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The Other Child: Health Narratives of Adults Raised with a Chronically Ill Sibling

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Running Head: THE OTHER CHILD

The Other Child: Health Narratives of Adults Raised with a Chronically Ill Sibling

by

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DISSERTATION

Submitted in partial fulfillment of the requirements for the degree
of Doctor of Psychology in the Department of Clinical Psychology
at Antioch University New England, 2012

Keene, New Hampshire



DISSERTATION COMMITTEE PAGE

The undersigned have examined the dissertation entitled:

**THE OTHER CHILD: HEALTH NARRATIVES OF ADULTS RAISED
WITH A CHRONICALLY ILL SIBLING**

presented on May 14, 2012

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In Dedication

To my Mom - Rosalie

Whose own story inspired the collection of these stories.

Acknowledgements

I would like to express an immense gratitude to the generous and strong individuals who so willingly and honestly shared their time and experiences for the purposes of this research. I'd also like to thank my dissertation chair, Dr. Martha Straus for her constant support and commitment to the project and to me, and my committee—Dr. William Slammon and Dr. Mick Foot—whose support and guidance also made this project possible and stronger.

Table of Contents

Dedication.....	iii
Acknowledgments.....	iv
List of Tables	vii
Abstract.....	1
Chapter 1	2
Statement of Concern.....	3
Research Questions.....	4
Chapter 2: Literature Review.....	6
Sibling Relationships	6
Chronic Illness	18
The Sibling Experience.....	22
Health/Illness Narratives.....	26
Chapter 3: Methodology	39
Qualitative Rationale and Naturalistic Paradigm.....	39
Sample.....	41
Methods and Procedures.....	43
Ethical Considerations	43
Quality Control Procedures.....	44
Data Analysis	45
Thematic Analysis and Coding.....	45
Chapter 4: Data and Results.....	49
At Home.....	50

Retrospective Early Needs.....	55
Anxiety.....	56
Guilt.....	58
Increased Empathy, Compassion, and Awareness.....	59
A Different Worldview.....	62
The Sibling Turn.....	64
Health Perspectives and Experiences.....	65
Chapter 5: Discussion.....	75
Mediated Adult Health Narratives.....	75
Helper-protector Role.....	78
Worldview.....	80
Disability and illness: A distinction without a difference?.....	81
Implications for Clinical Practice.....	82
Medical Professionals.....	83
Mental Health Professionals.....	84
Limitations of the Study.....	85
Implications for Future Research.....	86
Personal Reflections.....	87
Conclusion.....	88
References.....	90
Appendices.....	97

List of Tables

Table 1.0: Sibling to Sibling Widsom.....	104
Table 2.0: Summary of Major Themes and Examples	105

Abstract

The sibling relationship brings with it a powerful experience and unique effects on individual development. Within this paper the personal health narratives of adult siblings who grew up with a chronically ill brother or sister are explored in depth. Using a naturalistic, qualitative paradigm and approach to the research a small sample of participants (N=7) provided in depth, semi-structured interviews geared to explore their experiences growing up with their siblings, and later effects on the development of personal health narratives. Using thematic analysis, a number of themes were identified including: (a) at home: finding out, the early relationship, early environment, and family role; (b) retrospective early needs; (c) anxiety; (d) guilt; (e) increased empathy, compassion, and awareness; (f) a different worldview; (g) the sibling turn; (h) health perspective and experiences: retrospective health narratives at the family level, mediated adult health narratives, and general self-care. A model of understanding the development of health narratives and general self-care is offered for well siblings. The utility of these themes for clinical practice and directions for future research are discussed.

Keywords: health narratives, chronic illness, siblings

Chapter 1

In this dissertation I investigate the health narratives of adults who grew up as the healthy sibling of a chronically ill brother or sister. In doing so, I bring attention to an important part of the long-term impact of growing up the “well one” in a family. While a significant amount of research has been dedicated to the childhood experience of the siblings of chronically ill children, less is known about the health narratives of this population, their adult understanding of health and self care, and how their sibling experiences may have shaped their later health attitudes and beliefs.

It is well documented that the sibling relationship has a significant impact on the development of an individual. Siblings are part of our earliest memories, stories, and experiences. However, for some families, these normative relationships, experiences, and dynamics are altered early on by the diagnosis and experience of a child's chronic illness. While families find a variety of adaptive and functional ways to cope with the stress that accompanies such chronic illnesses, family life inevitably is transformed as a result, with clear implications for the other siblings within a family.

Given the profound reciprocal impact of siblings on each other's development, it is likely that a sibling's chronic illness will also have a lasting impact on the well brother or sister's understanding of his or her own health and illness. The goal of this dissertation is to better understand the health narratives of adults who grew up with a chronically ill sibling, particularly exploring the manner in which the experience shapes their own personal sense of health and illness. By better understanding the health narratives which this particular population may carry with them into adulthood, medical and mental health professionals can increase their ability to provide sensitive care and consideration for this population.

The concept of narratives has long remained a fixture of human experience. There is a wide array of narratives to be found within the human experience—self narratives, family narratives, societal narratives, etc. However, for the purposes of this project the focus will remain on health and illness narratives. These narratives can best be described as the stories an individual holds from which they ascribe meaning, value, and structure to their own health, illnesses, and well-being (Kleinman, 1988). Such narratives can also extend toward understanding how individuals take care of themselves, how they seek medical care, and/or their attitudes toward the medical field.

Statement of Concern

Medical and mental health professionals invest large quantities of time attempting to ascertain how individuals take care of themselves and trying to remedy maladaptive methods of care. Understanding the roots and underpinnings of how these methods of care first developed can often be a helpful starting point for practitioners in beginning to modify client behavior, motivation, and treatment compliance. The present study has identified growing up with a chronically ill sibling as a potentially influencing factor toward how individuals understand and attend to their own health and sickness.

As medical practice continues to develop new increasingly life-sustaining interventions and procedures, chronically ill patients are now more likely to live longer, fuller lives. As their life spans increase, siblings are ever more likely to become the primary caregivers of a chronically ill brother or sister later in life after their parents have passed away and/or before (Dew, Llewellyn, and Balandin, 2004). Appreciation of the complex relationships and the health narratives in play may aid health professionals in providing more effective support, interventions, and care for these adults, and those siblings who depend on them.

This proposed study seeks also to fill a gap in the research literature. While there are numerous studies regarding the younger siblings of chronically ill children (Dew, Llewellyn, Balandin, 2008; Wilkins and Woodgate, 2005; Williams, 1997), there is far less written that traces the development of “healthy” siblings over the years into adulthood (Meyer, 2009; Strohm, 2005), and no published reports addressing their health narratives.

Research Questions

The primary research question to be answered in this qualitative research seeks to explore whether *growing up with a chronically ill sibling shapes personal health narratives?* Embedded within this global concern, I hope to learn more specifically

- *What is the range of narratives found? Are there commonalities or salient themes within the narratives described?*
- *How do these narratives inform how these individuals take care of themselves?*
- *Do the narratives espoused by this population represent narratives which may be helpful or hurtful toward health and general well-being?*

What, if any, part of these narratives can be utilized to inform the provision of health care?

Personal Connections

In the tradition and spirit of qualitative research, I would like to share my own personal connections to the following work. My own mother grew up as the well sibling of a chronically ill sister. My mother’s experiences with her sister began in the late 1950s and ended into the early 1980’s, when my mother’s sister - my aunt - lost her battle with Type I/Juvenile diabetes. At the time of her diagnosis in the late 1950s, our medical world was still coming to understand how best to treat children with diabetes. Had my aunt been born today, she might very well have

lived a much longer and fuller life—a powerful health narrative in its own right. Over the years, I have seen poignantly the manner in which the experience of living with my aunt and her story have shaped and effected my family—most notably my mom—my family’s “well sibling.” I have taken note of the beauty, but also the deep challenge, that growing up a well sibling can pose. It is for this reason I seek now to better understand and illuminate some of the underpinnings and stories told within this experience. I did not formally interview my mom for the purposes of this research, but her voice and experience infuse the very catalyst of this work. In closing, the ultimate irony and regret, is that I myself never had the opportunity to meet my aunt as she passed away before I was born, yet that fact is perhaps underscoring to the power these experiences and stories held in my family and in their passing to the next generation.

Chapter 2: Literature Review

The following literature review focuses on four main topic areas: (a) sibling relationships, (b) childhood chronic illness, (c) the impact of having a chronically ill brother or sister, (d) and health/illness narratives.

Sibling Relationships

The sibling relationship is likely to be the longest of an individual's life. A brother or sister will be present in an individual's life from their birth into a family, and barring any mitigating life events, is likely to be with that individual long into old age, well after their parents have died (Dunn, 1983). By the end of a younger child's first year of life, it is estimated that he or she will spend almost as much time with a sibling as with his or her mother (Lawson and Ingleby, 1974). By the ages of four through six, children may spend twice as much time with a sibling as with a parent (Bank and Kahn 1975). While siblings typically do not continue to spend such significant amounts of time with one another over the lifespan, such early concentrations of exposure speak powerfully to their potential influence on one another. Such a major relationship will likely have an impact on personality, experiences, opinions, memories, and possibly even life choices. In addition to the general types of sibling influence, research has demonstrated powerful sibling effects on, or interacting with, variables including temperament, learning, psychosocial development, and parental influences (Dunn, 1983).

Although siblings dynamics were first studied in the twentieth century under the direction of Sir Francis Galton, a cousin of Charles Darwin (Brody, 2004), it wasn't until the 1980s that the literature began to ground itself in sibling relationships and their effect on the development of an individual. Broadly speaking, since this time, researchers and professionals alike recognize

the profound and nuanced impact siblings can have on an individual's development and family life (Brody, 2004).

Early sibling research. Sibling literature is often known for a focus on age, birth-order, gender, and birth interval in order to understand the overall experience of being a sibling and possible developmental effects these constructs might have (Schooler, 1972). One of the earliest and most prominent theorists to speak to the sibling experience was Austrian physician and psychotherapist Alfred Adler. Adler is known for a variety of contributions to the field of psychology; however his focus on birth order remains one of his major legacies. Adler suggested that birth order and sibling constellation in a family play a major role in the development of an individual. He made the distinction, however, that birth order was not about the ordinal position a child assumed in their family of origin, rather the psychological position the child occupied (Adler, 1930; Sweeney, 2009). For instance, he suggested the middle child often feels fit into the family due to their position, while the youngest has a more general tendency towards feeling favored or special due to their “baby” status (Sweeney, 2009). Factors identified that influence birth order and sibling constellation include family size, competition, gender, death/survivorship, favoritism, roles, and special siblings (Wedam, 2011).

Later researchers, such as Schooler (1972) suggest that generalizations based in such criteria are limitedly helpful. By contrast, more recent research focuses dynamically on the impact of siblings on one another and their relationship over time.

Later attempts at conceptualizing how a sibling influences a child's development focused on the difference between caregiver and sibling effects. Major theorists, such as Piaget (1965) and Sullivan (1953), posited the distinction between the two types; child/child relationships,

which are more reciprocal in nature, and child-adult relationships, which are more complimentary in nature. Both theorists suggested that the reciprocal child/child relationships were of particular importance to the psychological growth of an individual, highlighting the salience of sibling relationships according to such theories. Later Hinde (1979) pointed out that relationships between older and younger siblings may also take on important complementary qualities, closer to that of a child/adult dyad. However, Dunn (1983) further suggested that such classifications are by nature “artificial” and are meant more to draw attention to the methods by which development in siblings occurs, rather than to mark clear boundaries around the types of relationships.

Developmental impact of siblings. In 2004, in a review of more recent sibling literature, Brody classified sibling contribution to childhood development into three categories—direct effects, indirect effects, and differential parental treatment effects. Direct sibling contributions include the manner in which a sibling influences another brother or sister's linguistic, cognitive, and psychosocial development. Indirect methods of sibling contribution focus on the manner in which siblings come to shape what parents and guardians expect of other brothers and sisters from the same family unit. This effect exists notably as it relates to older-younger siblings. For example, Whiteman and Buchanan (2002) discovered that parental experiences of their first born children directly affected the manner in which parents predicted similar behaviors from their later-born children. Whiteman and Buchanan note similar effects can often be found with educators who may teach multiple children from the same family. A sibling's legacy may be either a blessing or burden to the brother or sister following in their path, a prime example of an indirect sibling contribution. Finally, differential parental treatment among siblings also has an impact on the development of the individual. Perceived differential treatment on the behalf of

one child was found to be benign to a sibling's development, so long as the child still experienced a warm relationship with the parent/s (Feinberg and Hetherington, 2001). However, not surprisingly, children who perceived such differential treatment and had a more antagonistic relationship with parents demonstrated poorer adjustment and functioning over time (Reiss, Neiderhiser, Hetherington, and Plomin, 2000). Questions of differential treatment may be particularly relevant to the current exploration; siblings of chronically ill children have parents who are frequently required to spend disproportionate amounts of time with their sick child and away from their other children. Over long periods, less attending may signify a type of differential treatment in the eyes of the child at home, creating an even greater need for an ongoing, warm parent-child relationship.

Quality of sibling relationships. Early relationships between siblings have generally been found to be prosocial in nature (Dunn, 1983). However, researchers believe that both the positive and negative interactions created between siblings give rise to the environments which nurse a young child's cognitive and psychosocial growth (Brody, 1998). Similarly, Brody also points out that the quality of sibling relationships can have a major influence on the quality and functionality of daily life for a family, often setting the emotional tone of a household. For example, a sibling with a more difficult temperament may be cause for a more negative environment, whereas a sibling with an easier temperament may lead to a more positive one.

Furthermore, the emotional quality of the sibling relationship has been shown to have relative consistency over the lifespan (Brody, Stoneman, and McCoy, 1994). Surveying 71 families using assessments and direct observational activities, researchers found that the quality and tone of sibling relationships remained relatively consistent over time. Similar research has found that such an effect was particularly strengthened negatively if a sibling relationship was

characterized by high levels of rivalry or if preferential treatment of another sibling was perceived (Ross and Milgram, 1982).

In a related study, Buhrmester and Furman (1990) conducted research with children in grades three, six, nine, and twelve using the Sibling Relationship Questionnaire (SRQ) in order to better understand the manner in which sibling relationships are perceived over time. They concluded that sibling relationships tend to become more equal and less imbalanced in power over the years. In addition, they also discovered that sibling relationships become less concentrated with warmth and conflict, and often decrease in overall intensity. Finally, birth rank, primarily the older/younger distinction, was found to be a determining factor of the types of reported experiences. Younger siblings tended to report less conflict with age, where as older siblings did not demonstrate such a decline.

Sibling temperament. Biological siblings share fifty percent of their genetic DNA with one another. However, as parents often report, two siblings can still appear to be significantly different from one another in every way possible. Some researchers believe that this may in part be due to the unique environment each sibling respectively creates for the other (Dunn, 1983). To explore this question, in 1989, Munn and Dunn directly researched preschool sibling's temperamental pairings. Using observational measures of sibling conflict and play behavior and maternal measures of child temperament, they collected data twice throughout a year long period. In accordance with their hypothesis, their results indicated that siblings who are characterized as quite different temperamentally from one another tend to have higher rates of conflict overall. Notably, age and gender were found to be irrelevant to the observed effect (Munn and Dunn, 1989). More specifically, as other researchers have further discovered, particular types of sibling personalities can lead to conflict among siblings. One interesting

exploration conducted by Stoneman and Brody (1993) utilized a multimodal designed research study looking particularly at the in-home interactions between siblings and reports from the older siblings. Across participants they found that when a calmer sibling and a more active sibling share an environment, the active sibling reliably determines the overall quality of the interactions created.

Learning. Older siblings are also thought to be effective teachers for younger siblings, instructing, directing, and modeling actions and behaviors over time. Such modeling is more likely to occur when there is a pre-existing warm relationship between the siblings. In sibling relationships with high conflict, modeling is less likely to occur (Brody, 1998). In middle childhood, researchers have found that children can effectively take on teaching tasks with their younger siblings (Cicirelli, 1972). More recent investigations into this area have demonstrated similar findings. For example, Gregory (2001) conducted a longitudinal study with a diverse group of similar-aged sibling pairs. Using classroom observations, taped reading classes, recorded home reading activities, reading diaries, and semi-structured interviews with siblings, a caretaker, and a teacher, Gregory's results ultimately point to a "unique reciprocity" (p. 301) which occurs between age-similar siblings. While it is important to note that the sibling pairs varied widely in their abilities and activities, across pairings Gregory described a type of "synergy" (p. 309) or play off one another between siblings, which went beyond traditional concepts of sibling "scaffolding" and "collaborative learning."

In addition, earlier research in this area demonstrated that not only are children capable of being effective teachers, but that they also demonstrate the ability to cognitively adjust to a younger child's level of ability (Meisner and Fisher, 1980). Utilizing a participant pool of 68 children, researchers formed pairs based on sibling status—whether the child of a given pair was

either an older sibling or a younger sibling in their family structure. When presented with a cognitive teaching task, older siblings versus younger siblings were more likely to make functional, age-appropriate adjustments for their younger subjects, as compared to younger siblings and only children.

Psychosocial Development. Siblings have been shown to have a notable impact on each other's psychosocial development (Bank, Patterson, and Reid, 1996). Conflict and harmony alike within a sibling relationship are important agents which have the potential to shape a child's development. While, in major doses, conflict can naturally have a negative impact on a sibling relationship, moderate conflict with siblings provides both with the opportunity to develop effective methods and models for problem solving, conflict resolution, and moving forward with a relationship (Brody, 1998). Two essential social-cognitive skills siblings may develop include perspective-taking of the other and thought direction towards another's feelings (Brown and Dunn, 1992; Youngblade and Dunn, 1995). Once established, methods for dealing with interpersonal conflict—adaptive or maladaptive - are likely to be transferred to other relationships across a sibling's life as well (Brody, 1998). For example, Stocker and Dunn (1990) conducted research on 124 families in order to better understand links between sibling relationships, friendships, and peer relationships. The authors discovered that sibling and peer relationships were actually negatively correlated with one another in many instances. Interpreting this finding, they suggest that siblings who learned effective conflict-management skills in their own sibling relationships had perhaps been better able and prepared to sustain close friendships over time.

Very early in life, siblings also demonstrate attachment to one another, often using one another as a secure base (Ainsworth, 1978). While most attachment literature has focused

primarily on the relationship between mother and child or child and caregiver, there is plentiful evidence to suggest that children attach to siblings easily and early in their lives, around the same time attachment with the mother/caregiver forms (Schaffer and Emerson, 1964). As an example, children admitted to residential facilities with a sibling as opposed to those without, demonstrated less overall distress (Heinicke and Westheimer, 1966). Furthermore, in a study of sibling attachment and the prevalence of later adulthood depression, researchers discovered that attachment to a sister for both men and women predicted less depression. In turn, higher rates of conflict with a sister predicted increased rates of depression in women (Cicirelli, 1989). Most recently, the salience of sibling attachment can be witnessed in the literature pertaining to sibling placement within the foster care system. Shlonsky, Bellamy, Elkins, and Ashare (2005) summarize the major findings which suggest that maintaining sibling bonds and attachment within the foster care system can be effective in helping produce better adjustment for children in placements.

Parental influence. Parents influence the interactions of siblings directly and indirectly. For example, Patterson (1984) found that the conflict management style and social skills of siblings are mediated and shaped by those demonstrated by parents and guardians. Patterson suggests that over time siblings are conditioned by the methods they observe their parental figures utilizing to end a conflict. For example, some parents will use laughter, talking, or compromise to end a conflict with another adult or child, while others may use yelling, arguing, and insults. Whichever methods appear more effective at ending a conflict in the child's eyes are those which will likely be imitated by the child in their relationships - sibling relationships in particular (Patterson , 1984).

Similarly, positive parent-child interactions have been shown to teach and promote pro-social behaviors between siblings, particularly behaviors related to ending a conflict effectively (Brody, 1998). For example, Brody found that when mothers demonstrated taking the time to discuss the needs of a younger sibling with another child, siblings were found to be more caring and friendly with the younger child.

The quality of the parents' relationship with one another also plays a significant role in sibling relationships in other ways as well. The imparting of a set of "norms" for sibling behavior is thought to be a significant parental task (Brody, 1998). Moreover, marital distress in families has been shown to predict poorer quality of sibling relationships (Brody, 1998). This trickle-down effect from parent relationships to sibling relationships is thought to occur primarily due to high levels of parental negativity which inevitably affects the quality of parenting. Daily functioning with a particularly negative parent may further deregulate a child, making him or her less likely or able to maintain positive sibling interactions (Fabes and Eisenberg, 1992).

Interestingly, however, research also discovered that siblings whose parents ultimately divorced reported increased closeness with their other siblings. Specifically, siblings may offer one another increased emotional support given the unavailability of their parent/s at the time of the divorce (Abbey and Dallos, 2004). It is important to note that this study was conducted only with females. The male sibling experience or the intra-sex sibling experience of divorce may be different. Other recent research has provided a more nuanced view of the sibling relationship in the context of parental divorce. For example, Sheehan, Darlington, Noller, and Feeney (2004) used questionnaires and semi-structured interviews to look at how adolescent siblings from divorcing families perceived their own relationships with their siblings. As compared to their age-similar peers from non-divorcing families, these siblings understood their relationships with

their brothers and/or sisters to be more emotionally intense. The adolescents specifically linked this emotional intensity to the occurrence of their parents' divorce, ongoing parental conflict, and/or the unavailability of their father.

Adult sibling relationships. While the previously summarized research has focused primarily on the effect of the sibling relationship on childhood/early adolescent development, the remainder of this literature review on siblings will summarize relevant literature on adult siblings.

In one study, Lee, Mancini, and Maxwell (1990) conducted research on 400 adult siblings to better understand their relationships from the perspective of contact patterns and motivation. Their main goal was to understand to what degree spending time and/or the drive to spend time with a brother or sister can explain the quality of the overall relationship and possible characteristics of the family of origin. Using three types of motivation for contact: general type, feelings of obligation type, and a discretionary type, the investigators explored the manner in which nine other independent personal and familial characteristics affected contact frequency. Siblings who were in more frequent contact with their brother or sister were those who lived closer in proximity, felt more responsible for the sibling, described more emotional closeness, experienced more conflict with the sibling, overall had fewer siblings, and were generally sisters. Those siblings who reported experiencing greater feelings of obligation to a brother or sister were those who described more emotionally intense relationships, lived closer to the sibling, and were less likely to currently have children living with them. Finally, siblings who chose to have greater contact with a brother or sister also reported more emotional intensity, also felt more responsible for their sibling, had fewer siblings overall, and were also sisters. Each of these constructs provides perspective on the characteristics which tend to govern adult sibling

relationships. For the adult siblings of chronically ill individuals, feelings of obligation toward their sick brother or sister may exert a significant influence on their overall contact motivation.

Another large-scale study of 7,730 adult siblings looked into the social support provided by these relationships in general (White and Reidmann, 1992). Three major quantitative findings from this research include: half of the participants were in contact with the sibling at least once per month, almost 2/3 of the participants identified a sibling as a close friend, and 30% of participants would contact a sibling first in the event of an emergency. In addition, White and Reidmann highlight the important construct of gender as it pertains to social support among adult siblings, indicating that participants with sisters reported overall more support than those without sisters. Interestingly, both having adult children and parents who are living reduced perceived support from siblings. Also, older age appeared to increase the perception of sibling support; however it did not increase the function of that support. White and Reidmann suggest that this finding likely speaks more to the strong psychological comfort of having supports available, despite the likelihood of utilizing them as one ages. Finally, social class and education have a positive relationship on perceived sibling support, with siblings who are better educated and who make more money experiencing higher levels of support from their brothers and/or sisters.

Researchers have also investigated the manner in which adult sibling relationships change over the course of major life events (Connidis, 1992). Major life events explored include, marriage, having children, divorce, widowhood, and the death or illness of a family member. Regarding marriage and having children, siblings generally reported feeling closer to their siblings, despite seeing them less, reporting maturity, similar interests, and the shared experience of having immediate families of their own as reasons leading to increased closeness. Divorce and widowhood were also generally perceived by individuals as a time during which siblings grew

closer emotionally and made more frequent contact with one another. Finally, the death or illness of a family member was reported to be another life event which prompted more emotional closeness between siblings. None of these constructs pointed to an emotional cooling of siblings relationships in the face of major life events.

Siblings and health. The primary literature pertaining to siblings and their effect on health is summarized in a recent study conducted by Falbo, Kim, and Chen (2009) regarding sibling status and its effects on health later in life. Here sibling status is defined both within and between families. Within- family sibling status refers to the birth order of siblings, while between-family sibling status refers to the overall number of siblings in a family. Testing a large sample of high school graduates (N = 3,968) from the preexisting Wisconsin Longitudinal Study, the authors ran an analysis to understand the manner in which sibling status effected health later in an adult's life. While socioeconomic status, adolescent aptitude, and educational attainment did have a significant positive effect on health, sibling status was found to have none. These results appear consistent with Scholer's (1972) literature regarding the ineffectual use of birth order/sibling status in application. However, while sibling status did not appear to have an effect on health in this study, it may be more likely that it would have an effect if one sibling were chronically ill, an effect I seek to discover in this project. In order to introduce the topic of illness into this review, the following section will present and briefly summarize major themes pertaining to the incidence of chronic illness.

Chronic Illness

Dowrick, Dixon-Woods, Holman, and Weinman's (2005) opening article to the *Chronic Illness* journal summarizes some of the major themes found in the research and experience of chronic illness. The authors define chronic illness as one which is persistent, does not remit

suddenly, and seldom can be cured altogether. It is important to note that such conditions can be physical, emotional, or cognitive in nature. The most prevalent chronic illnesses include cardiovascular diseases, various types of arthritis, respiratory conditions, AIDS, certain types of cancer, and some types of mental health problems.

Dowrick et al. (2005) go on to note that in the present day, more U.S. children than ever are receiving better care, making it possible for them to live longer lives in spite of chronic illnesses. In later adulthood, those afflicted with chronic illness are also living longer lives due to the same advances in medicine, making it possible to delay the terminal effects of chronic illness. Such facts speak to the increasing need of facing both the short and long-term complications and experiences of those living longer lives with chronic illness and the caregivers who support them (Dowrick et al., 2005).

Here it is important to make the distinction between several similar terms which are often used in the literature interchangeably, including the terms illness, disease, sickness, and disability. According to the definitions set forth by Kleinman (1988), illness is the personal experience of disease symptoms and disabilities in a person's life, while a disease is the problem as defined by medical professionals. Similarly, he describes sickness as the communal, societal understanding of a condition or disease. While each of these terms describes similar phenomena, they do so from very different vantage points. For the purposes of this research, I am primarily using the terms illness or sickness, reflecting my interest in the personal and interpersonal impact of the narratives I seek.

Although not the primary focus of this research it is also important to note how the similar, but distinctly different, term *disability* can best be understood. According to the World Health Organization (WHO) website (2011) a disability is a “complex phenomenon, reflecting

an interaction between features of a person's body and features of the society in which he or she lives." Correspondingly, it is also defined as an "umbrella term covering impairments, activity limitations, and participation restrictions." As evidenced by these terms, there remains significant overlap not only in their definitions, but also in the lived experiences portrayed by those defined by them. Important to distinguish is that people who are ill are not necessarily disabled and people who are disabled are not necessarily ill. Nevertheless, an individual can be both ill and disabled. A vast body of literature exists on these particular topics. Summarization of this literature is beyond the scope of this dissertation, however, due to general similarities, later research presented in this review will touch on disability research and its related sibling experience to inform this project.

Childhood chronic illness. In a 1998 survey conducted by Newacheck and Halfon on 99,513 children under the age of 18, the authors estimated that 6.5% of all children in the United States experience some type of chronic, disabling condition. According to this research, respiratory diseases and mental illness are the most common chronic problems. The majority of such conditions, broadly defined, were found in older children, males, and in children from low-income, single provider family units. Furthermore, for the children included in this survey research, it was estimated that such chronic conditions resulted in 66 million days of limited activity, 24 million absent school days, and an additional 26 million medical provider contacts per year. One tenth of the children surveyed were reported to be incapable of carrying on their primary life activity, e.g., play or school. Newacheck and Halfon (1998), highlight the "substantial burden" that chronic conditions and illnesses can have on a child and their family. They call for future study so that better "ameliorating adverse outcomes" can become a reality for these children and families (p. 610).

Twelve years later, Halfron and Newacheck (2010) appealed again to the health professions for heightened attention toward the increasing levels of childhood chronic illness. They explained there is evidence to suggest a dramatic shift from acute childhood illness toward chronic childhood illnesses over the past 50 years at least—with levels of such illnesses doubling between the 1960s and the 1980s. It is notable that after this period, in 1998, the federal Maternal and Child Health Bureau adjusted the definition of chronic illness, expanding it to include physical, developmental, emotional, and behavioral issues. Within the broader definition, rates of chronic childhood conditions jumped from an estimated 5% - 8% to 16% - 18%. While this broader definition explains current elevated rates, it does little to explain the original doubling of chronic illness seen from 1960s to the 1980s. Halfron and Newacheck offer several theories to explain this profound increase, including childhood obesity, early family disruption, measurement error, and the “evolving social ecology of childhood” (p. 666). They conclude, however, that major research remains to be completed before the field can more fully understand these increases.

The impact on family members and caregivers contending with chronic childhood illness is also well documented. For example, in a 1991 study comparing the psychological adaptation of the parents and families of chronically ill or disabled children versus those families with healthy children, it was found that families with chronically ill or disabled children on average tended toward raised rates of parental treatment for anxiety and increases in maternal negative affectivity (Cadman, Rosenbaum, Boyle, and Offord, 1991). Notably, single-parent families, social isolation, and substance abuse were not identified as significant concerns for these families of chronically ill children. Despite elevated stress indices, levels of family “dysfunction” did not differ significantly between the two groups of families.

More recent research, conducted by Boling (2005) on the experience of parental caregivers of chronically ill children, demonstrated the intertwining nature of the child's health with that of the parent. The study assessed 100 parent caregivers using the Medical Outcomes Short Form 36, the Beck Depression Inventory, and the Caregiver Quality of Life Scale for Cystic Fibrosis. Overall the surveys revealed statistically significant quality of life concerns for parent caregivers. Not surprising, but certainly troublesome, it was found that as a child's condition worsens, a parent's quality of life decreases notably, highlighting the direct effect between the health of the child and that of the parent. It seems highly likely that the same type of effect could also operate between a parent and a well sibling, and between the siblings themselves. Boling calls for increased attention to parental quality of life and appropriate supports and referrals by the medical community, reminding her reader that such initiatives will not only benefit the parent, but the care they are ultimately able to provide their child, and by extension, their other children as well.

The Sibling Experience of Having a Chronically Ill Brother or Sister

Over the past several decades a robust literature has explored the lives of siblings of chronically ill and disabled children, resulting in two large scale meta-analyses. In addition a comparatively large number of studies have been conducted on the siblings of *disabled* brothers and sisters. Similar themes, concepts, and populations emerge out of both bodies of literature; as such, meta-analyses from both areas of research will be summarized to inform the present study.

One 2005 meta-analysis of qualitative data regarding the childhood experience of having a chronically ill sibling identified 27 major studies for analysis (Wilkins and Woodgate, 2005). Across childhood, three broad themes emerged from the literature generated by these siblings and their caregivers: major changes in life, deep feelings and emotions, and unaddressed needs.

It is important to note that this meta-analysis focused primarily on the siblings of children with cancer.

Major life changes emerged as the most prominent theme for these siblings, poignantly highlighting the monumental day-to-day adjustments that these siblings face along with their families. Wilkins and Woodgate (2005) classified these major life changes as both losses and gains. Some losses include loss of parental attention, companionship, and routine. In earlier research completed in 2001, Woodgate suggests some siblings even lose a sense of themselves when their brother or sister is very ill. He goes on to state that these siblings “defined their world through the experiences of their ill siblings” - a particularly significant theme with implications for later life and the proposed research topic (p. 312). Still, personal gains do exist for these siblings as well, including increases in the capacity for empathy, compassion, additional day-to-day responsibilities, and, for some, overall family cohesiveness.

Next, regarding the sibling experience of intense feelings, Wilkins and Woodgate (2005) identified seven main groups including (a) sadness, (b) loneliness, (c) rejection, (d) anxiety, (e) anger, (f) jealousy, and (g) guilt. In categorizing and presenting these emotions, it is not meant to suggest that they are maladaptive in any way. The presence of these emotions is normative and even to be expected. The intense experience of any or a combination of all these feelings more aptly can inform the types of support a sibling may need over time.

Finally, Wilkins and Woodgate (2005) review the unmet needs of these siblings. Across years of research, siblings have systematically and predictably reported four needs including: more open communication between their families and themselves, sufficient information about their sibling's illness, support for their own lives and events, and personal participation in the care of their brother or sister. Wilkins and Woodgate note that such needs were consistently

unrecognized by caregivers, and suggested that they may have shaped the overall sibling experience very differently had they been addressed at the time.

In addition, Alderfer, Labay, and Kazak (2003) found evidence that some of the siblings of childhood cancer survivors also experienced elements of posttraumatic stress. Seventy-eight adolescent siblings of cancer survivors were tested on measure of anxiety, posttraumatic stress, and their perspective on their sibling's illness. Half of the adolescents surveyed disclosed mild PTS, while another 32% indicated more moderate to severe symptoms. Measures captured arousal, avoidance, and anxiety behaviors. Such results point powerfully to the support needed by these siblings into adolescence.

Several years later, in 2008, Dew, Balandin, and Llewellyn completed a meta-analysis of 21 studies looking at the experiences of siblings of individuals with lifelong physical disabilities. According to this review, several potentially mediating factors seem particularly salient: the type and severity of the condition, family makeup, birth order, gender, and socio-economic resources. While many studies found patterns regarding these factors and the experiences of siblings, no conclusive understanding of their impact on siblings was reached. Consequently, Dew et al.'s work points to the vast territory that remains to be explored in the field. Most studies reviewed focused solely on retrospective data looking at the childhood experience of the adult siblings. Few studies included longitudinal or more current data. Notably the bulk of the research also relied on mothers as the primary informants for the studies, and did not directly explore the experiences of the healthy siblings from their own perspectives.

In the few studies when siblings were personally asked about their experience with their disabled brother or sister, their responses tended to be more positive as compared to maternal responses. In turn, maternal responses tended to be more negative citing more aggression and

potentially negative effects on psychological development. Coleby (1995) suggested this general negativity found in maternal responses may be reflective of the “burden of care”—or the weight of responsibilities and fears—experienced by caregivers. In conclusion, Coleby calls for more research on the overall adult experience of having a sibling with a chronic condition, better data regarding the adult relationship between the well sibling and the disabled sibling, and informed methods of facilitating communication between the two individuals around health care issues that arise later in life.

Dew et al. (2008) also review two important studies from the perspective of the adult non-disabled siblings (Burton and Parks, 1994; Grossman, 1972). While important differences between illness and disability remain, these studies speak closest to the subject matter currently being explored. The adult siblings surveyed in the two studies disclosed a range of positive results due to growing up with a disabled sibling. These positive results include greater sensitivity to the outcomes of intolerance, tighter family connections, and thankfulness for their own health and functioning.

Finally, in addition to summarizing the existing literature, Dew, Balandin, and Llewellyn (2008) suggest that the relationship between a well sibling and a disabled sibling shifts over time, with increasing responsibility placed on the well sibling as a caregiver for their brother or sister; such concerns and shifts can arise as early as childhood (Pit-Ten Cate and Loots, 2000). Still, Dew et al. (2004) found that siblings generally characterize their relationships as solid and loving over time. While these summarized studies speak only briefly and non-directly on that matter, it could be inferred that sibling relationship may also differ dramatically depending on the type of condition with which an ill sibling is afflicted. While the well siblings of chronically disabled children may eventually end up in greater caretaking roles, siblings of chronically ill or

terminally ill siblings may or may not have such an experience. It seems likely that the type of condition may also help dictate the trajectory of sibling relationship over the long-term.

Mainstream literature for well siblings. Numerous memoirs, books, and support materials have been published in recent years for the siblings of the chronically ill across the lifespan. While an internet search delivers several dozens of these types of books, one that is frequently referenced and offers the more complete story of an adult raised with a chronically ill sibling is *Being The Other One: Growing Up with a Brother or Sister Who Has Special Needs*, by Kate Strohm.

In *Being The Other One: Growing Up with a Brother or Sister Who Has Special Needs*, Strohm (2005) details her own life experience of growing up with her sister, Helen, who suffered a cerebral hemorrhage at birth. In her text, she details the powerful and complex emotions and relationships she experienced with her sister over the ensuing years, and the equilibrium she has achieved only now, many years later. She goes on to categorize and normalize the wide range of emotions potentially experienced by a sibling in such a situation. She concludes her book with a call to parents and professionals to conceptualize the experience of a sick child from a whole-family approach, in an effort to prevent problems for siblings before they occur.

Health/Illness Narratives

Story telling and the construction of narratives is an old concept; one however which has gained significant research focus since the mid 1900s with the help of authors such as Vladimir Propp, Roland Barthes, Tzvetan Todorov, Claude Levi-Strauss, Walter Fisher, and Jerome Bruner, among others. Their theoretical formulations serve as the foundation from which we understand narrative structure and thought today. For example, Bruner (2004) suggests that we not only use narratives to organize and make sense of our lives, but that we actually “become the

autobiographical narratives by which we ‘tell about’ our lives” (p.694). One can observe these narratives in the play of a child, the frequent shifting attitudes of an adolescent, or the career choices of an adult. William Cronon (1992) suggests that we rely on these forms because:

...narrative is the chief literary form that tries to find meaning in an overwhelmingly crowded and disordered chronological reality. When we choose a plot to order our environmental histories, we give them a unity that neither nature nor the past possesses so clearly. (p. 1349)

One type of narrative includes the stories, metaphors, and understanding we hold as individuals about health and illness. Bingley, Thomas, Brown, Reeve, and Payne (2008) conclude that such stories “have much to teach us about living with illness, suffering, and the experience of care.” In the literature regarding this type of personal narrative, these constructs are interchangeably referred to as health narratives, medical narratives, illness stories, or illness narratives. While each term may refer more predominantly to particular aspects of health, generally speaking these narratives refer to how individuals understand and interact with their past, present, and future conditions of health. Within this project, when referring to participants and their narratives, I will use the more general term *health narratives*; given that the personal narratives elicited will likely not all strictly include accounts of illness. However, as reflected in the literature, the terms illness narrative or illness story are also prominent.

The concept of illness narratives is one which can be traced far into the past by examining the patient-doctor relationship (Bury, 2001). As early as the 17th Century, the doctors of the time were expected to listen to a patient's history and develop interventions in accordance. Patients' histories were likely to have included personal details about the patient's family, recent losses, personality characteristics, and, overall, a holistic understanding of the person's

background. Despite the fact that the resulting interventions were often misguided given present medical standards, their inspiration most often came from the stories and accounts the ill individual provided the physician. It was then the physician's job to find the best manner in which to attend to the presenting issues. While bleeding, purging, and cupping were primarily the interventions espoused by the doctors of this time period, this patient-doctor dynamic highlights the critical importance ascribed to the patient narrative.

In 1988, Arthur Kleinman authored his seminal work on illness narratives—*The Illness Narratives: Suffering, Healing, and the Human Condition*. This piece of work has been foundational in the resurgence of illness narratives in the literature and is one of the first works to chronicle the illness narratives of medical patients across illnesses, social position, and culture. In this book, Kleinman reflects that what a doctor treats as a *disease* often fails to represent the full *illness* experience. He frequently points to this disparity as one of the weaknesses of the practice of medicine, and calls for continued education and research to bridge the expanse between a specific disease and the personal experience and meaning for the ill person.

Almost ten years after Kleinman's *The Illness Narratives* was first introduced, Hyden (1997) produced a meta-analysis summarizing research findings on illness narratives. Hyden proposed in his work that three types of illness narratives were present in the literature thus far: (a) *illnesses that were narratives*; (b) *narratives that were about illness*; and (c) *narratives that were illness*. In the first type of narrative—*illnesses that are narratives*—the narrative serves as an effective way of organizing the complexity offered by the experience of illness. Secondly, *narratives about illness* refer to information about the illness and the more “detailed clinical picture of the patient” (p. 54). Finally, *narratives as illness* refer to situations in which a patient

is unable to utilize narrative structure to chronicle their experience or when the illness narrative itself negatively intensifies an individual's overall experience of their illness.

Within this analysis Hyden (1997) summarized the utility of illness narratives. He identified the five following uses of illness narratives: (a) as a construction of an illness world, (b) as a reconstruction of a life history, (c) as an explanation and understanding of illness, (d) as a strategic device, and (e) as a method by which to change a personal experience into a more collective one. He explains that each of these serves as an effective method by which to manage the short and long-term realities of living with a chronic illness or condition.

Hyden (1997) also notes that for the person with an illness there are inherent complications with the use of illness narratives. Most importantly, they contain no known end, and as such are constantly in flux, changing shape and form with time and experiences. More recently, however, narrative flux has come to be identified as an inherent power of the narrative, rather than a complication (Frank, 2007). In conclusion, Hyden details the manner in which various contexts can affect the type of narratives elicited by patients. For instance, often illness narratives are studied within a medical context, allowing for limited familiarity with what Hyden refers to as the “lifeworld” or the larger context in which the patient experiences symptoms. He reminds the reader that in order for researchers to truly comprehend the expanse of illness narratives, they must also be willing to look toward multiple environments in which such narratives will naturally be elicited (e.g., the home, the workplace).

Years later, Bury (2001) explained that a highly specialized, bio-medical approach to medicine provides progressively diminished focus toward the patient narrative. The patient-doctor relationship increasingly emphasizes concrete symptom detection and diagnosis; today,

the personal stories of the patients presenting have become secondary, if not altogether lost in some circumstances.

Over the most recent decades, however, four shifts have begun to occur in the field of medicine pushing patient narratives back into focus. Bury (2001) describes these as (a) increased frequency of treatment for chronic illness rather than infection, (b) the great expense of the biomedical approach causing a shift back toward primary care, (c) the increasingly democratic, consumerist attitude espoused by patients seeking care, and (d) the explosive expansion in the availability of medical information and resources. Taken as a whole, Bury suggests these shifts in the field have likely caused some of the renewed interest in the inclusion of the whole patient and their voice into medical care.

Major themes of illness narratives. Numerous theorists have attempted to define the themes or parts which comprise illness narratives for individuals experiencing chronic illness. For example, utilizing elements of grounded theory and social constructionism, Docherty and McColl (2003) identified four major themes in these stories: (a) the emotional reaction to the diagnosis, (b) the impact of the stress which comes from the illness, (c) personal views of death, and (d) general illness meaning. Despite the seriousness and immensity of these themes, in their sharing, Docherty and McColl highlight the powerful and moving impact each story had both on the storyteller and the listener; a glimpse into the therapeutic power these narratives are likely to hold.

Meanwhile, other researchers investigating illness narratives have identified additional themes. For example, Haidet, Kroll, and Sharf (2006) analyzed sixteen qualitative interviews conducted with primary care patients. Another four major themes emerged, those particularly regarding patient engagement in their care. They included (a) the centrality of the illness to the

patient's life, (b) the degree to which the illness story could possibly improve, (c) the number of illness related activities the individual must engage in, and (d) the individual's relationship to his or her physician regarding management of his or her condition. In their conclusion, Haidet, Kroll, and Sharf call on physicians to use these constructions as a backdrop from which to recognize and accept their large role and presence in the lives and narratives of their patients.

In a similar vein, Frank (2007) describes a theoretical framework from which to understand illness narratives. He offers that illness narratives function most robustly by allowing for personal understanding of the health-related event, rather than offering practical control over it. He goes on to classify five major themes or *dramas* he has found which emerge out of the illness narrative literature: the drama of genesis, the drama of emotion work, the drama of fear and loss, the drama of meaning, and the drama of self.

The drama of genesis involves a person's understanding of how their illness came to develop. Often this portion of an illness narrative can be highly specific in nature (e.g., *I was exposed to toxic chemicals in my workplace*). Other times a genesis story can lack content altogether (e.g., *My cancer just appeared*). However, regardless of how one understands the development of the illness, a conflict is established; one which often also includes resentments and frustration toward potential origins of the illness. Based in part on the work of ethicist Richard Zaner (2004), Frank suggests that not all genesis stories "take care of" individuals equally. He goes on to explain that there are better genesis stories which may offer less blame and more hope to individuals as compared with others.

Next, the drama of emotion work includes the internal management of affect an ill individual must engage in to maintain a positive impression both to themselves and those around them. Frank (2007) notes that this type of internal work can be costly to the individual who is ill.

For example, many individuals who are sick attempt to be stronger for their loved ones than they may have the ability to be, so as to spare their loved ones additional pain. This type of emotional work does no honor to the internal state of the individual as it is, rather it attempts unnaturally to manage the other's expectations of the ill individual. Frequently the pain and discomfort of the sick individual is disguised or minimized, so as to make others more comfortable in the face of the illness. This can further isolate an individual, making them less able to receive comfort and care from others. Equally damaging, this emotional management can occur with health providers and medical professionals, who are then unable to develop an accurate picture of their patients' suffering and experience and potentially provide care based on insufficient information.

The drama of fear and loss as described by Frank (2007) is particularly complex and far-reaching. Some of the potential losses and corresponding fears include the loss of a pain-free life, the loss of the ability to work independently, the loss of life plans, the loss of the future, and ultimately the loss and fear of losing life itself. Regarding these fears and losses, however, Frank demands that their naming is critical to an individual who is ill. Fears and losses which go unnamed and unspoken are of the most insidious and dangerous type. He suggests that dialogue is necessary for these individuals so that they may have a space within which the fear can be named, contained, and even temporally deferred. While he notes that support groups for sick individuals are often helpful for this task, often emotion management can take place instead, if others group members cannot truly tolerate the fears and potential losses the person is struggling with.

Next, the drama of meaning refers to the ability of an individual's story to affirm who he or she is as a person. Frank (2007) highlights the ability of a story to take care of its teller; one important way in which this occurs is the manner in which the story affirms the individual. The

experience of an illness without a personal story can leave an individual “unscripted (and) anxious” (p. 390). He makes the noteworthy point that health professionals, doctors, nurses, mental health professionals, or any other type of medical health professional have extensive training and conditioning over time, establishing cohesive stories of what health and illness means personally. However, a recently diagnosed individual is often thrown into an unfamiliar and unmapped medicalized world. Frank suggests that it is the job of the social sciences within medicine—behavioral health specialists, social workers, and counselors—to offer these individuals space, preparation, and suggestions for the journey of finding their own illness narratives.

Finally, the drama of self includes the possible personal identities that can be created by an individual in the face of illness. What type of self can the person be with their illness; what type of self can support them to live in a different, sturdy, emotionally-healthy way? Moving further into the literary realm regarding the power of drama, Frank notes it could have a variety of endings. However, in creating such possibilities, it allows a person to experience the potentiality of life and in doing so provides opportunities for self-discovery. Medicine is concrete and demands predictability. Dramas, however, are anything but concrete and predictable. Frank concludes, medicine is without question necessary for the treatment of illness; however the use of drama may be equally necessary for the individuals learning to live in the face of such illness. Frank (2007) concludes that better comprehension of these five components—the drama of genesis, the drama of emotional work, the drama of fear and loss, the drama of meaning, and the drama of self—can not only offer a framework from which an individual's experience can be conceptualized, but can also inform the work and care that is done on their behalf. While Frank

did not directly address this in his work, it could be inferred that caregivers also engage in their own individual and related dramas around their loved one's illness.

In another conceptualization, Holloway and Freshwater (2007), review the nursing literature to formulate a theoretical model of illness narratives based on the characteristic of vulnerability. While they acknowledge that all human beings tell stories, they posit that vulnerable human beings—particularly those who are ill—have an even greater number of stories to tell. The authors explain that telling stories or narratives about one's situation can frequently help a vulnerable individual to accommodate to their situation more effectively, providing authorship to an otherwise pre-constructed societal story of illness. They conclude that increased understanding of the stories offered by patients can make working with such individuals a more meaningful experience for all involved.

Other researchers in the field of narrative work have conceptualized illness narratives more concretely according to what is known as an explanatory model—or one which focuses more on the origins of the illness, its general course, and necessary treatments (Kleinman, 1980; Weiss, 1997). Stern and Kirmayer (2004) suggest that in addition to such an explanatory model, there may be other types of knowledge that factor into a individual's illness narrative. According to this literature, *prototypes* are past experiences which stand as models of a particular type of illness or health concern. *Chain complexes* refer to the temporal linking of health or illness events, where no causal link is implied.

The above formulations of illness narratives represent a few of the many frameworks from which these narratives can be broken down and better understood. These frameworks were chosen for their salience in the body of literature surveyed. While it could be viewed as sheer complication to have so many frameworks from which to understand these narratives, their

diversity speaks powerfully to the complexity and individuality with which patients construct and share their stories.

The previously presented frameworks give structure to the stories shared by individuals who are themselves ill, not the stories of those who are close to them such as siblings and caregivers. Nevertheless, such narratives provide a starting point from which to explore the narratives of the siblings themselves. In particular, I plan to use Frank's (2007) five dramas to inform some of the questions to begin participant interviews.

Cultural considerations. In order to best understand health narratives, it is also crucial to note the impact of an individual's social and cultural contexts on the development of such personal narratives (Holloway and Freshwater, 2007). Different cultures ascribe far-ranging value and meaning to the experience of illness and health. Illness narratives then must be understood within such a framework by medical professionals, so that they may be utilized in the most helpful and culturally-sensitive manner possible. Similarly, cultural sensitivity regarding illness narratives helps individuals feel that their beliefs and system of knowing are held and understood within the larger dominant culture.

For example, Edman and Kameoka (1997) analyzed the illness schemas of both Filipino and American women. When surveyed for physical, psychological, and spiritual-social explanations of illness, the researchers predicted and found that the Filipino women more often attributed illness to spiritual-social causes as compared to American women. When level of education was factored into the analysis, the researchers concluded that within the Filipino group of women, those who were more educated were least likely to utilize spiritual-social explanations for illness. Such differences in illness attribution could have major implications for diagnosis, treatment, and outcome for individuals of various cultural backgrounds. We are reminded by the

authors that the goal of seeking such understanding is not to change such narratives, but to appreciate their salience and appropriately modify interventions accordingly.

Price (1987) highlights another major aspect of the cultural context of illness narratives. She states, “Without exception, illness stories encode significant cultural knowledge about the role the narrator played in the events of an illness...” (p. 314). While cultures worldwide have dramatically different values, assumptions, and standards by which to manage and cope with illness, one must listen to an individual's story to understand how they have personally incorporated those cultural standards. For example, in her work with urban Ecuadorians, Price (1987) explores the manner in which these individual's illness stories are shaped by their cultural context. One prominent theme present includes the social roles individuals assume within the experience. For instance, young children, typically girls, are frequently called upon to be caregivers for smaller, ill children. While American children may also be called upon to provide care to ill siblings, this practice is not generally favored culturally, and may subsequently hold more individualized meaning within our culture.

Narrative medicine. Taken further into application, the focus and emphasis on narrative work is making its way into the health care field in a variety of ways. Medicine, nursing, social work, and psychotherapy alike have each made strides in recognizing and applying illness narratives to their patient/client care (Charon, 2006). Charon defines the practice of narrative medicine as an approach which pulls together the wide variety of issues that concern patients in a way that informs the care sick patients receive, gives witness to the living experiences at play, and builds a bridge between the ill individual and the well caregiver (2006). As the tides of medicine shift, many physicians and medical health professionals are embracing such an approach. Examples of narrative medicine at work can be seen as early as an initial appointment

between doctor and patient. Charon explains that when she meets with a new patient she begins with the following words, “I will be your doctor, and so I need to know a great deal about your body and your health and your life. Please tell me what you think I should know about your situation.” She remains mostly silent during the rest of the appointment, allowing the patient to fill in the necessary spaces. In such a way, the patient's narrative is made known from the inception of the relationship, in a manner that informs all that will come next. Dr. Rita Charon is currently a general internist, a professor of Clinical Medicine, and the Director of the Program in Narrative Medicine at the Columbia University College of Physicians and Surgeons. While narrative medicine is gaining ground in medical arenas and curriculums across the country, a full program such as Dr. Charon's, dedicated to the practice and teaching of narrative medicine, is rare.

Taken as a whole, the present literature comes together to inform and highlight the area of study proposed in this dissertation—the health narratives of adults who were raised with a chronically ill sibling. As demonstrated in the literature, siblings play a vital and formative role in the development of an individual. Particular sibling experiences appear to mediate the manner in which an individual develops his or her own worldviews. Chronic illness, in particular, seems likely to be a strong factor by which these world and health views may be mediated. As this particular narrative voice of the adult sibling is often lacking in the literature, it is goal of this proposed project to help hear and capture that voice, attending to both illness and health narratives.

Chapter 3: Methodology

Within this section the methodological rationale, participant selection/inclusion criteria, measures, procedures, and data analysis strategies used will be presented and discussed in detail. Ethical considerations and precautions regarding the research are addressed.

Qualitative Rationale and Naturalistic Paradigm

It is the goal of this project to better understand the personal health narratives of adults who were raised with chronically ill siblings. Qualitative research seeks to collect small, rich samples of an individual's lived experiences in the hope of affording the audience with a window into lived human experiences, access to fine detail around major themes, and the opportunity for multiple narratives (Smith, 2003). It is important to distinguish that this study will be cradled within a larger naturalistic paradigm, within which the assumption is made that data is obtained via interactions between the researcher and the subject (Lincoln and Guba, 1985). Furthermore, according to this tradition, data is understood to be shaped by the participant, which is then analyzed via "reconstruction" of major themes, ideas, and concepts (p. 332). This framework challenges traditional notions of "fact," allowing greater space for the consideration of individuals and their context within the research (Lincoln and Guba, 1985).

Narrative rationale. Subsumed within the qualitative tradition, a narrative framework was utilized for this project. Narrative approaches to psychological themes and ideas, particularly ones which are health-related, have become prevalent over the past several decades, due in large part to the efforts of individuals such as Frank (2007), Bury (2001), Hyden (1997), and Kleinman (1988). However, the very premise of narrative work—or story telling—has been foundational to cultures worldwide since the advent of written and spoken word. Murray (2003) explains the vital role narratives and stories play in an individual's daily life stating aptly, "The primary

function of narrative is that it brings order to disorder” (p. 114). In the construction of a narrative, an individual imposes a structure to something that may not explicitly have one, like a feeling, an experience, or a series of ideas. For instance, when someone tells a story about an aspect of his or her life, there is a wide array of narratives that can be shared, however the structure and meaning a narrative takes on is provided by the storyteller sharing it. The power of a narrative lies in the inherent structure it is given, through a beginning, middle, and end. These constructions help us “provide structure to our very sense of selfhood” (p. 115). In addition to contributing order and structure to people's lives, narratives connect events, emotions, feelings, and experiences in a coherent and meaningful manner; a manner that may be dramatically unique from person to person. Given the power of this narrative tool to capture an individual’s personal meaning and experience, it has been the method of choice for this project.

Construction of questions. Given the narrative nature of this project, semi-structured interview questions were constructed in such a way to best support the elicitation of participant narratives. Ayers (2008) recommends researchers utilize ample open-ended questions from which to provide participants sufficient space to express themselves most fully. In addition, it is suggested that interview questioning build upon one another, allowing the sequence of questioning to itself stand as a type of narrative. Finally, appropriate encouragements are suggested for the interviewer to use while in conversation with a participant, such as, “Can you explain how...” or “What occurred after that?” (Ayers, 2008). Finally, it is important to note that several of the questions constructed for participant interviews were influenced by the dramas presented by Frank (2007). See Appendix A for interview questions.

Sample. Participants for this research included seven adults all over the age of 18. Individuals were recruited from a doctor’s office, a graduate institution, and via word of mouth.

Letters of permission were obtained and submitted to the Human Research Committee (HRC) at Antioch University New England from both of the organizations during the initial stage of the dissertation process. Recruitment of participants occurred primarily via bulletin postings and mass email. Each participant was given a \$15 gift card as a token of thanks for their participation in the study.

Generally, a sample of convenience, such as this one, is selected from individuals available to the researcher, rather than from the general population at large (Herek, 2009). While it should be noted that a particular segment of the population may self-select to participate in such research, it is equally important to this type of research to include participants who are open and enthusiastic about sharing their stories with others.

Participant selection, inclusion criteria, and participant demographics. Participants were recruited via bulletin postings at a doctor's office, via a large academic email listserve, and via word of mouth. Please see Appendices B and C for recruitment materials. Once identified as interested, participants were screened for their inclusion in the study. Seven participants were recruited, interviewed, and included in the present study. All seven of these participants were (a) over 18; (b) met face-to-face with the investigator for 60-90 minutes; (c) generally grew up in good health; and (d) grew up with a younger or older brother or sister who was formally diagnosed or identified with a chronic illness or condition in childhood; (e) and who remains living today. For the purposes of this study, chronic illness and/or condition was defined as one that is persistent, unremitting, and usually without cure (Dowrick Dixon-Woods, Holman, and Weinman, 2005).

Of the seven participants included in this project, six were female and one was male. They ranged in age from 29-67 year old and were all presently living in the Northeast area of the

United States. All of the participants interviewed were presently employed and lived with family or loved ones. Participants identified the following employment: two psychologists, a social worker, a teacher, a stay at home mother/former nursing assistant, a graduate student in psychology, and a landscape architect.

Sibling illnesses identified in this project included diabetes, polio and physical trauma, two traumatic births and ensuing complications, chronic kidney failure, behavioral disruption and an eventual diagnosis of schizophrenia, and heart conditions as a consequence of Down Syndrome. The medical distinction between illness and disability is not as clear in the experience of several subjects; some of these illnesses also border on disability as well (e.g., Down Syndrome with heart complications).

It is also important to note that several of the included participants also identified a more complex health story in their lives. For instance, some subjects identified multiple siblings who were chronically ill, and/or a parent or caregiver who was chronically ill at the same time as a sibling. Stories such as these were all included in the study. As established early on, so long as the previous criteria are met, and a defined situation is present, a participant was still included in the study. Moreover, the uniqueness of the stories and factors involved are also likely representative and indicative of the complexity and multi-dimensionality of the lives of the involved families.

Measures and procedures. Semi-structured, one-on-one interviews were completed during 60-90 minute intervals. and were conducted at a variety of public meeting spots, most typically local libraries. With the permission of the participant, each interview was audio recorded. Each interview was broadly structured with a pre-determined set of questions. See Appendix A for the list of initial questions. However, it was common for interview conversations

to stray from the question at hand and eventually return to topic, often yielding important perspective and data.

Each interview consisted of three parts, occurring in the following order: (a) Informed consent, (b) interview questioning, and (c) debriefing. Each participant signed and was provided with a copy of the project's informed consent policy including a statement on confidentiality, disclosure regarding audio recording and the storage of audio tapes, access to the study findings, and the contact info for the primary investigator. See Appendix D for a copy of the informed consent. After each interview ended, the participant was invited to engage in an informal debriefing regarding the interview, express how they experienced the interview, and was invited to answer any questions. Several participants were interested in further information and literature on the topic and this was provided to them at the interview. In the case of one participant, there was interest in future processing and increased support around shared experiences; therefore, appropriate referrals were made. Fifteen dollar gift certificates were mailed to the participants following the interviews, as tokens of appreciation.

Ethical considerations. The topics being investigated in this project are sensitive in nature, and caused some participants some emotional distress. This consideration was included in the study's informed consent; however, the potential for this distress was minimized, given the voluntary nature of the adults' involvement in the research and their clear understanding that they could stop the interview at any time. Regardless, many participants noted the unusual, but positive quality of the opportunity to share their experiences, and commented that they enjoyed the thought of contributing to the body of knowledge in some way.

Furthermore, the relational methodology of any narrative inquiry requires additional attention to ethical considerations (Clandinin and Caine, 2008). While standard ethical issues

such as confidentiality, privacy, and informed consent are naturally given solid consideration and care, the personal nature of narrative interviewing and the sensitive stories elicited demand even greater care to the manner in which participants were treated and by which data were later manipulated and presented. Accurately portraying participant tone, voice, and detail is a primary method by which narrative methods can be sensitively and ethically maintained (Clandinin and Caine, 2008). The use of direct quotes to support emergent themes was also helpful toward this end.

Quality control procedures. Each interview was audio recorded upon the written consent of the participant. Morgan and Guevara (2008) suggest that audio recordings of qualitative interviews provide a less detailed summary of qualitative data than a video recording, but certainly more detail than field notes. Particularly given the more intrusive nature of a video camera and its potential inhibiting effect on participant disclosure, audio recording interviews for the inclusion of tonal quality and voice emphasis were deemed sufficient for the purposes of this project. The audio recordings produced from each interview were kept in a strictly confidential, locked location.

In addition, I kept field notes during each interview meeting. See Appendix E for a note template. These notes primarily consisted of demographic information and notes to myself suggesting important ideas and themes for later cross comparison among notes, audio recordings, and transcriptions. These field notes were also kept in the same strictly confidential and locked location.

Data analysis. Data analysis began with my transcription of the audio interview tapes. A narrative analysis was assumed for the purpose of this project's data analysis. According to Riessman (2008) narrative analysis can be broken into four different types, including thematic,

structural, dialogic-performative, and visual narrative analysis. It is important to note that thematic and structural approaches form the foundation of narrative analysis, from which the others build. For the purposes of this research, I took a thematic approach to narrative analysis. Prior to detailing this method, it is critical to understand where this methodology locates itself within the larger qualitative context. Lincoln and Guba (1985) describe a “continuum” of analytic styles on which an “inductive-generative-constructive-subjective” approach takes up one end, and a “deductive-verificatory-enumerative-objective” approach takes up the other end, with a number of combination approaches dotting the space between. A thematic approach to data analysis falls more closely toward the “deductive-verificatory-enumerative-objective” end of the continuum, as its goal would be to boil down and capture salient ideas, themes, categories, and constructs found within the participant narratives gathered.

Thematic analysis and coding. Thematic analysis is a “data reduction and analysis strategy by which qualitative data are segmented, categorized, summarized, and reconstructed in a way that captures the important concepts within the data set” (Ayers, 2008, p. 1). In addition, this method can be understood as an illustrative approach by which “patterns of experience” are gleaned. Thematic coding is the primary process from which this analysis occurs. According to this process, data is broken into relevant segments and further categorized into meaningful themes.

In general, coding can be approached in a variety of ways. In quantitative studies and in some types of qualitative research as well, axial coding occurs with a pre-determined set of codes to be located in the data. A more open approach to coding, however, would entail beginning with some preliminary codes, based on previous research and knowledge, with the goal of adding to these codes as data is further processed and analyzed. Ryan and Bernard (2000) speak to a more

pre-determined approach to data analysis, explaining that themes can often be “fuzzy” and may be labeled prior, during, or after data collection (p. 780). Willms, Best, Taylor, Gilbert, Wilson, Lindsay, and Singer (1990) offer that those embarking on qualitative analysis should begin with general themes pulled from their familiarity with the literature and build upon their themes throughout their analysis. Based on this tenant, the current analysis began with five major themes pulled from the existing reviewed literature on siblings’ adjustment to chronically ill siblings: (a) unaddressed needs; (b) guilt; (c) anxiety; (d) increased empathy and compassion; and (e) health concerns. As additional themes were identified and labeled, they were added to the initial five. A final outline of emergent themes will be provided at the outset of the Results chapter, prior to their formal and detailed presentation and discussion.

More specifically, this thematic analysis was completed via methods described by both Polkinghorne (1995) and Ayres (2008). I combed through and read each participant transcript a minimum of three times. Beginning with the five previously identified themes, initial readings of the narratives allowed for the identification, labeling, and classification of these, as well as other key themes, concepts, and ideas within the transcripts.

Ayers (2008) explains that solid classifications are discovered via a process that factors in both within-subject and across-subject salience of a theme. A theme must demonstrate its power within an individual narrative, before it can be looked for across subject narratives. Ayers also emphasizes the reciprocal nature of coding and themes, stating, “Coding facilitates the development of themes, and the development of themes facilitates coding.” (p. 1). These basic tenants will be kept foundational to the coding process adopted for the purposes of this analysis.

In order to remain close to the tone, voice, and details shared by participants, in vivo coding was also utilized in the analysis of narratives. In vivo coding refers to the use of actual

words shared by participants to label dominant themes (Benaquisto, 2008). Subsets of populations often have certain vernacular words or language to describe experiences or artifacts. It was vital to capture any such language, as it emerged in the narratives of the adult siblings interviewed for this project.

Qualitative researchers frequently maintain ongoing notes and logs of the process of coding and analysis as they work (Benaquisto, 2008). This process is also known as “memoing” and it occurs throughout the coding process. Notes generally include insights, ideas, patterns, themes, and working connections. This activity is often done with the assistance of a computer software program; however, for the purposes of this project I assumed this task in handwritten form.

Ayres (2008) reminds the researcher using this technique that thematic analysis is more than a simple listing of major ideas and descriptions taken out of the narratives. Taken further, subsequent readings of the transcripts will allow emergent themes to be further synthesized into broader, more inclusive “patterns of experience.” For instance, themes including the *absence of parents, being home alone, and care-giving by extended family*, may be more meaningfully combined and discussed under the inclusive category of *alternative caregiving* (Charmaz and Mitchell, 2001; Erickson, 1986). The ultimate product of thematic analysis is not meant to create a solid framework or grounded theory; rather, its goal is to present findings that are “meaningful” and “useful” to the reader.

A number of qualitative researchers, including Benaquisto (2008), believe that coding and the analysis of qualitative data generally can’t be directly taught and explained, rather it requires a more creative and self-reflective process of data management. It was my goal to

engage in this creative, self-reflective process within the parameters and guidelines previously presented.

As is often common with narrative research, a great multitude of themes and ideas emerged from this data analysis. For the purposes and scope of this dissertation research, only the dominant emergent themes will be presented for discussion. However, it should be noted that the majority of emergent themes were subsumed into larger categories, revealing a comprehensive portrayal of the stories and experiences shared.

Chapter 4: Data and Results

This section will capture and review in detail the major themes and ideas emerging from the experiences shared by participants. The following is a brief outline of these results and the major categories they fall into: (a) *at home: finding out, the early relationship, early environment, and family role*; (b) *retrospective early needs*; (c) *anxiety*; (d) *guilt*; (e) *increased empathy, compassion, and awareness*; (f) *a different worldview*; (g) *the sibling turn*; (h) *health perspective and experiences: retrospective health narratives at the family level, mediated adult health narratives, and general self-care*.

I note that all five of the originally designated themes remain in some form in this final analysis. The theme of *unaddressed needs* was modified to *retrospective early needs* to better capture and explain the phenomena found in this project, and soften the connotation of “unmet.” Generally speaking, the needs shared by these participants were ultimately met in some form over the course of their lives, making this adjustment to terms more representative of a global experience. In addition, the category of *increased empathy and compassion* was extended to also include *awareness* as well. During analysis, this theme became salient, and connected to the themes of empathy and compassion. It did not appear to stand alone. Therefore it was added to broaden the previous category.

In addition, *health concerns* was extended and detailed to include a distinction between past and present health narratives, and general selfcare. *Anxiety* and *guilt* were kept titled as they were. Finally, the themes of *at home, a different worldview, the sibling turn* were added and appear to most comprehensively round out the lived experiences shared during this project. It is noteworthy that several of these themes are not directly connected to the research questions at hand. However, they form a solid foundation for informing later health narratives, and set the

stage for better understanding the context in which these individuals developed the perspective and understanding they have. See Table 2.0 for a summary of these thematic categories.

At Home

Finding out. Given the narrative and story-like quality of the experiences collected during this project, each participant shared, in some form, their experience of finding out about their brother or sister's illness and/or how they came to know about it. For some it was coming to know their sibling was different in some way. For others there was a formal diagnosis, and the ensuing treatment and experiences. Within these distinctions there was also a quality of how evident the illness was or was not. In some instances there was an unexpected quality to the illness, "My parents didn't expect him to have Down Syndrome." For a few participants, it was more noticeable that something was not right, as one participant recalled:

"My brother was born when I was four years old. He was born here in (the state), but being immediately apparent that something was pretty wrong, he was transported (elsewhere) and it was apparent that neither of his kidneys functioned very well."

Many of the siblings spoke about acceptance of the ill siblings' diagnosis or condition and the process that entailed. For some this process was more stressful than for others. "(We) were really stunned, but within that first year we got into a groove of accepting..." versus, "All I can remember about that is that I spent most of my time thinking my brother was going to die." It is crucial to note here that age, gender, and illness/trauma are major differentiating factors in the variations of acceptance. However, both experiences describe an ongoing process of understanding and cognitive distilling that accompanies this discovery, or finding out process.

The early environment. As might be expected based in the previously presented literature, all of the individuals interviewed expressed directly or indirectly some

acknowledgement of the increased energy and space their chronically ill sibling occupied in their household growing up. One participant describes,

“My mom was very wrapped up with her...I think it was very much the center of our family. I was very tuned into my sister and hyperaware of her. She was the kind of kid who took up a lot of space in the house...I think the message my brother and I got as kids was ‘you’re okay, you’re good and you need to help.’ (I) became really good at that.”

For this individual, as well as others, there also appeared to be an internalization of unspoken expectations from the environment. This often led to doing what you had to do with or without parental support, e.g., “No one ever stressed about our homework, we just did it. Truthfully, it’s not what we needed.”

For another participant there were distinct memories of partaking in the rituals connected with the sibling’s illness:

“So I can remember doing the exercises with him and I remember no small part of my therapy was talking about that...there was a way in which I was jealous...I remember my mother’s hyper-vigilance toward (him). I thought she loved him more than me, because he got so much attention.”

For another participant, there was a strong sense of continuing to have the same childhood experiences she might otherwise have had despite circumstances with her sibling.

“I got sent to see a therapist...I remember just rolling my eyes and knowing why I’m here...I know why they’re sending me. They’re worried I’ll be so put upon because all the attention is on my brother. And I think I almost had a reaction to that too. All this attention is going to him and everyone’s worrying about me being worried about the attention. I’m not worried about the attention, I’m just gonna go act out and do whatever I’m gonna do anyways...they expected me to have these one set of issues, and I developed an entirely different set.”

For many there was also the strong memory of spending time away from the family while the sibling was being taken care of, e.g., at the hospital, getting treatment, etc. For some there was anger and intensity that came from these experiences, while for others there was a sense of resignation. Personality, other early experiences, and availability of supports likely play a strong mediating role in whether emotions of anger, resignation, or the spectrum between the two were

experienced. Speaking to other early experiences, a number of participants reported an external focus outside their family towards healthier, typical family structures, attitudes, and environments. One individual shared:

“And what I did—we lived in a tenement at first—how I survived—it was because it was a little Italian community. They all had their little businesses and stores and kids around. Those were my friends and I saw how they were acting and how their parents were and their siblings were. I wanted to be with them and I learned from them. I felt that they taught me and helped so much. I think I would not have made it if it wasn’t for those kids and living in that community.”

The Early Relationship. Many individuals described tangible and significant differences in the quality of relationship developed with their sibling. One participant described a different kind of relationship with her brother who suffered from chronic mental illness, “I could never see my brother and say ‘let’s go somewhere together.’ We were buddies but we couldn’t do things together...” She went on to explain that the limits within this relationship took their toll interpersonally between the two siblings through the years.

Another participant noted that while growing up, her chronically ill brother often wanted and needed more attention than she could provide as an adolescent herself. “I really wanted to be doing my own thing and he wanted my attention...I didn’t know how to give (it).” For this participant, as well as for others, there was an increased demand from a parent for them to be the more responsible party for the sibling relationship. “...she really put it on me...you need to understand this situation.” Overtime, however, this individual, along with others, expressed the developed ability and desire to be supportive of whomever the sibling wanted to be later in life. This is likely a process that may have naturally occurred independent of the atypical circumstances; however, it is important to note the increased responsibility present or felt at early ages for the older, well sibling, given their position in the family.

For another individual, the quality of the early relationship with her sibling was characterized by their interactions at the same school, a desire to protect her sibling, and general difficulty watching the sibling need to adapt and compensate for his limitations. For others, there was strong identification and idealization of the sibling who was ill and struggling, particularly identification regarding their strengths. One individual went so far as to describe it as: “In retrospect, there’s a blurring of the boundary—who’s him and who’s me.” He goes on to explain in greater depth how much he even simply enjoyed spending time and being in the presence of his sibling.

Family role. Woven within the shared experiences of these siblings was a story of family sacrifice for the sibling in need, both from individuals and the family unit as a whole. One participant shared the experience of watching both her parents prepare and ready themselves to give her brother a kidney. Another shared the lengths his mother went to in order to acquire the best treatment available. Naturally, these sacrifices and experiences were sources of stress for many of the families. One participant even described the stress rising to the level of an embarrassment: “I think (he) was a source of embarrassment to my parents—I think it really bothered them. They had had this child and I think there was a lot of worry on their part about him.” For another there was a severity with which her parents reacted to the diagnosis, “my mother was very emotional and stunned...she tried to control every aspect of everything in her world...” Regardless of the parental reaction or action, the well sibling monitored it closely. These early and ongoing stressors are likely to factor into the development of personal health narratives and attitudes.

Several individuals also spoke to the role taking that occurred, or is still occurring, in their family of origin. One individual noted that to this day she is still the one in her family who

places a greater degree of pressure on her sibling to stay active and moving, where her parents continue to play a more nurturing, comforting role for her ill sibling. Many other participants spoke of being a “helper” or “being out of the way” all which can be considered relative roles within a family unit. Others also spoke of the respective roles parents—mothers and fathers—have taken in dealing with the ill sibling respectively. Generally speaking, there was a strong mother presence in the stories shared, with the majority of mothers identified as the primary caregivers of the ill sibling.

Finally, within the family role shared by this sample, there was strong sense of the “what could have been...” had decisions and choices made on the sick siblings’ behalf been different.

One participant shared candidly:

“It’s interesting that I’m doing this now, because for the first time in my life I guess I’ve become at all critical of how my parents based some of these decisions (for sick sibling) and it’s really just new to me...”

More than even questioning decisions made, there was also a poignant realization for some of the well siblings regarding what their ill sibling was missing out on in life. As one participant reported, “I will never quite understand how you feel and you might not quite understand what you don’t have. And that might be good, I don’t know...” Another participant even recognized what types of behavioral and psychological treatment may have benefited her sibling had he been born at another point in time. These musings were not shared in criticism of parents, but were more indicative of a different kind of heartfelt hindsight regarding circumstances that would certainly have been outside of parental control at the time.

Retrospective Early Needs

As noted earlier, this categorical theme was adapted from unaddressed needs to retrospective early needs to better capture the accuracy of the data shared from participants.

Many experiences shared included needs that were met, as well as needs that weren't recognized until well into adulthood.

A number of individuals expressed a memory of not knowing or understanding exactly what was wrong with their sibling. One woman describes: "I was kind of growing up and not totally getting everything..." while another sibling details the actual diagnostic process of "not knowing exactly what was wrong" with the sibling. For many there was a sense of missing information or partial knowledge of the situation. One individual explained: "I grew up knowing, but not knowing about illness..."

Regarding the well siblings' personal needs, there was a recurrent theme of how those needs were generally met, but perhaps not prioritized in their family of origin. For one participant, this interview was one of the first times she had thought about aspects of growing up with her sibling in these terms:

"I never actually thought about that before, because I just think I'm her sister and literally have never thought about it in terms of me, until you're asking me right now. So I'd say subconsciously if I can go into it, usually things that I like or that I want are really pushed back, in our immediate family and in our whole family. It's what (she's) doing, what (she) needs."

Finally, many of the siblings shared their need to differentiate, and separate from their family origin. Generally and psychologically speaking, differentiation is a developmental task of adolescence/adulthood, but for these individuals there was an added significance and meaning to how and why they needed to find separateness from their family. For one woman even being given her own physical space in the family home was a major source of comfort and separateness from her sibling:

"We shared a room when we were little. She would rock in her bed...and then I was put in the guest bedroom and had my own room...it just became clear to my parents. I think it was a very good thing they decided to do it and were able to do it."

For another individual this differentiation appeared to come in the form of identification with something outside the home, such as sports, and was described as an “escape.”

More than just needing physical space in the home from the higher need sibling, many siblings identified their need for emotional space from their whole family as well. In many instances this manifested in taking time to leave or break from the family. In sharing her own metaphor of the experience, one participant shared how important it was to her to make this separation from her family:

“Being the frog in the pot when the water’s turned up...things were so focused on my sister...When I went off to college, I was kind like—I’m not going back home. I don’t care if I hate college—I’m not going back home. My parents were very loving, wonderful people. But there was not a lot of space there for me...”

Anxiety

A variety of different types of anxiety were shared by participants based in the experience of having a chronically ill sibling, but one of the earliest and most salient was the fear and anxiety that accompanied the near loss or the idea of losing their sibling. One participant recalled: “Something about older siblings to younger siblings, I cried more than he did...I lived in this absolute terror.” Another individual explained that there had been three times her parents had been informed her ill brother had passed away, only to learn that he was still hanging on. This anxiety likely manifests in a number of ways in a family. One particular event that brought inherent anxiety was the birth of other children in these families. One woman described her parents’ deep worry regarding her own later birth and how that translated into their need for “things to be okay” throughout areas of life.

One participant also shared her experience of childhood anxiety that manifested in more somatic, physical complaints when she was young. Such effects were identified as having a vague, but noteworthy connection to the experience of living with her sibling. She details:

“But I know when I did go to first grade, I was so scared I would throw up every single day. I was scared to death and I was afraid of all the kids. They’d always have to send me home. I’d have a little bit of milk, throw it up and they’d say you want to go home? And I’d say yea I want to go home.”

While such an early experience of anxiety might be based in a number of factors, it is notable that it was shared in this context, and that it may have been tied to the experiences occurring back at home. Moreover, for this woman, whose sibling struggled with mental illness, there was an added anxiety for her in experiencing his symptoms of paranoia and fear. Prior to finding the support of others in her situation, understanding his symptoms was intensely difficult and wrought with a type of anxiety in reaction to his symptoms.

Another individual speaks to the perpetual and constant level of concern pervasive in the household: “I grew up in a family where MS, depression, and arterial sclerosis were all there—I was pretty unscathed. But I never lived without something life threatening to someone in my family.” He goes on to explain that he experienced a very particular kind of vulnerability as a child, “always afraid”—a fear that seemed to extend beyond himself, into childhood relationships with others as well:

“Let me tell you a story...I ran into this guy from high school the other day. He comes up to me and says ‘Didn’t I used to beat you up every day?’ I say ‘Yea, you did.’ And he says ‘I’m sorry, you just seemed to give off this message—‘Beat me up.’ And it wasn’t until you contact me that I made some of the connections between these (sibling) experiences and that (shared story).”

For this man, there was a particular kind of vulnerability, perhaps associated with the stress at home, which he unknowingly carried with him outside the home as well. Even if this connection wasn’t made explicitly at the time, there was an important retrospective connection between the sibling experience and the manners in which it may have manifested interpersonally.

For another woman there is an anxiety and increased awareness of personal genetic risk for developing her sibling's condition, an anxiety that is particularly realized leading up to her physical each year:

“My health is good actually and I usually get nervous when I go for physicals because of the diabetes and I don't check my sugar in the year at all ever, because I know the symptoms...But generally I get a little nervous around physical time because I'm wondering...”

Finally, for many, there was a more generalized, ongoing worry for their sibling, their condition, and a chronic stress regarding an unknown future, e.g., when will the next surgery be? Who will take care of them when my parents are gone? Are they okay? Will they ever find a partner of their own? These worries were threaded within a more transient anxiety that increased around particular events, conversations, or interactions with the sibling and/or the family.

Guilt

Guilt was not a theme that was predominantly found across the interviews held. While it is a theme found in the existing literature, it was not reflected with equal strength in this data. The themes shared that do connect to its presence in the sibling experience are presented here for inclusivity, and to provide the most comprehensive picture possible. For one of the interviewees her experience of guilt was very poignant, particularly as it related to the experience of her brother living with mental illness:

“And what I feel is a lot of guilt because I wonder what could I have done? And I think I should have been able to do something about him. I should have helped him. I thought I did everything I could, but I should have been able to help him.”

This woman had previously stated how much and to what great lengths she had gone for her brother; however, it is clear and powerful to know the feelings of guilt and responsibility that still remained. For another woman the complete experience of growing up with her sibling,

totalled with feelings of guilt and a pressure to be good, helped contribute to her later experience of a severe depression.

Forms of guilt were also identified in more day-to-day ways for a few of the siblings interviewed. One individual shared the difficulty with which she watched the illness begin to affect her sibling's body, realizing that he was not going to appear outwardly average as she does. Another sibling shared the process of feeling bad or guilty that she could function more normally, without much thought, and often needed to do so in front of her sibling. Generally speaking, these themes around guilt appeared secondary to many other themes found.

Increased Empathy, Compassion, and Awareness

Across all seven participants interviewed, whether directly stated or implied in conversation, there was a powerful admiration shared for their sibling, and what each had gone through and dealt with. One participant reported:

“...I just think he's an amazing person and like I said, there's not a whole lot of people that I admire, but he's one of them. I just think that he sets an example for what people can be and he didn't accept the fact that he had a disability or any kind of problems. He just got up every day and went out there and lived his life and did the very best he knew how.”

Another woman shared regarding her brother, “(I have) a lot of general appreciation—for what the human mind can do, and the body—it's very impressive.”

As one might imagine, based in this admiration and other experiences, many of the siblings described having very positive, loving relationships with their ill sibling. While each referenced some necessary emotional work or adjustments that were necessary to get to that point, there was a tangible sense that warm, supportive relationships had formed despite challenges inherent in the lived situations and environments. One sibling shared the depths of her connection to her sibling, stating:

“...and I told him this a long time ago—if there was some kind of part of my eye that I could give to him, I would do it, but there isn’t. It’s not the cornea. There’s nothing you can do...But I would have gladly given him one of my eyes.”

In addition, for many of the siblings, there was a spoken and felt drive towards advocacy for the sibling that had developed over the years. One woman detailed her pull to become a more public defender of her sibling’s diagnosis and condition, speaking up in situations in which it was not always easy to do so. She shared that while she feels pulled toward this kind of work, she also realizes there is a risk of “becoming that person...” whom people stop listening to. For this reason, she expressed her more recent decision to channel some of that energy more proactively towards her studies, and the direction of her graduate work. For this individual there was deeper meaning in directing her efforts of advocacy in a more intentional, focal direction.

Speaking to a heightened sense of awareness, many of the siblings explained a type of personal filter they felt they had developed in relation to others, a filter that aided them in better reading people and recognizing others who may hold similar values. Initially, this idea was shared by the first participant, as she described:

“It’s funny—even friends of our family call it like the ‘John-test.’ When you’re bringing a significant other home—how do they respond to John? You know cause I’m a package deal... I definitely have high expectations. I think I judge people, not just their actions, I know people can be uncomfortable and start to learn, but sort of their degree of kindness...”

This woman went on to explain that she had experienced other versions of the John-test throughout her life in other ways—recognizing individuals and institutions more acutely who do not embody the values which she identifies with, based in the experiences and love of her brother. Similar versions of this John-test were noted throughout other interviews, with another woman noting that without completely knowing why, because of growing up with her sibling, she felt better able to read people and their motivation. One might guess the idea of this filter or increased ability to read individuals may stem from early childhood, during which this practice

becomes regular for a well sibling—scanning the environment and understanding, not only for themselves, but in protection of their sibling. This idea will be discussed in further detail in the next section.

Another participant echoed the idea of a social filter developing as a result of having a high need sibling, reiterating that it positively influenced the quality of relationships and individuals she sought out. However, she also added that this same filter can also keep an individual consciously, or unconsciously, choosing the same personal role in those relationships—a caregiver, supporter role, that often comes second hand to individuals who have grown up with a high need sibling.

Similarly, in speaking to this caregiver, supporter role, a protective helper role emerged saliently out of many of the experiences shared by the sibling participants. Often this role emerged early in the childhood experiences shared:

“And kids could be very mean...A lot of (me) wanting to protect him and watch out for him...but usually I was the one watching like a little hawk for people to do that. Feeling like I needed to step in.”

Another participant describes the manner in which this protector role was reciprocal, “I was always very protective of him...I tried to protect him. And he and I were very close. And he was very protective of me too.” However, for some there was also a natural fatigue that came with this protector role, “So part of my job as (his) sister is to always be the squeaky wheel, but part of me is like ‘I’m tired of being the squeaky wheel...’”

Out of these experiences naturally emerged seven individuals who were in some ways more equipped to know how to meet others’ needs or who at the very least had had considerably more exposure to such a process. As might be imagined, many of them experienced some degree of inherent parentification in their families of origin, naturally falling into the category of the

child who needed less, and was capable of more. For many, this had a clear thread to their later career choices and professions. While it must be noted that recruitment for this project occurred in heavily psychologically affiliated arenas, and participants were self-selecting, six of the seven interviewees had themselves gone on to assume roles in helping professions (e.g., psychologists, counselors, nursing aid, teacher).

A Different Worldview

Even more than specific roles, or increased awareness, siblings expressed a variety of poignant worldviews based in their experiences with their sick sibling. Speaking to the general experience, one woman shared that “(it) just affected our family and the way we see things...” She went on later to describe herself as “more defensive” with a “hyper-vigilance stance to the world and to people all the time that I didn’t realize I had.” She connected this in large part to growing up in the protector role and went on to explain the manner in which she has learned to tame and utilize this power in a more proactive, actualized manner.

Another sibling, speaking to this idea, explained that in becoming more “tuned into” her sibling emotionally, she has been better “tuned into” emotionality in the environment. Again these experiences connect significantly to the previously discussed protective helper role, but also speak to the manner in which these siblings understand and interact with the world differently.

Another participant shared that her personal threshold for “making excuses” for others had been lowered significantly due to her experiences with her sibling. Speaking to her experience of hearing others talk of their illness or condition:

“Well a lot of times I think they’re whiney babies. I’m struck by the fact at how extraordinary my family was and how we didn’t accept the fact that because you had some kind of limitation that it should stop you from doing what you want...”

Still for others there was a shattering, or altogether absence of certain world illusions that many other children are allowed for a longer time. One participant likened the experience to Post Traumatic Stress Disorder (PTSD), and her premature awareness of the danger in life:

“It’s like people with PTSD—they’ve lost the illusion of safety—and I think I grew up in a family that had lost that illusion of safety and so I always know that something can go wrong.”

For this woman and others, this lost illusion of safety naturally spilled later on into their experience of pregnancy, birth, and parenting when they had infants of their own;

“I think a lot of mothers check their babies in the middle of the night to make sure, but I have this vigilance about accidents and health. I don’t care how rare it is, it was really pretty rare for my mom to have the baby she did, that illusion of safety that makes people not feel anxious, I don’t think I have that...It doesn’t matter how rare when you’re the one in how many hundreds or thousands. Shit happens.”

Another mother shared:

“I think when I was pregnant, that story...was definitely a part of me. I don’t think I did anything differently, but I definitely had the awareness that this could go bad. Maybe in a way that my friends didn’t have that same awareness that bad things could happen and that people don’t always survive.”

For these women, and likely many others, it is not just that an illusion has been lost, but perhaps that such an illusion was never built in the first place, given their early environments.

Particularly with regard to their own parenting, several individuals noted the impact on being a parent their sibling experiences have had on them. One father explained that he had received so little clear information about his ill sibling growing up, so he in turn became a “straight shooter” in every attempt to leave space for honesty with his own child. It was an approach he looked back on with intentionality and pride; an approach that ultimately helped him cultivate a stronger relationship with his own child. Another participant shared that having grown up with her sibling made her more acutely aware of the individual needs of each of her children. She went on to explain her intentional decision to spend more one on one time with each child

for this reason. Generally speaking, in these instances, being an adult sibling had a positive effect on these participants' approaches to, and understanding of, their own parenting.

The Sibling Turn

Some of the participants described their sibling's condition stabilizing over the years, while for others it worsened. For some there was an intense sense of responsibility, which naturally led to the expectation for, what one woman termed the sibling "turn," at caretaking. In many instances there was a gradual increase in this turn, with the sibling providing adjunct support to their older parents, while for some there was a clearer demarcation at which point they would be their sibling's caregiver or guardian. For one woman, this role had already begun at a young age, despite parental presence, "I sometimes feel as though I am her mother sometimes. And it's not that she ever asks for that, it just naturally goes into that role." This woman explained feeling an early increase in her responsibility and a corresponding decrease in her personal freedoms, quite similar to the pattern expected in motherhood.

For those individuals with a clearer demarcation of their guardianship or caregiver status to their sibling in the future, there was a degree of stress that accompanied this responsibility. In speaking to the assuming of this role, one woman shared:

"...there's this underlying current of stress. I let little things overwhelm me and I'm not sure why, but I'm sure it's because this is at the background. Part wonders about my future. It's definitely like one of those things that's always there...adds to the stuff that wants to push you."

The adult sibling turn at care giving appeared to often be accompanied by the simultaneous care of older parents, further compounding the stress experienced by the well sibling. One woman shares her experience of that time in her life:

"...but I was also taking care of my mother who was now in a nursing home...And I had to see him one day and her another while I was working 40 hours a week...So I could spend an entire day with him and run my errands in the evening and see my mother in between after work or on Sundays. In the meantime, I had my own children and my own husband..."

Another participant shared that it was in recognizing the mortality of her parents that she recognized this dual role she would hold for her brother and her parents. In and of itself, this stage of life is a monumental and stressful one for many individuals. However, with the added factor of a high need sibling, these siblings seem well positioned to need additional supports and resources as they multitask and provide to those depending on them.

Health Perspective and Experiences

Turning to the central focus of this project, the siblings interviewed shared a wealth of information regarding their own histories as these experiences interacted with health, their present challenges, and how they have come to take care of themselves and their health.

Following careful consideration of the data gathered, the health experiences and perspective shared by siblings have been grouped into three categorical types. These include retrospective health narratives at the family level, mediated adult health narratives, and general self care. As this section proceeds, I will explain how I understand these narratives falling within these respective categories and their labeling.

Retrospective health narratives at the family level. In terms of the day-to-day functioning around the sick child's care and treatment, one participant remembers her task to, "Keep him calm and stay out of his way." Later, she explains that she learned to take care of herself by making better choices than her other siblings had. For example, she attended to diet and exercise classes to stave off potential diabetes and heart disease. Another sibling remembers a significant amount of time spent "making sure he (the sick sibling) was okay..." Many of these memories extend back toward the earlier discussion regarding the sick sibling taking up a fair amount of energy and space in the respective household.

Many of the participants remember their basic health needs being met over the course of their childhood, but generally do not remembering needing the doctor or medical attention often. One man shared that he felt different criteria had been created for him in terms of what was considered important in terms of health. Another participant provided an example of a time when she experienced her own mother's approach to health issues more dramatically, she shared:

“I grew up in a family where you went to the hospital to die and you didn't go to the doctor unless you were deathly ill. I remember once I sprained my finger playing basketball—I'd pulled it all the way back and it had a huge blood hematoma—or whatever—the whole palm of my hand and my hand was cramped up like that and my piano teacher was worried about it. But my gym teacher said—if your mother won't take you to the doctor I'm going to take you. And shamed my mother into taking me. If they hadn't taken me, my finger would still be cramped up...”

One interviewee introduced an important factor to consider in this work—the culture of the time period each of these siblings grew up in. As noted earlier, participants spanned three generations, from 29 to 67 years old. Within this one study, we are looking at the experiences of children who grew up anywhere from the early 1950's right through to the 1990's. Of his own Baby Boomer experience, he shared:

Participant: “The culture was to protect the kids...So I grew up knowing and not knowing about illness...a family value that says don't tell kids bad news.”

Interviewer: Did you feel left out in some way?

Participant: I don't think they think of it as leaving the kids out of the equation...Did I feel left out of the equation? I didn't feel like I was in the text book...”

This man went on to describe his own early reactions to somatic and health complaints within his family of origin. He honestly and candidly describes exaggerating minor events for increased attention, understanding that this could serve a purpose. He reports continuing to have somewhat exaggerated reactions to his own physical complaints through today, but notes that had he not done some of his own personal work he, “could have easily become a hypochondriac

under the right circumstances.” Finally, he shared that as a child he learned illness to be a serious thing, but also a thing by which an individual must “manipulate” and/or “work the system” of health care to have one’s needs adequately met. He explains learning this while watching his mother and brother navigate the complexity of the health care system and later feeling those same systemic demands himself.

Pushing through. A number of participants shared various styles of how they and others learned to respond to health concerns, during childhood, in light of their sibling’s illness. For many who shared their experiences of this, the term “*push*” or similar variations came to the forefront of the conversation. One participant explains, “Well I tend to just push through. I’m not the greatest at stopping. Because it’s always worked for me in the past...I think I usually just curl up and get through it and hope it goes away.” For another individual she recognized early as a child that she was “fine” relative to her sick sibling and generally began to feel less need. Another participant explained a similar style of “power(ing) through”—sickness and health issues—in part a byproduct of being a mother, but also self-identified as based in an early “covert message...to be okay.”

Several participants spoke powerfully to another covert message that often comes with the territory of watching the care of a sick sibling and their more significant needs—the participants’ needs were less important. Over time, several noted they had internalized this message. As one participant describes :

“I think if you witness someone not getting what they need, and you feel like someone is not getting something, you start to think too okay—maybe I won’t get what I need too?”

This is a powerful narrative, on the individual or group level, and has implications for the manner in which these individuals interact with their health and the health care system. This

questioning of whether or not one's needs are met will likely emerge as an individual interacts across care giving environments—in particular health care systems.

Mediated adult health narratives. A majority of participants interviewed described a shift over time in how they had come to understand their health: a gradual mediated understanding between health narratives in their family of origin and the present. These changes appeared notably connected to major life events such as the following: a personal health crisis later in life, intensive therapy, having a family of one's own, breaking away from the family of origin, and/or a supportive, warm relationship. In short, the trajectories these personal health narratives took were not exclusively and rigidly influenced by the experience of growing up with a chronically ill sibling, but were also in some significant way mediated by major events or transitions over the course of life. For this reason, the following categorical theme will be explored as Mediated Adult Health Narratives.

Most of the participants had experienced some of their own health concern over the course of their lifetime. As could be expected, some had more serious health concerns than others, e.g., cancer, heart condition. However, in terms of generally approaching one's health, these narratives shared some comparable trajectories.

For example, one woman shared, that in part due to her early experiences, she feels as though she is a “worrier and a checker” leading to a more generalized anxiety regarding her health. Speaking directly to the previously mentioned worldview, she explained knowing that “something can go wrong” in terms of health. In response she explains being far more proactive with her health. This style often leads to positive increases in self-awareness, and the detection of early warning signs, but also requires her to keep check on her anxiety, and how it is operating in her life. Similarly, another individual shared how over time she has come to “never take her

health for granted” recognizing that she is “fine and very lucky” as compared to her sibling. However, she does note that she takes extra caution around health concerns connected in some way to her sibling’s condition (e.g., her eyes, heart, etc.).

Another participant explained that his early experiences with his ill sibling led to a “medical snobbery” from which he must reliably find the best providers; in doing so has himself “become expert at finding the experts.” He connects this significantly, as noted earlier, to the experience of watching another be cared for. He goes on to explain that over the course of his own life, his attention toward physical concerns has waxed and waned, with an increased vigilance and compliance presently characterizing his approach to health.

Harkening back to an earlier described style, another individual explained her style of continuing to push herself to her physical limit and the toll that has taken on her body. She shared:

“What I learned though—I learned a lesson. I got hurt this past winter because of all the snow. I had to send someone to clear the snow on his house. There was no one who would go. I overdid it and I pulled my rotator cuff. It was really painful. I couldn’t move it...I’m too old for this. I shouldn’t have even done that when I was younger...I think this year I found that I have to take care of myself.”

Another participant described a particular type of self-sufficiency around health matters that has become her style over the years. She describes an overall increased health awareness, seeking out books and/information on how to lead a healthy life. She notes that watching her own sibling struggle has reminded her that “life is precious” and in recognizing that, she attempts to achieve a more balanced approach to her health—exercising caution where she needs too, but also allowing herself to enjoy life as well (e.g., diet, exercise, work). In this more balanced perspective, she shared that she has learned to be “more on her toes” given her sibling’s

condition, but she also understands that she can't, "entirely control every aspect of her health," a sobering, but realistic reality for all individuals.

Role of Other. Generally speaking all of the individuals included in this study shared very low expectations of the significant others in their lives during periods of time when in need physically. A direct question to this effect (see list of questions) was asked of each individual regarding their understanding of the role others take in caring for them physically. Of all the participants who answered the question directly, there was an overwhelming reliance on the self before others when sick or in physical need. One woman shared that she still "does not feel comfortable asking anyone for anything" in the majority of situations, while another explained that she is "always trying to be self-sufficient based on my sibling's experience, based on my own personal experiences." There was, however, for some the learned ability to allow others into that helper role over time. This seemed to be the case for those who had become parents or who had experienced a significant health concern of their own. Again, this is important territory—the role of other—with solid implications for how these individuals may interact with the professionals and others they come into contact with in the health care system.

General Self-Care. The final major thematic category collected from this project's data is general self-care. While the title can certainly be interpreted in a broad way, it was chosen to reflect additional narratives—health and non-health related—that appear to play a significant part in the functioning of the well siblings.

In some capacity, each participant spoke to their style of self-care and how that has changed over the course of their lives. I defined self-care as how one is able to get their own physical or emotional needs met, and in what ways they are able to do so.

One participant shared that after his initial experiences with depression after leaving home, he came to learn how to better manage stress in his life; he also monitored himself for whether something in his life needed to change. Another participant's own struggles with health and her early experiences with her sibling helped her start to learn how to take better care of herself (e.g., taking days off of work when necessary, seeing the doctor, etc.). She noted that it was not an easy process by which she learned to take better care of herself and to protect and prioritize her own health.

Another individual pointed to a personal change in self-care and how she understood this evolution. She explained:

“I’ve been much better with this job, which is a very physical job. I’m much more careful. I’ll actually take days off now. I didn’t use to and it’s just tough on joints and muscles—you have to just let stuff rest.”

This is another instance in which there was a mediating factor helping the individual understand a different way of interacting with her health, which had previously been “to just push through.” This woman described a longer process of learning this type of self-care suggesting that both her own aging and her experience with her sibling may have had a role on this transformation.

Another participant shared that in terms of emotional self-care, she has worked to understand whom in her life she can rely on. She explains,

“Still to this day my mom will call me and be all anxious and I’ll talk her down. I don’t tend to share with her. I have people in my life I do share with. But I think she needs me to be good...”

In a similar vein of self-care, this participant explained how helpful it was for her to start recognizing the limits of what her relationship with her sibling could be. This was not a decision that was emotionally easy, but for this woman it meant a more realistic and bounded understanding about the best way for her and her sister to interact, both now and in the future,

e.g., frequency, place, types of contact. This played an important role not only in care of self and family, but went far in building the sibling relationship in the most positive ways possible.

Another important, and related, self-care concept raised by several of the participants includes that of self-advocacy. Several individuals make the strong case that knowing oneself, and one's needs, is crucial to this experience. One individual raised the topic of self-advocacy in relation to the health care system itself, and the inherent struggle we all face in trusting our health to others. His own early experiences with his sibling appeared to inform and shape his personal ability to do this.

Finally, speaking to this concept of self-advocacy, each individual was asked towards the end of the interview what advice they would provide to a sibling in the same situation they had been in when younger. Several individuals noted they would encourage a well sibling to find their own advocate, have a separate life, and to develop deeper awareness of themselves and their own needs. Conversely, a number of individuals suggested that a well sibling should never be told to "be stronger," ignore their own needs, or feel guilty about their siblings condition. The power and richness of this shared wisdom is noteworthy, and for that reason is presented in full in Appendix F. This type of advice and wisdom may in fact be some of the most vital for informing resources and support for well siblings, given these participants' unique position and perspective on the experience.

Participants also spoke about finding balance in their lives. One woman described this balance in their relationship with her sibling. She noted that while the two of them together have their established routines and enjoy one another's company, having her own independence is critical to her own good self-care. She and others shared the significance of solitude as a powerful tool for recharging oneself before re-entering the home environment.

Many participants also got help from professionals and groups, and these self-care strategies were very important to them. Many normalized, and recognized the ongoing strong emotions that they continue to have, regarding the experience of growing up with their siblings. One woman explained that she “stuffed stuff” as an adolescent and it naturally came out later in her life, and in her own therapeutic experiences. Another woman described that having her “own advocate” in her therapist without any “pushing” was critical to her coming to terms with some of her early experiences. Many of the adults interviewed made note of the importance of cultivating relationships that helped them feel less isolated; they described supports across their lives and what a difference those relationships have made in managing their sibling experiences. One woman noted that going on to have other normative sibling-like experiences with her in-laws, has been a great experience, helping her place her earlier narrative in perspective.

Several participants reflected the lifelong process involved in maintaining a healthy style of self-care, noting that they continue to learn how to manage their emotions as new experiences, and times of life occur with their siblings. One woman admitted that there are tangible limits to her self-care, noting that she had not been on vacation in years, but recognized she is still learning how to balance her life better. In lieu of vacations, this woman had taken up poetry, Thai Chi, and joined a support group to help her manage and process her emotions.

Participants all expressed their openness and willingness to share their experiences with others who grew up as they had; they recognize that such generosity has benefits to them as well. Many of the adults even noted that the experience of partaking in this study was a positive, experience for a similar reason.

Chapter 5: Discussion

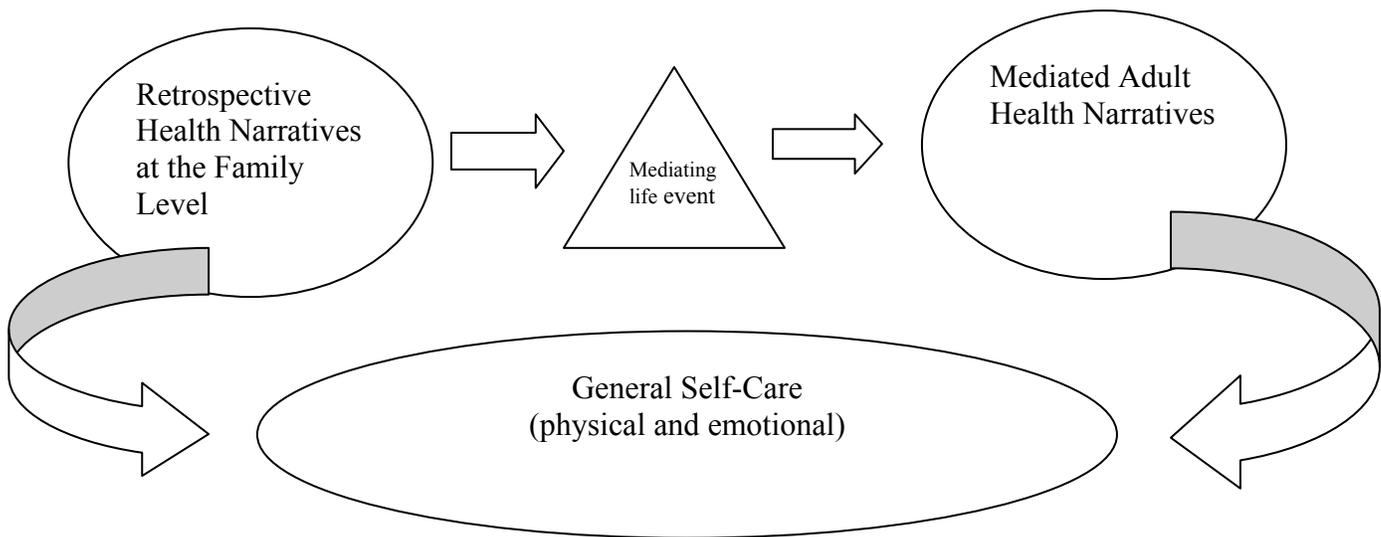
Adult siblings who grew up with a chronically ill brother or sister present a wide range of rich life narratives. Within this dissertation, eight major categorical themes were identified, each with subcategories: (a) at home: finding out, the early relationship, early environment, and family role; (b) retrospective early needs; (c) anxiety; (d) guilt; (e) increased empathy, compassion, and awareness; (f) a different worldview; (g) the sibling turn; (h) health perspective and experiences: retrospective health narratives at the family level, mediated adult health narratives, and general self-care. A compiled chart with detailed examples of these themes can be found in Table 2.0.

Out of the rich data obtained within this project, I will focus this discussion on three ideas most salient for their clinical applicability and potential contribution to the health narrative literature. These ideas include: the concept of mediated adult health narratives, the internalization of the helping role, and differences in worldview. Following this thematic discussion, I will consider unexpected results, including the blurred line between disability and illness in this study, clinical implications, limitations of the study, implications for future research, and my own personal reflections on the experience.

Mediated Adult Health Narratives

In beginning this work, I asked the question: *how do these narratives inform how individuals take care of themselves?* As I analyzed the experiences and narratives shared, I identified a series of ideas, and an overall pattern by which a structure can be provided to answer this question. The idea behind this structure offers that these narratives describe an evolving process, mediated by the conscious awareness and experience of a transformative life event. By means of such events, individuals come to the realization that they need to make more protective

and self-sustaining choices. Out of this mediated process, individuals learn a more general self care. However, for the siblings represented here, there would appear to be an additional layer of complexity brought to the process from their experiences within their family of origin, and the powerful observations and internalized messages found within their childhood homes. The following diagram represents this idea pictorially:



Each of the participants interviewed shared a powerful, life changing experience which aided them in adjusting and re-working the way they initially had approached their health and general self-care. Whether it was a life threatening illness of their own, the experience of becoming a parent, or simply the act of leaving the home environment, there appeared to be a pivotal moment or series of moments by which previously-held health narratives were added to and/or modified, leading toward more balanced, informed narratives.

This process, by which health narratives and general self-care is shaped, may be driven and supported by normative human development, and the natural maturation of individuals that

occurs as they age and incorporate their experiences into their understanding. However, participants also needed to have launched or broken away from their family of origin so that this process might occur. Many of the individuals interviewed discussed at length how important it was for their development to have time away from the family to continue personal development that might otherwise have been impossible within the structure of the family. While separation or launching from a family of origin may be a task for many young adults, the importance of its occurrence for the well siblings of chronically ill children seems particularly salient to the later mediation and learning of self care.

I had not anticipated the consistency of this mediated health narrative. Indeed, based on the literature, and my personal experience, I expected to find a far bleaker picture of the way in which such health narratives come to be formulated and understood from the adult perspective. Yet, what I found was quite the contrary. The mediated process, and shared experiences, point to a hope and positivity that I had not anticipated. Many of the early childhood studies, while generally pointing to positive outcomes for well siblings, they also painted a far more damaging picture in terms of emotional and psychological effects, including resentment about unmet needs, guilt, and anxiety (Alderfer, Labay, and Kazak, 2003; Dew et al., 2008; Wilkins and Woodgate, 2005). While these concepts were certainly identified in the data collected, they are by no means the focus, or predominant take away message.

Helper-Protector Role

Inherent to the position of the well sibling in a family, there were clear expectations and roles that the well child took on, namely, the helper-protector role. This role was assumed for

many early in childhood, as they naturally became protectors and overseers to their brother or sister's welfare in school, and outside the home. Participants explained this role as it played itself out again often in the types of other early adulthood relationships they developed; for many it also connected to their professional choices, placing them again in helper roles. This idea of the helping role and the manner in which it is realized occurs both in subsequent relationships and career choices over the lifespan.

A number of individuals interviewed discussed directly or indirectly the helper roles they later assumed in personal relationships—with spouses, partners, and friends. There was a natural tendency for these siblings to take on such a role, based in their familiarity with it from childhood with their own sibling and in their families in general. One woman noted in retrospect that this helping role was one she needed to be careful of as she went to college and made a new group of friends. She noted that it was often particularly easy to make connections with others, especially if she stood in that nurturing, helping role. However, as she identifies, this role can leave a person without their own needs acknowledged or met within a relationship, especially if presented with another who cannot provide some type of complimentary balance to this style. Being a helper-protector brings with it both connectivity and relation, and the potential for exploitation. On the positive side, this helping quality also aided individuals in the preservation of strong relationships, both with their ill siblings, and others in their lives. It is a quality that while heavily based in early experiences, continues to operate in a variety of ways in the formation and maintenance of important relationships over the lifespan.

Another particular way in which this helper role was realized for many of the individuals interviewed was in their professional development and career choices. Six out of the seven

individuals spoken with identified themselves as working within a helping profession, e.g., psychology, social work, nursing, teaching.

In an effort to understand the qualities of those who choose the helping professions, many researchers have sought to understand the mechanics that determine an individual's choice or career trajectory. One such theorist and researcher is Antonietta DiCaccavo, who in 2002 completed survey-based research that investigated the function of early caretaking roles on the motivation to become a psychologist. Consistent with her original hypothesis, DiCaccavo's research supports the idea that individuals who pursue careers in counseling psychology also identify early caretaking roles in their family of origin. She explains that this is in part due to these individuals' natural capacity for the work, but also their inherent drive toward indirectly understanding and processing their early experiences. The careers and professional work undertaken by the participants interviewed for this project remain consistent with DiCaccavo's work and findings. Participants in this research found themselves in early caretaking roles, and in a variety of ways later came to channel that energy into their professional endeavors.

However, as DiCaccavo suggests the mechanism behind these choices may be twofold—both because these individuals are good at what they do and also because on some level they still seek to understand and resolve the experience. Consequently, there may also be some risk in assuming a career choice that is so closely linked to emotionally charged and personal experiences. At the same time, this insightful group possesses an emotional charge and personal connectivity to the work makes them particularly effective and adept at their commitment to helping others. It may be of even greater necessity, however, for these individuals, given their longstanding connection to the role, to be dedicated and committed to their own emotional and

personal self care (e.g., work-life balance, individual therapy, supportive work environments, etc.).

Worldview

Finally, the siblings interviewed shared a variety of interesting and complex ways, by which they had come to hold particular worldviews based in their experiences with their brothers and sisters. Here, the term worldview was chosen to represent major ways of thinking about the world and others. These perspectives have implications for the manner in which people then go on to interact with the environment, and within relationships. For instance, one individual shared notable increases in personal hyper-vigilance, while another explained broken illusions of safety, all based in part in their experiences with their ill sibling. These worldviews went on to have a noticeable and measurable impact on the functioning of the well sibling. For example, one well sibling shared that in her experience of being a mother, she understood that something could always go wrong, that for her an “illusion of safety” had never been established due to her earlier experiences with her sibling. As a result, this led to increased worry and concern for her child, in ways perhaps greater than a parent who did not grow up with an ill sibling. For parents conditioned by these early experiences there may be a reality known only to them that fuels later views and interactions with the world and others. Had they not experienced growing up with their siblings, their style of parenting may have in fact been less formed by this knowledge of early and persistent illness.

Similarly, hyper-vigilance, and/or a heightened sense that something can go wrong, was also found in relation to personal health awareness for participants. While there is a practicality in approaching one’s health with increased caution and awareness that sometimes bad things can happen, such attitudes can also lead to self-fulfilling prophesy. Indeed, researchers have found

that a more optimistic, positive attitude when heading into a medical procedure, may in fact aid in the healing and recovery process (Chamberlain, Petrie, and Azariah, 1992). Participants in this study may have “known too much” about the medical world. It was, perhaps, harder for them to maintain an optimistic attitude prior to medical procedures, and through their recovery process. This may apply as well to the adult siblings of chronically ill children.

Disability and illness: A distinction without a difference?

Within the medical and psychological literature, there is a clear line drawn between chronic illness--defined as the experience of a disease that is persistent, unremitting and usually without cure (Kleinman, 1988) and disability, typically viewed by professionals as a “complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives” (World Health Organization, 2011). In my recruitment, materials, and intent, I imagined that I would be speaking to the experience of growing up with a chronically ill sibling. However, I soon discovered that, in the real world, the distinctive line between illness and disability is not so obvious. As many of the interviews progressed for this study, it became clear that few if any of the chronically ill siblings were “just” chronically ill.

I have three thoughts about this unintended and interesting development. First, rather than being a confound within the work, I would like to suggest instead that the medical distinctions may be rarer than imagined. The association between illness and disability appears to be close and possibly bi-directional. For example, one sibling suffered with chronic kidney disease, but also had significant learning and developmental concerns; while another sibling was quite ill at birth, but went on to develop significant delays and behavioral deregulation. A chronic illness (like kidney disease) can be disabling, and a disability (like Down Syndrome) can include attendant chronic illness. Treatment for childhood cancer frequently leads to learning disabilities;

some interventions for disabilities include intensive medical treatment. During these interviews, I became increasingly aware of a much more complex interaction and blurring of the distinction between illness and disability.

Second, such categories may also just have less salience to children growing up with a high-need sibling; the important element rather being the relative level of need for attention, and familial worry. Finally, beyond the labels, and out of a variety of sibling illness and disability, come some very similar themes and ideas, both in retrospective experience, and in current health narratives. Qualitative studies, like this one, challenge the traditional categorization of illness and disability as lived by well siblings.

Implications for Clinical Practice

There is no discrediting the fact that we live in an intensely-medicalized world packed with new medical technologies and advantages. However, along with the numerous benefits of these advances, we often sacrifice the value of hearing individual voices and experiences. For adult siblings who have grown up with a chronically ill brother or sister, it seems vital that a doctor, counselor, or other health care professional have some degree of awareness of the themes and personal stories their patients might share with them, such as those identified in this study. It behooves healthcare providers to know this about their patients and provides an important point of reference to inform medical decision-making (e.g., such as medical compliance, hesitancy regarding medical procedures, anxiety and worry, and/or concerns in the patient-professional relationship).

Clinical implications for medical professionals. For doctors and physicians, one manner of implementing the use of these narratives in their work might be to identify key threads in a patient's speech and presentation. For instance, for the patient who repeatedly talks about

pushing themselves, or for an individual who states they're too busy to take care of themselves, this language may provide the professional an ideal starting point for further conversations (e.g., How else do you push yourself? I'm afraid what will happen to you if you don't take care of yourself. Who else in your life can help take care of you?). The language itself used here is less important than the genuine and reflective inquiry aimed toward empathic concern and preventative care.

In addition, it may also be important for professionals to understand the manner in which such siblings have come to have a variety of different worldviews based in early experiences. For instance, for the individual who may come to a medical professional with the stronger internalized question of *will my needs be met?*; it may be helpful for a professional to identify this theme in the experiences and stories shared by a patient/client. Having this awareness, a professional will likely be better able to meet their patient or client's individual needs or at the very least identify what those needs are. Understandably, given the time constraints of our present managed health care system, primary care physicians and specialists may not always have the time for the intricacies these conversations entail for patients. However, this is prime territory for Behavioral Health and Social Work Departments to be involved in - as many already are.

Clinical implications for mental health professionals. For counselors, therapists, and other mental health workers, the primary application of this work may be in the identification and processing of health narratives in the therapeutic work being done. Continuing to connect identified themes to early experiences and ongoing patterns would be a vital way of integrating them into the therapy experience. Within this process, there is also the opportunity to explore narratives that are both helpful and harmful to general well being (e.g., "Life is precious." vs. "Something bad will likely happen."). Identifying the helpful and harmful narratives individually

held may then serve as a foundation to later modification and additions to these narratives.

Therapists can also support their clients to identify and practice sharing these health narratives in order to better advocate for themselves more persuasively with health care providers.

For therapists working with emerging adults, the transition to adulthood for well siblings may require additional attention to separation and individuation. This study reveals that launching from the family is as an important occurrence in the life of well siblings, if not only for the opportunities it fosters, but for the self-care it then helps to inform. For a therapist working with a well sibling, it may be of paramount importance for them to assess, and support, an individual's level of differentiation from their family of origin. For some, it is likely that they will need this psychological distance in order to develop a more mediated set of health narratives or self concepts.

Finally, per the earlier discussion of the well-siblings' enduring commitment to being in a helping role, therapists may also be on the outlook for burnout and/or variants of caregiver fatigue in their clients who identify as well siblings. This burnout or caregiver fatigue might present within personal relationships, and work-related experiences. Moreover, as chronically ill siblings benefit from medical advances and technologies and lead longer, fuller lives, the chances of the well sibling needing to assume formal caregiver, guardianship roles for these siblings continues to increase. For this reason, it may become increasingly common for therapists to treat well siblings in the formal role of guardian or caregiver. Perhaps their presentation for therapy may not be based on their formal role as caretaker; however, this responsibility may be adding to the client's more manifest difficulties. Notably, when individuals present for supportive counseling around the care of elderly parents, therapists have a particular therapeutic understanding regarding what this means in terms of the life span, tasks, and generational roles.

This caregiving burden is increasingly likely to be compounded when well siblings are also asked to care for their unwell siblings as well as aging parents. Should this be the case, a unique constellation of feelings and emotions are likely to arise in the therapeutic work presented, based both in early experiences, and the significant caregiving now required by loved ones.

Limitations of the Study

This qualitative study involved a very small sample, chosen for convenience over diversity or other strict criteria for inclusion. Given this, there is likely a higher chance of overlap among narratives, and commonalities between participants, than there might otherwise have been from a larger sampling pool. It is also possible that some of these participants may be outliers from the norm based on their higher levels of educational attainment, high participation in helping professions, and large network of social supports.

It is also important to note that the individuals included in this study were all, or had all at one time, been involved in their own personal work for concerns, directly or indirectly connected to their experiences with their sibling; whether by means of individual therapy, support groups, or other counseling across the course of their lives. This likely plays a major role in the way these individuals have grown to understand and share their experiences, and may limit generalization to a cohort less immersed in self-reflective practice. However, taken another way, the insightful narratives of these participants, who have had counseling, may suggest its real benefit for this population.

Implications for Future Research

The potential future directions for this research are great, and might entail further exploration of any or all of the themes that emerged from this work. Any one theme identified might give platform to an entire project in and of itself, perhaps including quantitative as well as

qualitative exploration. For example, the idea of sibling filtering of social relationships may be an area fertile for future research and understanding. Other interesting research endeavors might include examining whether there is a gender difference to be found in these health narratives. This sample included only one male participant, so cannot even begin to address this question.

It would also be useful to explore the implications of sibling loss following protracted illness. How do these narratives differ for individuals who have subsequently lost their sibling to the illness or condition? Next, speaking to research that may address the application of these narratives; it would be fascinating to understand whether or not the identification and/or utilization of such narratives in practice may or may not effect outcomes of care in medical or psychological practice, e.g., treatment adherence, improvement of symptoms, etc. Finally, given that all of these participants had completed some type of personal therapeutic work and/or identified some type of mediating event in their lives, it would be important to understand with further research, the difference in formation, if any, in health-illness narratives of well siblings who have not had such therapeutic support.

Finally, it is important to acknowledge that there are a wide array of factors that were not controlled for in this study, which may in fact influence and shape very different findings. Some of these factors include birth order, sibling gender, size of family, socioeconomic status of family, available resources, race, culture, level of educational attainment, and visibility of the illness/disability.

Personal Reflections

Throughout this project, and as I reflect back upon it, I capture my personal reflections into two broad areas. First, I continue to be deeply moved by the stories and experiences shared by the siblings who so generously sat down with me for this dissertation research. While the

subject matter was deeply personal and emotional, there was an honesty, candor, and willingness from which these narratives flowed. As a therapist in training and practice, I am often struck by the sheer volume of personal information and detail I am entrusted with. Within the context of therapy, this disclosure has come to be normalized; it's part of the therapeutic process. I am astonished to experience this same level of disclosure and intimacy in the context of research. In approaching this qualitative project—my first—I was struck with the ease and organic quality by which participants shared with me these difficult and often painful experiences and stories. I remain grateful to these participants who so willingly and generously allowed me a window into their story. I hope sincerely that this dissertation does justice in its reflection of their lived experiences, and potential for clinical application.

Secondly, as I gathered and reflected on the above stories, I revisited my own mother's story of being a well sibling to inform my understanding of the experience. These connections emerged particularly around themes describing the early environment and the helper role. My mother stands apart in my mind as the full embodiment of this helper/protector role, not only in her ongoing nurturing relationships with others, but also in her nursing background. After completing this research, I am even now struck with just how enduringly resonant and powerful these stories are. It was obvious to me from the outset that this was rich territory. I did not expect to learn this much, or to be this moved by exploring stories carrying similar themes and - like my own mother's - each carrying a momentum and energy of its own.

Conclusion

In closing, the sibling experience, already uniquely powerful, is enriched and profoundly transformative when a brother or sister is chronically ill. The narratives of well siblings describe significant worldviews, ideas, and perspectives, informed by these early and ongoing special

sibling relationships. There is a personal and clinical utility in understanding and acknowledging how these narratives came to be, and how they continue to operate. Balancing an identity infused with caring for others, and newer narratives that make room for the importance of self-care are a developmental task for well siblings. Therapists, medical health professionals, and families would each benefit from attention to these evolving stories, informed so profoundly by the complex and enduring connection between an unwell sibling and the other child. In the detailed snapshots captured by these siblings, a rich territory emerges for understanding the individual complexity and layered narratives inherent within this unique and powerful sibling experience.

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Appendix A: Question Set

1. Tell me about yourself and your sibling.
2. Tell me what it was like for you growing up with your sibling day-to-day.
3. How has your own personal health been over the years?
4. What does it mean to you to take care of your health?
5. Have you ever been seriously ill? What was your experience like?
6. When you are not feeling well how do you take care of yourself? Who helps you take care of you? What are your expectations of yourself? What are your expectations of others?
7. When you aren't feeling well yourself, what is it most typically attributable to? (e.g., stress, poor sleep, germs, etc.)
8. When others relate stories of illness or disability to you what do you find yourself saying, thinking, doing?
9. How do you feel your experiences with your sibling's illness have affected your own view/attitude toward personal health/wellbeing?
10. In what, if any, ways are you different because of your experience with your sibling?
11. What advice would you give to a younger child or adolescent sibling of a chronically ill sibling looking back on your experiences? How would you have wanted things to be different? The same? What helped? What did not help?
12. How do you emotionally manage your sibling's illness and your role in your sibling's life past, present, or both?
13. Over the course of your life what has it meant to you to have a sibling who is ill?

Appendix B: Sample Recruitment Poster and Business Card

Seeking Participants for Research

Are you an *adult with a* brother or sister who was chronically ill during childhood?

Would you be willing to discuss what it was like to grow up with your sibling?

If you answered yes to the above questions, please take a card.

Participants will be compensated with a \$15 restaurant gift certificate!

Please contact Danielle Hughes at

Thank you in advance!

If interested in participating in this research,
Please contact:

Danielle A. Hughes
daniellaHughes@gmail.com

Appendix C: Recruitment Email

Dear Student/Employee:

I am currently recruiting participants to partake in a research project examining the health stories and experiences of adults who grew up with a chronically ill brother or sister. Antioch University New England's Human Research Committee has approved this research (Protocol #: XXXXX).

In order to participate, you must be over 18 years of age, have grown up with a chronically ill sibling, and be available to meet with the primary investigator for an approximately 90 minute long interview. Your participation in this research is entirely voluntary and your personal information would be kept completely confidential. Some minor demographic information will be required. You will receive a \$15.00 token of appreciation for your participation in the study. In addition, you will also have access to study results, should you want them.

If you are interested in participating and/or would like to learn more about the study please reply directly to via First Class

Thank you so much in advance for your time and consideration.

Sincerely,

Danielle Hughes

Appendix D: Informed Consent

Principal investigator:
Danielle A. Hughes, M.S.
daniellaHughes@gmail.com
781-413-7658

Advisor:
Martha B. Straus, Ph.D.
mstraus@antioch.edu
603-283-2187

For questions/concerns about your research rights, contact:
Human Research Committee (Institutional Review Board or IRB)
Antioch University New England
IRB protocol #:
40 Avon Street
Keene, NH 03431

What is the study about?

This study involves individual interviews for the purpose of better understanding the experiences of adults who grew up with chronically ill siblings. This study also hopes to better understand the way in which these experiences affected a person's view of health and self-care.

Why are you asking me?

You are one of 6-8 participants included in this study. You are being asked to participate because you have indicated that you have a chronically ill brother or sister with whom you grew up.

What will I be doing if I agree to be in the study?

If you agree to be in the study, you will be asked to complete an approximately 90 minute interview with the primary researcher. You may experience some mild emotional stress discussing any matters that are sensitive or personal in nature. Please keep in mind that you are entitled to stop the interview at any time if you so choose.

If you would like access to the study's results, you may choose to be contacted after the completion of the study. Please indicate below whether you would like to be contacted with the results:

- Yes, I would like the results. No, I'm not interested at this time.

Is there any audio or video recording?

This research project will include audio recording of interviews. This audio recording will be available to be heard and transcribed by the researcher. Other possible listeners include the researcher's dissertation chair and/or committee. The recording and transcription will otherwise be kept secure and confidential in a locked location. The recording will be kept for 24 months and destroyed after that time. Because your voice will be potentially identifiable by anyone who hears the recording, your confidentiality for things you say on the recording cannot be absolutely guaranteed. However, the

researcher will do everything in her power to limit access to the recording as described in this paragraph.

What are the dangers to me?

Every research study carries with it some risk. The risk involved in this study is considered to be minimal. As suggested earlier, you may experience some emotional discomfort or stress in talking about difficult or personal topics. Should you feel the need to continue processing your experiences with someone, please know the primary researcher can provide you with referrals for supports and/or counselors in your local area.

If you have any questions about the research or your rights as a participant please contact Danielle Hughes, M.S. or Martha Straus, Ph.D. You may also contact the IRB at the numbers indicated above with questions as to your research rights.

Are there any benefits for taking part in this research study?

Participation in this study will provide an opportunity to confidentially articulate and share your individual experiences. In addition, your participation will also likely help researchers and others in the field better understand key elements of growing up with a chronically ill sibling and it's longer term impact on health for the well sibling.

Will it cost me anything? Will I get paid for being in the study?

There is no cost to participating in this study. You will receive a \$25.00 gift card as a token of thanks for your participation.

How will you keep my information private?

Every effort will be made to keep your personal information confidential and private. On all paper documentation you are only required to use your first name. All research materials will be maintained in a secured, locked location and will be destroyed after 24 months.

What if I do not want to participate or I want to leave the study?

You have the right to withdraw from participation in this study at any time for any reason. There will be no penalty to you and you will still receive your compensation.

Voluntary Consent by Participant:

By signing below, you indicate that

- This study has been explained to you.
- You have read this document or it has been read to you.
- You have asked any questions you may have had and received adequate answers.
- You may contact this researcher at any time with any questions or concerns using the provided contact information.
- You may contact the Human Research Committee (HRC) supporting this research regarding your rights as a participant.
- You have been given a copy of this consent.

- You agree to participate in this study.

Participant's Signature: _____ Date: _____

Participant's Name: _____ Date: _____

Signature of Person Obtaining Consent: _____

Date: _____

Appendix E: Field Note Template

Name/Initials of Participant:

Age/Gender/Race/Ethnicity:

Date:

Time:

Location:

Individuals present:

Notable words:

Themes:

Behavior/Tone:

Personal Reactions:

Initial Participant Reactions/Debrief:

Table 1.0

Sibling to Sibling Wisdom

What advice would you give to a younger child or adolescent sibling of a chronically ill sibling looking back on your experiences? How would you have wanted things to be different? The same? What helped? What did not help?

What helps	What does not help
Feeling listened to	Being told what to feel
Having a personal advocate, e.g., counselor	Being told to “be stronger”
Encouragement to “put down that role.”	Pressure to be perfect
Meeting other siblings in same role	Implication of moral obligation to change life plans because of ill sibling.
Recognizing you’re doing the best you can	Unnecessary curiosity from outsiders
Having your own life	Ignoring personal health concerns
Being aware of the details of the sibling’s illness	Predicting the future.
Finding a way to manage the anger	Feeling guilty.
Live your life.	
It will get better.	
Go to the doctor. Take care of your own health. Don’t take your health for granted.	
Pursue your dreams anyways.	
Get to know yourself.	
Don’t make yourself the second patient.	
Develop your capacity for empathy.	
Find out what the ill person wants.	
Talk to other people.	
Know your limits.	
Live in the now.	

Table 2.0

Summary of Major Themes and Examples

Theme or Subtheme	Example
At Home	
Find out	<p>“...but being immediately apparent that something was wrong...”</p> <p>“...my parents were not expecting it...”</p>
The early environment	<p>“My mom was very wrapped up in her...”</p> <p>“She/he took up a lot of space...”</p>
The early relationship	<p>“I really wanted to be doing my own thing and he wanted my attention...”</p> <p>“...there’s a blurring of the boundary...who’s him, and who’s me?”</p>
Family role	<p>“I think he was a source of embarrassment...”</p> <p>“...being out of the way...”</p>
Retrospective Early Needs	<p>“I was kind of growing up and not totally getting everything...”</p> <p>Escape</p> <p>Finding one’s own emotional and personal space.</p>
Anxiety	<p>“They need things to be okay...”</p> <p>Baseline worry for the ill sibling.</p> <p>Some personal anxiety re: health and risk</p>
Guilt	<p>“I wonder what more I could have done...I think I should have been able to do something about him...”</p>
Increased Empathy, Compassion, and Awareness	<p>“(I have) a lot of general appreciation for what the human mind can do, and the body—it’s impressive.”</p>

	<p>“...But I would have gladly given him one of my eyes.”</p> <p>The “John-test”/Sibling filter</p>
A Different Worldview	<p>“It just affected our family and the way we see things...”</p> <p>“Illusions of safety” lost.</p> <p>Hyper-vigilance and worry re: parenting</p>
The Sibling Turn	<p>“I sometimes feel as though I am her mother...”</p> <p>“...there’s this underlying current of stress...part worries about my future.”</p>
Health Perspectives and Experiences	
Retrospective health narratives family level	<p>“Keep calm and stay out of his way.”</p> <p>“You went to the hospital to die and you didn’t go to the doctor unless you were deathly ill.”</p> <p>Push</p>
Mediated adults health narratives	<p>“Becoming expert at finding the experts”</p> <p>“I’m a worrier and a checker...”</p> <p>I need to take care of my health, “life is precious.”</p>
General self care	<p>“I’m much more careful with my body...”</p> <p>Creating emotional and personal space for one’s needs</p> <p>Finding personal balance in life</p>