mental illness in research conducted by Kinsella et al. (2006) and Dimitropoulos et al. (2009).

Seven participants described changes in their attitudes and behaviors towards food as a result of experiencing their sibling's disordered eating behaviors. Two siblings reported that watching their sibling suffer from an eating disorder, exacerbated their own disordered eating habits of unhealthily restricting their food intake. Other descriptions of changes in eating behavior included a hyperawareness towards how much they were eating, overeating as a reaction to their sibling's restricting, and an avoidance of eating while their sibling was physically present. The number of participants that describe their own eating habits as impacted by their sibling's illness is alarming. Siblings are genetically at risk for the development of eating disorders (Bulik et al., 2000; Klump et al., 2009) and the environmental presence of their sibling's disordered eating could place them at an even greater risk of developing disordered eating. Thus, siblings of sufferers clearly need both emotional support and education about the symptoms of eating disorders as prevention interventions.

Behavioral Responses to Sibling

Participants described varied responses to their sibling including both withdrawal behaviors and helping behaviors. Siblings who physically withdrew from the environment described how this behavior temporarily helped them emotionally distance themselves from their family and their sibling's disease. Coping by psychologically

distancing themselves from their sibling was a major theme found in a longitudinal study on siblings of persons with anorexia and schizophrenia (Taylor et al., 2008). In terms of helping behaviors, siblings saw themselves as helping by increasing their communication with their sibling; several siblings who were away at college reported calling their sibling regularly to check-in on their sibling's emotional state. Siblings also described the importance of maintaining a positive outlook for their sibling which one participant described as "exhausting." In a previous study, siblings have described being elicited by their parents to help their sibling including being their sibling's confidant and a monitor for their sibling's behaviors (Dimitropoulos et al., 2009). One participant in the present study reported that her parents would ask her to check-in with her sibling each day about how she was feeling and functioning. This finding of helping behaviors brings forth questions of the perceived burden for siblings on being placed in a care-giving and monitoring role in their family.

Perceptions of Family Dynamics

The majority of participants reported high levels of tension, stress, and fighting in their family environment while their sibling was ill. Siblings' reports of the family environment during the time of their sibling's illness, brings forth a question of whether the family tension was present before the illness and was a risk factor. Studies looking into the association of family environment and the development of eating disordered behavior have yielded mixed results. Some studies have shown an association between family dysfunction according to the FACES-II scale (Family Adaptability and Cohesion Scale) and eating disorders (Kluck, 2008; Lundholm & Waters, 1991; Wisotsky et al.,

2003). These studies reported overall findings that as perceived family dysfunction increases, eating pathology became more severe. While studies like these have identified an association between family dysfunction and eating disorders, one cannot assume that family dysfunction causes eating pathology. In this study, siblings seemed to describe their family tension and fighting as increasing when their sibling's disordered eating habits became more severe. Thus, according to sibling reports in this study, the nature of the sibling's eating disorder placed stress on the family as well.

Siblings reported inconsistent responses by family members towards their sibling's eating disorder. Some members were described by participants as supportive of treatment while other family members seemed to be in denial of the severity of the sibling's illness. This inconsistency in responses reinforces findings in interviews with siblings by Dimitropoulos et al. (2009). Dimitropoulos et al. found that these inconsistent responses by parents and siblings caused conflict within the family. For siblings in the current study, the denial by a parent or a sibling of the seriousness of the illness and the reports of fathers' negative reactions was associated with feelings of anger and frustration among participants. Siblings reported anger towards their parents or siblings who did not recognize the seriousness of their sibling's eating disorder symptoms which is consistent with reports by siblings in the study by Dimitropoulos et al. (2009). Two participants specifically described their older female sibling as being in denial about their younger sibling's illness. They described levels of anger toward their sibling for the denial and subsequent lack of participation in the family therapy for their sister. Both of these siblings-in-denial were much older than the sibling sufferer; thus, participants whom identified their frustrations with these older sisters were much closer in age to the

sufferer. These participants described being more protective and sympathetic of their sibling sufferer and more active in their sister's treatment process. This finding brings forth questions of how birth order and proximity of age to the sibling sufferer affects sibling's roles. There is also the question of whether siblings closer in age to their ill-sibling are more vulnerable than other siblings.

The unhealthy coping mechanisms described by participants sheds some light on how affected siblings felt emotionally while discovering their sibling's struggles with an eating disorder. Coping by increased substance use and self-harm behaviors by four participants is disquieting. These findings regarding the dangerous escape mechanisms used by siblings demonstrate the need for siblings to receive more professional help. The importance of early intervention for sufferers of eating disorders and their siblings is imperative.

Recommendations for Mental Health Professionals

Participants made several recommendations for mental health professionals working with families affected by eating disorders. The majority of participants asked for more education about their sibling's illness and how to respond to their sibling in a helpful manner. Participants also stressed the need for more mental health support for siblings of persons with eating disorders and emphasized how all siblings need to be included in family therapy sessions. The importance of education about eating disorders for siblings was in line with interviews of siblings by Dimitropoulos et al. (2009). What does education look like and when do siblings need intervention by professionals to provide education about eating disorders? From these findings it seems as though

siblings need education before the onset of the illness as a form of prevention. This education about eating disorders could be disseminated through the school system to students in early adolescence. Education could include information about the difference between healthy and unhealthy eating habits; the signs of eating disorders; possible causes; and resources for how to get help for these illnesses. This prevention education could also include information on what to do if someone is concerned about a friend or a family member struggling with disordered eating.

Findings in this study showed how siblings did not have prior education about eating disorders and that they really did not understand what was occurring with their sibling. Early on in their sibling's illness, participants described not understanding their sibling's symptoms and feeling angry that their sibling could not quickly abandon their unhealthy behaviors by eating more or stopping their purging. Many siblings described a sense of not understanding what was happening with their sibling and a chronic sense of frustration and fear. One participant particularly emphasized her fears about her younger siblings witnessing her ill-sibling's disordered eating, and their belief that these behaviors were healthy or normal. She stressed the absolute need for clinicians to include younger siblings in therapy and to educate them on healthy eating behaviors. Out of her recommendation emerges the question: How do clinicians, in a supportive manner, communicate the possible causes, symptoms, and seriousness of eating disorders to siblings of different ages? Clearly, siblings of all ages must be made aware that there is not one simple thing that caused their sibling's eating disorder to emerge. The development of eating disorders usually lies in a combination of interwoven factors including social, environmental, biological, and/or family dysfunction. Siblings must

understand from communication by professionals and parents that they are in no way at fault for their sibling's eating disorder.

With research indicating siblings being at increased risk for developing an eating disorder, clinicians need to inform these siblings of the difference between healthy eating, dieting, and symptoms of an eating disorder. Clinicians need to make siblings aware that opposed to healthy dieting, eating disorders are an illness that pervades all aspects of an individual's life. Eating disorders are emotionally based diseases and the eating behaviors are only a symptom to the emotional and stress problems; disordered eating is a way for an individual to try to control, avoid, and hide emotional pain or stress. Siblings must gain an understanding from professionals that there are many things they cannot do for their brother or sister sufferer including forcing them to eat or stopping them from purging. Like some of these participants described realizing over time, siblings need help recognizing that their sibling sufferer is the vessel for change; he or she must want to deal with his or her emotional pain and receive treatment for it.

Strengths and Limitations

The strength of this study is that it provided rich and detailed narratives of the perspectives of siblings growing up with a sister who suffers from an eating disorder. The participant narratives brought to light the varied and intense emotional reactions siblings experienced in response to their sibling's illness. The narratives demonstrated how sibling's own eating habits were affected and how they each coped with witnessing their sibling's struggles. The detailed recollections of these siblings also emphasized the

family environment while their sibling was ill including their parent's and sibling's responses to their sibling.

A limitation of this study and a common problem for qualitative research is generalizability. As a result of a relatively small, homogenous sample and the personal nature of the observations made by the researcher, results may not generalize to other groups of siblings. Despite extensive outreach efforts to siblings of individuals suffering from eating disorders, the population proved to be difficult to recruit. I contacted a large number of clinicians specializing in the treatment of eating disorders across geographic locations and survivors of eating disorders to assist in recruitment efforts. Research has revealed that the stigma surrounding eating disorders is higher than other severe mental illnesses including depression and schizophrenia (Stewart et al., 2008). I wondered if the stigmatization and shame surrounding eating disorders prevented some individuals from participating in the study. Consequently, although intended to be larger, the number of participants was limited to ten. For future research, a larger, more racially diverse, sample size including both male and female sibling sufferers is recommended through even more aggressive outreach and recruitment.

Furthermore, since this study was exploratory in nature and was conducted with open-ended interview questions, potential bias could occur in the manner in which questions were asked and how questions were followed up during these interviews. In addition, the impact of completing some of the interviews over the phone as opposed to in-person has to be taken into account. Data compiled from the interview questions were largely based on recollection. For most participants they were currently experiencing their sibling's illness, however for some participants they were recalling events in the

distant past before their sibling went into recovery. Therefore the accuracy of the recollection of sibling's perspectives needs to be considered.

Research Implications

This study was exploratory in nature with the hope that it might guide research in the future on this topic. Due to the small pool of participants in the study, future research needs to focus on the recruitment process and obtaining a larger pool of siblings. Further research into the emotional impacts of growing up with a sibling with an eating disorder in comparison to a control group is needed. As indicated by the large number of participants who reported changes in their eating behaviors, more research needs to examine the impacts of the symptoms of an eating disorder on siblings' eating habits. Furthermore, therapeutic interventions which support the needs of siblings need to be employed while future research needs to test these interventions; this may include exploring the effectiveness of support groups for siblings of individuals with eating disorders and more extensive inclusion of siblings in family therapy sessions.

Conclusion

My hope was that this study would give mental health clinicians a richer picture of the experiences siblings endure while their sibling battles an eating disorder. As Moser et al. (2005) pointed out, clinicians must be aware of the unique influences of the sibling relationship. If there is a lack of awareness of the influence of the sibling relationship by clinicians, then treatment for these individuals can be riddled with impasses and therapeutic failures; consequently, these siblings will not receive the crucial

help that they need as “secondary victims” to these serious illnesses. My wish is that the findings from these recollections open up a new lens of empathetic awareness in clinicians who work with those affected by eating disorders including both sufferers and their family members.

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Appendix A
Human Subjects Review Committee Approval Letter

December 17, 2009

Sarah Quish

Dear Sarah,

Your amended materials have been reviewed and you have done a fine job in their revision. All is now in order and we are glad to give final approval to this very interesting and useful study.

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.

Good luck with your project.
Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Jennifer Perloff, Research Advisor

Appendix B Informed Consent Form

Dear Participant,

My name is Sarah Quish and I am currently in the process of obtaining a Master's in Social Work from Smith College. Thank you for your interest in my study. I am conducting a study exploring sibling's perspectives on having a brother or sister who suffers from an eating disorder. This study will look at sibling's responses and reactions to their brother or sister's eating disorder. This is an area that has been ignored and understudied in the mental health field. The data from this study will be used for a Master's in Social Work thesis, presentations and publication.

You are being asked to participate in this research study if you a) are over the age of 18 years and b) have a biological brother or sister who has suffered from an eating disorder. As a participant in this study, you will be asked to do a one-on-one interview over the phone or face to face. At the beginning of the interview, you will be asked a brief set of demographic questions about your age, gender, and ethnicity. These questions will be followed by a series of open-ended interview questions focusing on your experience of having a sibling suffering from an eating disorder. You will be asked questions like: How did you learn about your sibling's eating disorder and how did you respond to your sibling? Participation in this interview will take between 45 and 60 minutes. Interviews will be tape recorded and these tapes will be numerically coded to ensure your confidentiality. Afterwards, I will transcribe these interviews.

Since this study asks for disclosure of personal experiences with your sibling, it may elicit emotional discomfort for some. Remember, you can end the interview at any time or decline to answer any question. In case you feel the need for any further support after the interview, I will provide a list of mental health professionals in the area. All identifying information provided in the interview will be kept confidential.

You may benefit from knowing that you have contributed to the knowledge of the impacts of having a sibling who suffers from an eating disorder, which is a relatively unstudied area of research. I hope that your responses regarding your experiences can help give social workers a better understanding of what it is like to have an ill-sibling so that they can provide more helpful interventions. Another benefit of your participation is that you may find new insight into your relationship with your sibling by talking through the experiences you have had with your sibling's illness. There will be no financial compensation for participation in this study.

Every effort will be made to preserve confidentiality as consistent with Federal Regulations and the mandates of the social work profession. To ensure the confidentiality of all study participants, the recorded interviews and transcriptions will have assigned numbers to each participant with the list of numbers kept at a separate location, all of which will remain locked up for a period of three years, in accordance

with Federal Regulations. After this period of three years, all forms of data will be destroyed.

Participation in this study is completely voluntary. You may refuse to answer any interview question(s), and you may withdraw from participation at any time without penalty. If you withdraw from the study, all materials pertaining to your participation will be destroyed immediately. You have until March 15th, 2010 to withdraw from the study; after this date, I will begin writing the Findings and Discussion sections of my thesis.

If you have any further questions about this study, participation, rights of participants, or this consent form, please feel free to ask me at the contact information below. You also may contact the Chair of the Smith College School for Social Work Human Subjects Review Committee at (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 of Participant	_____ Date
_____ Signature of Researcher	_____ Date

Thank you for your time, and I greatly look forward to having you as a participant in this study!

Sarah Quish

Appendix C

Screening Questions

- Are you over the age of 18 years?
- Are you a biological brother or sister of an individual who suffers from an eating disorder or has suffered from an eating disorder?

If the participant meets all of these criteria, then an interview time will be scheduled.

Do you have a sibling who suffers from an Eating Disorder?

Would you be willing to share your experiences with your sibling's illness?

I am conducting a Master's-level study examining sibling's perceptions of having a brother or sister with an eating disorder. I am seeking adults, 18 years and older, who have a biological sibling who suffers from an eating disorder. The study involves a brief interview (45 to 60 minutes) over the phone or in person.

If interested in participating or to inquire further, please
contact:

Sarah Quish

Appendix E
Preliminary Demographic Questions

Code # _____

Demographic Survey

1. What is your age? _____
 2. What is your gender? _____
 3. How do you identify racially? _____
 4. How do you identify ethnically? _____
 5. How old is your sibling who suffers with an eating disorder? _____
 6. How many siblings do you have? _____
 7. Where both your parents on the scene while your sibling was ill? _____
 8. How long ago did you notice your sibling's problems with eating? _____
 9. Have you lived with your sibling while they were battling this eating disorder?

- How many years did you live with him or her? _____

Appendix F Interview Guide

- 1) How did you first learn that your sibling had problems with disordered eating?
Did you know that your sibling had an eating disorder before they were diagnosed?

- 2) What was your sibling's disorder like?
Could you describe what your sibling's eating disorder looked like?
What was it like living in the house at that time or visiting with your sibling?

- 3) How did you feel when you learned your sibling had this problem with disordered eating?
How do you think your feelings about your sibling's illness have changed over time?

- 4) How did you respond to your sibling when you knew he or she was suffering from an eating disorder?

Rescue vs. Withdrawal behaviors
 - Did you try and help him or her? How?
 - Did you pull away or withdraw from your sibling? In what ways? How did you feel about this response?

- 5) What were the challenges you faced, each day, living with/having a sibling affected by an eating disorder?

- 6) How did you cope with these challenges of having a sibling with this illness?
How did you take care of yourself?
How did you take your mind off your sibling's illness?
Were there other things going on for you at this time?

- 7) How did your family deal with your sibling's eating disorder? Specifically, how did your parent(s) deal with it? Your other siblings?
How did you feel about the way your family members reacted to the illness?

8) What was eating and food like for you after you discovered your sibling's eating disorder?

Were your own eating habits affected by your experience with your sibling?

9) Is there anything else you feel I should know, or anything else you would like to share about this topic?

Appendix G
Recruitment Email

Email sent to Clinicians who specialize in the treatment of eating disorders.

Dear _____,

My name is Sarah Quish and I am graduate student at Smith College School for Social Work who will be conducting a research project exploring sibling's perspectives on having a brother or sister who suffers from an eating disorder. I am curious to know more about how siblings are impacted by this experience. I am writing to you as a clinician who specializes in treatment of eating disorders and looking for any assistance or advice in obtaining participants for the study. I am currently looking to interview adult siblings (18 years and older) who have a brother or sister with an eating disorder. During the interview, I will explore the reactions and responses sibling's used in the face of their sibling's illness. The interview will be brief, (45 to 60 minutes) and occur over the phone or in-person based on the geographic location of the participant. I appreciate any advice on finding siblings who may be interested in participation in this study. Thank you for your help.

Sincerely,

Sarah Quish
Smith College School for Social Work