

# Siblings and Illness: A Study of How Children Are Differentially Impacted by the Chronic Illness of a Sibling

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Using data from the National Longitudinal Survey of Youth-Mother and Child samples, I investigated the relationships among child and adolescent depressive symptoms, having a chronically ill sibling, and other child and familial demographic variables. From research on social support and social role transitions, with the stress process as a theoretical model, I hypothesized that children with chronically ill siblings experience more depressive symptoms. Specifically, I looked at age, gender, birth order and family size as potentially reducing the effect size of having a chronically ill sibling. Findings showed that having a chronically ill sibling is associated with demonstrating more depressive symptoms both in the bivariate and multivariate analyses. Although age, gender, birth order and family size do not interact significantly with having a chronically ill sibling in predicting depressive symptoms, they do present interesting findings about childhood depressive symptoms in general. Thus, the results of this study suggest specific and meaningful paths for future research.

“Our life was just focused in so many ways around her health, and around her surgeries and her needs and ultimately, the transplant. And when she passed away in the summer, it was almost like I awoke one day and thought, my gosh, I have a son who is 18 years old, and I’ve almost missed his life.”

- Rebecca Scarpati, on her son Rafe and now-deceased daughter Cyan (Green 2010)

We live in a technological age of progress, an era where medical advances have allowed chronically ill children and youths to live longer and to reside at home in the care of their families rather than in a medical institution (Hollidge 2001). Today’s statistics from the Centers for Disease Control and Prevention report that 17.1 out of every 100,000 children in America will be diagnosed with cancer before the age of 19, and 7.1 million children currently have asthma (2011); the Epilepsy Foundation states that 120,000 children under the age of 18 have their first seizure every year (2011); and the American Heart Association reports that about 150,000 people under the age of 18 have diabetes, and between 1 and 4 out of every 1000 live births suffer from congenital heart defects (2011). The advancements in medical care have allowed more of these children to survive into adulthood, which is a miraculous feat. However, because of these advances, certain new complications for the families of sick children have emerged that were not previously evident. Children, their parents and their siblings now have to contend with chronic

illness as an ongoing life-strain, something that is a consistent feature of their everyday lives as a family.

## *Childhood Chronic Illness and Families*

Hundreds of books have been published on the topic of chronic illness in children, and numerous websites have begun to target childhood chronic illness and its impact on family systems. Some, like [www.bravekids.org](http://www.bravekids.org), are specifically targeted at the sick children themselves. The website is branded as “on-line resource center for children with disabilities or chronic life-threatening illnesses that provides over 11,000 resources, medical information and emotional support for children with special needs such as autism, cancer, cerebral palsy, ADD & many more” (Brave Kids 2011). Other general health websites, including [www.kidshealth.org](http://www.kidshealth.org) and [www.healthlink.org](http://www.healthlink.org), include specific sections on childhood chronic illness. Clearly there is a demand for information about chronic illness and its impact on children; the information itself is both sobering and frightening.

A chronic illness is a life-changing event, not just for the sick child but for the entire family unit. As such, chronic illness poses a number of challenges to family units as a whole, and to the corresponding members within them. In many cases the illness itself becomes the principle organizing factor of family life, posing subsequent problems such as the deference of all other family needs to the child’s illness (Cohen 1999). It becomes the most popular topic of conversation, the most important thing to schedule on the calendar and the most prominent expense. Often this leads to a complete restructuring of family routines and focus (Newton et al 2010), disturbing the overall sense of normalcy for the family unit

(Bluebond-Langer 1996). This change in routine and lack of normalcy can be especially difficult for children to comprehend (Steinberg 2010).

Siblings in particular face challenges associated with the chronic illness of a child within their household. They often “find their lives are constantly interrupted by medical emergencies that trump well kid cares like birthday parties and soccer games” (Green 2010). These challenges include the shift in parental attention toward the sick child (Johnson 1997), the complication of the sibling relationship and rivalry (Fleitas 2000), and potentially even a period of separation from one or both parents and the sick sibling (Jaworski 1999). As a result of these household changes, siblings may face a relationship based more on caregiving than mutual companionship (Taylor et al 2008). In the wake of a parent or sibling’s absence, other children often are forced to step up and fill the vacated household roles.

One book aimed at parents of chronically ill children and their siblings is titled, “What About Me?” The back cover states, “A sick or injured child can disrupt the best of families. Parents are frequently focused on the sick child so that well siblings may feel abandoned. A well child may feel guilty that they are annoyed with all the attention that their sick sibling is receiving. Conflicting emotions can overwhelm the healthiest child” (Bentrim 2010). Clearly, siblings of chronically ill children are heavily impacted by childhood chronic illness. They have to learn to speak frankly about tough issues at a young age, with one 19-year-old saying, “They told me, you know, Cyan is living off of borrowed time, you know. She was supposed to die a week after she was born. And you know, and they kept - well, maybe she’ll live a while” (Green 2010). Illness takes its toll on all who are touched by it, especially on childhood siblings.

However, the literature shows that negative impacts are not inevitable, as siblings tend to react in both positive and negative ways (Bluebond-Langer 1996; Bellan and Kovacs 2006). Fleitas (2006) classifies responses to sibling illness as either reactions of stress (for example, feelings of loneliness, resentment, fear and guilt) or reactions of resilience (feelings of independence and altruism); the fact that both sets of reactions exists means that there is the potential for some siblings to fare better than others. This then raises the question of what determines positive or negative outcomes? What determines which siblings will cope better with chronic illness?

### ***Research Beginnings and Implications***

I first became interested in siblings and chronic illness after volunteering at Kosair Children’s Hospital in Louisville, Kentucky and at the Monroe Carrell Jr. Children’s Hospital at Vanderbilt in Nashville, Tennessee. As a volunteer, I frequently interacted with patients and their siblings and began to detect a pattern. I noticed that the siblings of patients who were being treated for chronic illnesses were markedly different from siblings of those patients being treated for minor illnesses or injuries. The siblings of chronic patients seemed more subdued and quiet, or angry and rambunctious, and were much more comfortable with their surroundings due to the amount of hours logged in various healthcare settings by their siblings over the years. Ultimately, much of the attention in hospitals is focused on the patients themselves. However, the siblings to me were the most interesting and heart-breaking people that I came into contact with during my volunteer experience. These children have had to face so much in their short lives, including frequent exposure to the often unforgiving environment of hospitals and the ever-present possibility that their sibling might die. Many of these children spend more time visiting their brother or sister at the hospital than playing with friends or riding bikes.

After speaking with staff members at the Ronald McDonald House in Nashville, I realized that it would not be feasible to carry out a survey or ethnography of patients and their families for privacy and ethical reasons. Because a chronic illness is in itself a very stressful and difficult time, further questions and observations might be too difficult for many families to cope with. I then turned to data from the National Longitudinal Survey of Youth (NLSY) to study the effect of having a chronically ill brother or sister on a person’s mental health. The NLSY79 is a nationally-representative survey of youth that has been conducted every year since 1979, which specifically asks questions about both chronic illness and mental health, the two variables that I am most interested in.

In studying the impact of chronic illness, I ask one main question: *Do siblings of chronically ill children have poorer mental health outcomes, specifically more depressive symptoms, than those without chronically ill siblings?* Subsequently, I ask: *If so, what individual and familial characteristics*

*predict which children with chronically ill siblings will fare better mentally than others? Specifically, does birth order, gender, age or family size moderate the negative mental health effects of having a chronically ill sibling?*

The answers to these questions remain some of the most important yet elusive answers in medical research today, and require a transdisciplinary approach in answering them involving the fields of ethnography, anthropology, sociology and psychology (Shudy et al 2006). Although my quantitative sociological approach can only provide partial insight, I hope other scholars will further explore and build upon my research through other methods and disciplinary lenses. There are three specific areas of literature that this research question builds upon and engages with, which together inform my hypotheses and provide the conceptual grounding for interpreting my results. These areas are:

- *The stress process* as a model for looking at stressful life events and mental health outcomes;
- *Social role theory* and its implications for siblings of chronically ill children; and
- *Social support* as a potential moderating factor

This thesis addresses a pressing concern in modern society, the need for appropriate interventions for siblings of chronically ill children to facilitate better mental health outcomes. A recent survey of 217 major pediatric healthcare institutions in the U.S. and Canada found that only 48% offered some kind of support for the siblings of their patients, and would require more staff, funding and space to appropriately assess siblings before and after for evaluative purposes (Newton et al 2010). A consensus has been reached that siblings of chronically ill children are at a greater risk for poor mental health outcomes than those without; however, the research has yet to determine what specific familial and individual characteristics help in predicting these mental health outcomes. Drawing upon two broad concepts in sociology, the theory of social roles and the idea of social support, and using the stress process as a theoretical model, I hope to clarify previous contradictions about which type of siblings fare better mentally (Kaminsky and Dewey 2002; Labay and Walco 2004; Houtzager et al 2005; Hamama et al 2008). Doing so will allow healthcare professionals to tailor interventions specifically to siblings who

exhibit the identified high-risk characteristics for poor mental health outcomes, therein promoting better results for the siblings and the families as a whole.

Chapter 2 discusses three bodies of literature. First, I investigate the literature on the stress process to provide a theoretical framework for understanding childhood chronic illness as a stressor for siblings. Second, I investigate the literature on social role theory and how children with chronically ill children are affected by role changes. Third, I investigate the literature on social support and its importance for child development. The purpose of addressing these three bodies of literature is to explain my main hypothesis, that children with siblings who are chronically ill are more likely to have poor mental health outcomes.

Chapter 3 gives information on the data set used in my research. I list the dependent, independent and control variables and their relevant statistics, and also the analytic strategy for how I approached my research question with the data at hand.

Chapter 4 lists the main results, first in terms of bivariate correlations and then in terms of multivariate regression models.

Chapter 5 lays out the main findings by hypothesis. My main hypothesis, that children with chronically ill siblings will show more depressive symptoms, was supported through both the bivariate and multivariate results. However, the secondary hypotheses about age, birth order, gender and family size reducing the effects of having a chronically ill sibling were not supported.

Chapter 6 summarizes the results in relation to the literature review, offering several explanations for why only the main hypothesis was supported. I then touch briefly on the methodological limitations of this study, and what could be altered in future studies. Finally, I offer suggestions for interventions and future research on the topic.

## CHAPTER 2 – LITERATURE REVIEW

### *The Stress Process*

The stress process is a theoretical model that examines the interaction of stressors, moderators, and outcomes within the sociological study of stress (Pearlin et al 1981; Pearlin 1989). Stressors refer to life events or chronic life strains, either social or psychological, that hinder a person's ability to adapt to situations. Some common stressors include losing a job, the death of a close family member or the

diagnosis of a chronic illness. Moderators are extraneous factors that either improve or worsen the relationship between the stressor and the outcome. Outcomes are the variables under investigation which can be influenced by stressors; they can include a myriad of health, mental health and social conditions, ranging from heart problems, to anxiety, to social dilemmas at work. Pearlin (1989) states that to truly understand outcomes, one must capture all possible stressors and moderators. The interaction of the three gives a clearer picture of what causes certain behaviors and outcomes, and what type of interventions could be done to alleviate the effects.

Numerous relationships between life events and strains and potential outcomes have been studied using the stress process as a theoretical model, including spanking and child depressive symptoms (Christie-Mizell et al 2008), caregiving and quality of life (Chronister and Chan 2006), racial discrimination and psychological distress (Ong et al 2009), and school climate and teacher burnout (Grayson and Alvarez 2008). In each study, researchers captured a particular stressor and outcome of interest, then used the stress process model to investigate the relationship between the two and any potential moderating factors. While it is impossible to capture all possible stressors and moderators, there is still much that can be learned about their impact on the outcome of interest.

This study uses the stress process model as a theoretical framework for investigating the impact of pediatric chronic illness on siblings. Chronic illness is the stressor; birth order, gender, age and family size are the moderating factors; and mental health as measured in depressive symptoms is the outcome. The stress process allows us to examine potential moderating factors for their impact on mental health, thus showing us certain individual and familial characteristics that can help predict which siblings of chronically ill children will have better experiences. This information allows professionals to focus on specific siblings with certain characteristics in an effort to alleviate depressive symptoms.

### ***Social Role Theory***

The study of social roles, or characteristic human behaviors, occupies a large space in the field of sociology and has implications for many topics involving social behaviors (Biddle 1986). Five different theories exist within this broad umbrella, including functional role theory (Parsons and Shills

1951); symbolic interactionist role theory (Mead 1934); structural role theory (Mandel 1983); organizational role theory (Gross et al 1958); and cognitive role theory (Moreno 1934). Although each defines social roles slightly differently, they agree in that social roles are generated by expectations learned from experience; that humans are aware of these expectations; and that roles allow us to study human behavior knowing that “human beings behave in ways that are different and predictable depending on their respective social identities and the situation” (Biddle 1958, p.68).

In the context of siblings of chronically ill children, three concepts pertaining to social role theory become extremely important – role transitions, role strain, and role overload. Role transitions are the movements between old and new social roles; an easy role transition is one characterized by a minimal amount of normative change and ample resources to make the transition (Burr 1972). Numerous role changes and transitions are associated with higher levels of normative change overall, which can be difficult for a person to cope with. The assignment of multiple social roles to one person can make for difficult adjustment if the roles are not compatible (Cottrell 1942). Siblings of chronically ill children often face a high number of role transitions, as the household dynamic is changed and the well children must take on new tasks and responsibilities, and sometimes occupy seemingly incompatible roles simultaneously such as caretaker and child.

The result of these role transitions is often role strain and role overload; role strain refers to the stress a person feels when one struggles to comply with one’s given role, and role overload refers to the increase of role strain due to the addition of too many new roles and expectations (Goode 1960; Biddle 1986). Children with chronically ill siblings might face role strain when asked to take over as the primary caregiver for their younger siblings while their parents focus attention on the sick child. They experience strain because they must assume both the role of parent and child at the same time. They might face role overload when asked to take on new chores and duties around the house, while still being expected to fulfill their own household duties as well. Often, role strain and role overload can occur simultaneously within the same subject, when their new social roles are both emotionally difficult to accommodate and too numerous.

Many victims of traumatic and difficult life events face role transitions as they adapt to their new environments; it makes sense then that children whose siblings are facing chronic illness would encounter these same role transitions, and thus role strain and role overload. In the study of siblings of children with cancer, higher levels of role strain and role overload have been correlated with higher anxiety and stress levels (Hamama et al 2008). Hence, I expect siblings of all chronically ill children to have poor mental health outcomes when compared to children without sick siblings due to their high number of role transitions, and subsequent increases in role strain and role overload.

Several studies have addressed the concept of role transitions in siblings of chronically ill children. One study specifically addressed the sibling relationship, but in the context of a single hospitalization and not a chronic illness; however, through intensive interviews of the 59 sets of parents, they did find that siblings who experienced the most life change (comparable to role transitions) experienced more negative reactions to the hospitalization (Knafl 1982). Another study focused on children who donated bone marrow to their chronically ill sibling. This is a clear example of role strain and role overload, and hence the findings that donor siblings showed high levels of anxiety and low levels of self-esteem are not surprising (Packman et al 1997). Thus far, these studies have been helpful in our understanding of role transitions, but have yet to address specifically children whose siblings have chronic illness as a whole.

Two more studies looked at children whose siblings have cancer, which is the most common chronic illness that is studied in children due to its long-term health consequences and potential for morbidity. One study of 29 siblings of children with cancer (some from the same families) used self- and parent-report methods to examine the relationship between empathy and psychological adjustment. They found that older children, who often face more role transitions, displayed an increase in social and academic problems versus younger siblings; however, all siblings displayed some degree of problems (Labay and Walco 2004). A second study of 83 siblings of children with cancer from 53 different families specifically looked at outcomes one month after diagnosis; using tools to assess the children's quality of life and cognitive coping, and a parent interview,

they found that, compared to children without sick siblings, these children with siblings with cancer had lower quality of life and higher levels of negative emotions. They also found that girls and older siblings were more susceptible to these negative outcomes (Houtzager et al 2005).

The previously mentioned research has shown that siblings of chronically ill children do face negative outcomes, potentially due to their role transitions and subsequent role strain and overload. Some studies showed that often it is the older and female siblings who are asked to bear the brunt of these new responsibilities, and consequently suffer poorer mental health outcomes. I will attempt to strengthen these assertions through my research, using a larger sample size of children with various different chronic illnesses and controlling for more variables to add weight to my findings and corroborate these previous findings. In doing so, I will make a stronger case for role strain and role overload as a predictor of mental health outcomes in siblings of chronically ill children.

### ***Social Support***

The stress process model looks at social support as a potential mediating factor in predicting outcomes of stress (Pearlin et al 1981). The concept of social support is defined as relationships that produce feelings of attachment, security, being loved, being part of a group, reassurance of self-worth, availability of informational, emotional, and material help and reliable alliance with others (Weiss 1974). Within the familial relationship, parents tend to be the main source of social support for children (Steinberg 2010). However, siblings also play a role in providing social support; outside of their sometimes fierce rivalries, siblings are an important source of support for one another (Branje et al 2004).

Social support is especially important for people experiencing tragedies and difficult life events. The resources provided through this support allow people to better cope with difficult situations because they are emotionally well-supported, and hence experience less stress (Taylor 1995). People who have higher levels of social support (whether that means *many* close relationships or several *very close* relationships) are better able to cope with stressful life events and strains; the support helps to blunt the effects of stress (Ootim 2001). In the context of this research question, social support is helping to mediate

the effects of the stress caused by having a chronically ill sibling.

Several studies have found that the presence of social support is clearly a predictor of better mental health outcomes – siblings who experienced high levels of social support fared better than those who did not, reporting less anxiety, depression and behavior problems. One such study compared 47 children with siblings who had cancer and had been referred to a professional for behavioral problems to 25 siblings that had not been referred for problems; after a child-completed test of depression, anxiety, behavior and emotional social support, and a parental-response as well, they found that siblings with higher levels of social support had much lower levels of depression and anxiety, and fewer behavioral problems (Barrera et al 2004). Interestingly, they found more reports of problems in girls than boys. Another study looked specifically at the social support given to each other by healthy siblings, as opposed to all family members, in 285 Dutch families. The results showed that siblings who supplied each other with lower levels of social support had more externalizing behavior problems (Branje et al 2004).

The problem comes when trying to determine which groups of children experience higher levels of social support, as this should allow us to predict which groups of children are better able to cope with the illness of a sibling. Several studies of well children have found that girls both provide more and receive more social support than boys (Flaherty and Richman 1989; Unruh et al 1999). However this seems to contradict other previously-mentioned findings that female siblings of chronically ill children report more overall poor mental health outcomes (Barrera et al 2004; Houtzager et al 2005). Along these same lines, some research has found that a larger family size facilitates better outcomes due to more social support provided by siblings (Kaminsky and Dewey 2002), while other studies report the opposite (Labay and Walco 2004; Hamama et al 2008). One explanation for this is that role strain and role overload seem to predict a different outcome for siblings than does social support; in a large family, children will experience greater social support but also have more duties and tasks to take on because a larger household is more difficult to run. Hence, it is important to look at the amount of role strain and role overload versus the amount of social support for each specific child to accurately predict their mental health outcomes.

I hope to clarify these contradictions through my research by controlling specifically for socioeconomic factors. For example, in larger, lower SES families, the effects of social support and role strain might be mitigated by the additional burden of scarce resources, which are spread thin across all children in the family. SES might explain a great deal of variance in mental health outcomes, obscuring or interacting with the effects of role strain and social support. In addition to examining the effects of SES, I also hope to strengthen the assertion that social support is an important factor predicting mental health outcomes for children with chronically ill siblings by using a large sample with a variety of important controls and trying to distinguish what types of children are likely to have these outcomes. Finally, I narrow my focus explicitly on depressive symptoms as my area of interest is in mental health outcomes.

### ***Hypotheses***

Drawing upon the ideas of social role theory and social support, and using the stress process model as a guide, I propose the following main hypothesis:

- *(1) Siblings of chronically ill children will have more depressive symptoms than children without chronically ill siblings due to changing social roles and diminished social support*

The literature also leads to several other subsequent hypotheses about the moderating and reducing effects of several characteristics. These hypotheses are:

- *(2) Due to their increased likelihood of experiencing role strain and role overload, older siblings who are expected to take on new duties and responsibilities will experience more depressive symptoms. Thus age (2.a) and birth order (2.b) will moderate the effect size of having a chronically ill sibling*
- *(3) Due to their increased likelihood of experiencing role strain and role overload, female siblings who are expected to take on new duties and responsibilities will experience more depressive symptoms. Thus gender will moderate the effect size of having a chronically ill sibling*
- *(4) Due to their likelihood of experiencing more sibling social support, siblings from larger families will experience fewer depressive symptoms. Thus family size will*

*moderate the effect size of having a chronically ill sibling*

## CHAPTER 3 - METHOD

### *Data Set*

My research design is based on secondary analysis of survey data, from both the original National Longitudinal Survey of Youth (NLSY79) and the National Longitudinal Survey of Youth Child (NLSY79 Child) sample. The data from these surveys were collected under the sponsorship of the U.S. Departments of Labor and Defense (Center for Human Resource Research 2002). Although the original NLSY79 data overrepresented racial minorities and economically disadvantaged white youth, survey weights can be included in the data for representativeness. The original NLSY79 surveyed young men and women every year beginning in 1979, with their initial ages ranging from 14 to 21. They asked questions about respondents' education, health, family life and assets and income. Beginning in 1986, a new cohort was created from the children of the female NLSY79 respondents called the NLSY79 Child sample. An expanded form of mother-child data collection was undertaken biennially since 1986 through 2008, including interviews with both the mothers and their children. Questions measuring cognitive ability, temperament, motor and social development, behavior problems, and self-competence of the children as well as the quality of their home environment were all asked.

For the relevant data used from this survey, there is an N of 1098 children ranging in age from 4 to 14 years old. Because of the inclusion of children from the same family and similar characteristics found among siblings, I ran a proc surveyreg in SAS to account for the clustering of children into familial groups. The results from this procedure were so similar to the results from ordinary least squares regression that I decided to use the more manageable and easier to work with results from ordinary least squares regression. However, to take a conservative approach in an effort to mitigate some of the effects of respondents being from the same family, I included the variables of birth order, number of children in the household and whether or not the child lives with their biological father to account for the covariance found among siblings.

### *Measures*

### *Dependent Variable*

A measure of childhood and adolescent depressive symptoms was the dependent variable for this research project. The measure is a 5-item subscale of the Behavior Problems Index, a 28-item test used to assess childhood behavior problems (BPI; Peterson & Zill 1986). Using maternal reports, the five items from the BPI used to measure depressive symptoms in this study asked whether the child (a) "experiences sudden changes in mood/feelings," (b) "feels/complains that no one loves him/her"; (c) "is too fearful or anxious"; (d) "feels inferior or worthless"; or (e) "is unhappy, sad, or depressed"; each item ranges from 1 (not true) to 3 (often true). They were then summed to create an overall score for depressive symptoms, with a mean of 6.45 and high internal reliability ( $\alpha=0.72$ ).

### *Independent Variables*

My main independent variable is whether the child has a chronically ill sibling. This measure is taken from maternal reports in the survey on whether each of their children has a health condition or limitation; responses were coded as "learning disability," "minimal brain dysfunction, minimal cerebral dysfunction, attention deficit disorder," "hyperkinesis, hyperactivity," "asthma," "respiratory disorder or sinus infection," "speech impairment," "serious hearing difficulty or deafness," "serious difficulty in seeing or blindness," "serious emotional disturbance," "allergic condition(s)," "orthopedic handicap," "mental retardation," "heart trouble," "chronic nervous disorder," "chronic ear problems or infections," "blood disorder or immune deficiency (e.g. sickle cell anemia)," "epilepsy/seizures" or "health condition not listed". If the mother responded "yes" to any of the following, all of that child's siblings were then coded as having a chronically ill sibling, with 1 being yes. 11.7% of the sample had a chronically ill sibling.

The four other independent variables specific to the hypotheses are age, gender, family size and birth order. Age ranged from 4 to 14 years old, with a mean of 11.00 years. Gender was measured through the variable "female" and was coded as 1 for females. 47.8% of the sample was female. Family size was asked of the mothers as the "number of dependent children in the household", and was listed as the total number of children in the household including the subject (mean=2.41). Birth order was taken from maternal reports, and was reported as the number that

represents the child's place in the order of their siblings; it ranged from 1 to 11 (mean=2.63).

### *Control Variables*

The child's race, living in an urban area, living with the biological father, mother's marital status, mother's college education and household income were all controlled for, as other studies of mental health have indicated that these measures are important for the overall outcome. Race was split into two binary variables coded as African-American (1=yes) and Latino (1=yes). Whites were used as the comparison group. 23.3% of the sample was African-American and 21.0% of the sample was Latino. Living in an urban area was taken from maternal reports of their current living situation, and was coded as a binary variable; 74.8% of the sample lived in an urban area. Whether or not the child lives with their biological father was asked of their mother, and was coded as 1 for yes; 57.2% of the sample lived with their biological father. Mother's marital status was taken from maternal reports, and was coded as 1 for married and 0 for everything else; 68.3% of the sample had a mother who was currently married. Mother's college education was asked of the mothers, and was coded as 1 for having completed college or a higher level degree; 37.8% of the sample had a mother who had earned a college degree or higher.

The final control variable, household income, was a special case. Because income is notoriously difficult to work with and often skewed, certain measures were taken when including it in the analysis. The original variable (mothers were asked what their "total net family income for 2008" was) ranged from \$0 to \$454,737, with a mean of \$95,458 and a standard deviation of \$95,357. But because the researchers capped income at \$454,737 (representative of the top 2% of households in America), our data is skewed. The median is \$71,600; one third of the subjects made between \$0 and \$47,700, one third made between \$47,700 and \$100,000, and the top third made over \$100,000. Thus, to account for this skewed distribution, I took the natural log of income to correct for skewness (mean=10.96).

### *Analytic Strategies*

I estimated a cross-sectional analysis using ordinary least squares regression (excluding missing data) for my variables in 2008 to test my main

hypothesis that having a chronically ill sibling will be related to having more depressive symptoms. The analysis included six models. The first model included the child demographic variables in an effort to determine their effects on my dependent variable (depressive symptoms) before adding my main independent variable. My second model added the main independent variable, that the child has a chronically ill sibling. This allowed me to assess the impact of the main independent variable before adding family and mother characteristics. The third model added family variables (birth order, number of children in household, and lives with biological father). The fourth, fifth, and sixth models subsequently added characteristics of the mother (marital status, attaining a college degree or more, and household income) to account for the mother's impact on a child's depressive symptoms. To test my secondary hypotheses regarding the specific impacts of age, birth order, gender and family size on depressive symptoms for children with chronically ill siblings, I estimated interactions (i.e., Having a Chronically Ill Sibling X Age).

## CHAPTER 4 - RESULTS

### *Bivariate Results*

Table 1 shows the bivariate correlations between all of the variables used in this study. Here I am testing the main hypothesis that siblings of chronically ill children will have more depressive symptoms than children without chronically ill siblings due to changing social roles and diminished social support. Of particular interest are the correlations between the dependent variable, depressive symptoms (labeled "child depress"), and all other variables, and between the main independent variable, having a chronically ill sibling (labeled "child has sick sibling"), and all other variables.

The dependent variable – depressive symptoms – is significantly correlated with age ( $r=.156$ ,  $p<.001$ ), having a sick sibling ( $r=.206$ ,  $p<.001$ ), mother's marital status ( $r= -.184$ ,  $p<.001$ ), and household income ( $r= -.135$ ,  $p<.001$ ). Depressive symptoms is also moderately correlated with the child living with their biological father ( $r=.067$ ,  $p<.05$ ) and weakly correlated with mother's level of college education completed ( $r= -.055$ ,  $p<.10$ ). All other bivariate correlations involving depressive symptoms are not significant.



Having a chronically ill sibling is significantly correlated with, again, depressive symptoms ( $r=.206$ ,  $p<.001$ ), is moderately correlated with gender ( $r= -.077$ ,  $p<.05$ ) and household income ( $r= -.072$ ,  $p<.05$ ), and is weakly correlated with living in an urban area ( $r= -.055$ ,  $p<.10$ ). All other bivariate correlations involving having a chronically ill sibling are not significant.

Table 1. Descriptive Statistics and Correlations: the National Longitudinal Survey of Youth (N=1098)

	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Child Depress													
2. Female (Yes=1)	.046												
3. Age	.156***	-.012											
4. Black (Yes=1)	-.024	.011	-.005										
5. Latino (Yes=1)	-.042	.034	-.049	-.285***									
6. Urban (Yes=1)	-.019	-.023	-.016	.107***	.068†								
7. Child Has Sick Sibling (Yes=1)	.206***	-.077**	.049	-.014	-.036	-.055†							
8. Birth Order	.026	.064†	-.120***	.136***	.092**	.040†	.013						
9. Number of Children in Household	-.023	.031	.047	.048	-.036	.049	-.028	.563***					
10. Lives with Biological Father (Yes=1)	.067†	.003	.691***	-.076**	-.068	.006	.024	-.139***	-.031				
11. Mother is Married (Yes=1)	-.184***	.013	-.059†	-.217***	-.042	-.098**	-.031	-.190***	.091**	.123**			
12. Mother Completed College or More (Yes=1)	-.055†	-.066†	.008	-.128***	-.213***	-.006	-.016	-.207***	.083**	.109***	.293***		
13. Household Income (logged)	-.135***	.013	-.007	-.197***	-.114***	-.031	-.072**	-.260***	-.002	.124**	.496***	.374**	
Mean	6.445	478	11.002	233	210	.748	.117	2.629	2.410	.572	.683	.378	10.957
Standard Deviation	1.685	.500	2.489	.423	.408	.435	.322	1.524	1.214	.495	.466	.485	1.395

† $p < .10$  \* $p < .05$  \*\* $p < .01$  \*\*\* $p < .001$

Table 2. Childhood Depressive Symptoms regressed on selected National Longitudinal Survey of Youth - Mother and Child Sample (N=1098)

	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6
<b>Child Demographic Variables</b>						
Female (Yes=1)	.170†	.222†	.217†	.230†	.227†	.233†
	(.101)	(.099)	(.099)	(.098)	(.098)	(.098)
Age	.105	.099	.140	.108	.107	.105
	(.020)	(.020)	(.028)	(.028)	(.028)	(.028)
Black (Yes=1)	-.145	-.131	-.206	-.334	-.341	-.365
	(.126)	(.123)	(.126)	(.126)	(.127)	(.127)
Latino (Yes=1)	-.191	-.164	-.234†	-.269	-.282	-.300
	(.130)	(.127)	(.130)	(.128)	(.131)	(.131)
Urban (Yes=1)	-.036	.005	.020	-.040	-.038	-.032
	(.118)	(.115)	(.115)	(.114)	(.114)	(.114)
<b>Variable of Interest</b>						
Child Has Sick Sibling (Yes=1)		†1.065***	†1.043***	†1.024***	†1.023***	†1.004***
		(.155)	(.154)	(.152)	(.152)	(.152)
<b>Family Variables</b>						
Birth Order of Child			.084†	.021	.017	.007
			(.041)	(.042)	(.042)	(.043)
Number of Children in Household			-.076	-.007	-.003	-.000
			(.050)	(.050)	(.051)	(.051)
Lives With Biological Father (Yes=1)			-.272†	-.113	-.109	-.097
			(.140)	(.140)	(.141)	(.141)
<b>Mother's Characteristics</b>						
Mother is Married (Yes=1)			-.666***	-.656***	-.568***	
			(.115)	(.117)	(.127)	
Mother has College Degree or More (Yes=1)				-.052	-.006	
				(.112)	(.114)	
Household Income (Logged)					-.079†	
					(.043)	
<b>R-Squares</b>	.029	.070	.077	.105	.105	.108

† $p < .10$  \* $p < .05$  \*\* $p < .01$  \*\*\* $p < .001$

Note: Unstandardized coefficients with a standard error are shown in the parentheses.

## Multivariate Results

Table 2, Models 1-6, shows cross-sectional models for child and adolescent depressive symptoms. Model 1 shows a baseline model, which included basic child demographic variables. In this model, both

age and gender were significantly related to depressive symptoms. Both age ( $b=.105$ ,  $se=.020$ ,  $p<.001$ ) and being female ( $b=.170$ ,  $se=.101$ ,  $p<.10$ ) were positively related to depressive symptoms, hence older and female children showed more depressive symptoms.

In Table 2, Model 2, the main independent variable, having a chronically ill sibling, was added to the model. Having a chronically ill sibling was positively related to depressive symptoms ( $b=1.065$ ,  $se=.155$ ,  $p<.001$ ). Meanwhile, age remained significantly related to depressive symptoms ( $b=.099$ ,  $se=.020$ ,  $p<.001$ ) and the size of the effect of gender increased by 30% ( $b=.222$ ,  $se=.099$ ,  $p<.05$ ); both relationships (for age and for being female) remained positive. This model also showed the greatest increase in  $R^2$  across all models, going from .029 to .070 with the addition of the chronically ill sibling variable.

In Table 2, Model 3, family characteristics are added to the model to account for the impact of family context on a child's depressive symptoms. Having a chronically ill sibling remained positively related to depressive symptoms ( $b=1.043$ ,  $se=.154$ ,  $p<.001$ ). Both birth order ( $b=.084$ ,  $se=.041$ ,  $p<.05$ ) and living with one's biological father ( $b= -.272$ ,  $se=.140$ ,  $p<.10$ ) are also significantly related to depressive symptoms, birth order in a positive manner and living with one's biological father in a negative manner. Hence children who are later in the birth order showed more depressive symptoms. Age ( $b=.140$ ,  $se=.028$ ,  $p<.001$ ) and gender ( $b=.217$ ,  $se=.099$ ,  $p<.05$ ) both remained significantly related to depressive symptoms, and being Latino became negatively related ( $b= -.234$ ,  $se=.130$ ,  $p<.10$ ).

In Table 2, Model 4, mother's marital status is added to the model. Having a chronically ill sibling remained positively related to depressive symptoms ( $b=1.024$ ,  $se=.152$ ,  $p<.001$ ). Having a mother who is married is also negatively related to depressive symptoms ( $b= -.666$ ,  $se=.115$ ,  $p<.001$ ). Interestingly, both birth order and living with one's biological father are no longer significantly related to depressive symptoms once mother's marital status is accounted for. However, age ( $b=.108$ ,  $se=.028$ ,  $p<.001$ ) and gender ( $b=.230$ ,  $se=.098$ ,  $p<.05$ ) both remained significantly related to depressive symptoms, and the size of the effect of being Latino became greater ( $b= -.269$ ,  $se=.128$ ,  $p<.05$ ). Being African-American also became negatively related to depressive symptoms ( $b= -.334$ ,  $se=.126$ ,  $p<.01$ ).

In Table 2, Model 5, mother's education is added to the model. All variables remained significant at the same previous levels from Model 4, and whether or not the mother obtained a college degree was insignificant.

In Table 2, Model 6, household income was added as the final variable in the model. It is significantly related to depressive symptoms in a negative way ( $b = -.079$ ,  $se = .043$ ,  $p < .10$ ). All other variables remained significant at the same previous levels from Models 4 and 5.

In addition to the results shown in Table 2, I also estimated interactions between age, gender, birth order, and family size, and having a chronically ill sibling, to test my secondary hypotheses (2, 3 and 4). The results were not significant for any of the four combinations and as such were not included in this discussion. These analyses are available upon request.

## CHAPTER 5 - DISCUSSION

### *Main Hypothesis*

Using the Stress Process Model as a theoretical framework, my main hypothesis (1) based on the literature review was that siblings of chronically ill children will have more depressive symptoms than children without chronically ill siblings. These siblings experience changing social roles and diminished social support, both of which the research shows to be correlated with higher levels of depression and poorer mental health (Taylor et al 2008; Newton et al 2010). At the most basic bivariate level, we can see that the correlation between a child having depressive symptoms and having a sick sibling is higher than the correlation between having depressive symptoms and any other variable in the model, which lends support to my hypothesis. Clearly having a chronically ill sibling is associated with having more depressive symptoms for the children in my analysis.

Moving into the bivariate results, we see that this hypothesis is even further supported. Looking across the six models solely at the  $R^2$  value alone, the addition of having a chronically ill sibling into the model made the greatest impact by far.  $R^2$  increased by over 140% moving from Model 1 to Model 2, while the largest increase for any other addition of variable(s) was 36% when mother's marital status was added in Model 4. No other variable accounted for more of the variance in depressive symptoms than having a chronically ill sibling. Hence, not only is

having a chronically ill sibling strongly related to having depressive symptoms, but it is arguably the most important variable that is included in this model.

While the beta weight of having a chronically ill sibling did decrease slightly across the models as more variables were accounted for, it remained significant at the  $p < .001$  level throughout the analyses. The only other variables that remained significant throughout at this level were age and mother's marital status. Ultimately we can say that having a chronically ill sibling is a clear stressor that is associated with childhood and adolescent depressive symptoms, fitting with my stress process analysis of the impact of having a chronically ill sibling on childhood depressive symptoms. This corroborates the findings of previous studies on the poor health effects of having a chronically ill sibling, (Labay and Walco 2004; Houtzager et al 2005; Hamama et al 2008). Since my study uses a larger sample size and includes a greater variety of chronic illnesses, I have helped to further strengthen the assertion that siblings of children with chronic illnesses face poorer mental health outcomes.

### *Secondary Hypotheses*

My secondary hypotheses (2, 3 and 4) were that age, birth order, gender and family size would moderate the effect size of having a chronically ill sibling on depressive symptoms. To test these hypotheses, I ran analyses of the interactions between each of these four variables and the variable for having a chronically ill sibling. When these interactions were added into the regression model, none of the four interactions were significant. Hence, I did not find support for any of my secondary hypotheses in this analysis. On some level, this is not surprising to me. Previous researchers have struggled to discover which siblings fare better than others because of the sometimes conflicting relationship of changing social roles and social support. Larger families with more members may be able to provide more emotional support to children, but they also have more social roles that can be affected and altered after the diagnosis of a child (Kaminsky and Dewey 2002; Labay and Walco 2004; Hamama et al 2008). Similarly, older children and girls both receive and give more social support, but are more likely to be affected by social role changes (Flaherty and Richman 1989; Houtzager et al 2005). Hence, these two aspects that are critical when determining mental health

outcomes for children with chronically ill siblings may in fact be cancelling each other out in most cases, making it difficult to predict which siblings will be most affected by a chronic illness.

However, there were some interesting findings about these four variables individually, not in the context of an interaction. Both child's age and gender were among the initial demographic variables added to the model. At the bivariate level, age was significantly correlated with depressive symptoms ( $r=.156$ ,  $p<.001$ ). It was a significant variable in the multivariate analyses as well, remaining significant at the .001 level across all six models. The positive relationship shows that older children in general show more depressive symptoms than younger children, something that is important for parents to be aware of when raising children. As both age and having a sick sibling are very strong predictors, I suspect that, in spite of a lack of an interaction effect in my results, the two are likely related. The stresses of growing older and entering adolescence are likely impacted by having a sick sibling. But, the effect may not be the same for all older children with depressive symptoms (hence no significant interaction effect in my study). Future research, both qualitative and quantitative, needs to look more carefully at how older children, already predisposed to depression, are influenced by the further stress and strain of a sick sibling.

Gender was also a significant variable across all of the models, with a positive relationship between being female and having depressive symptoms. Once again, although this may not directly interact with having a chronically ill sibling, it is still important for parents to know that being female is related to having more depressive symptoms when they are raising their daughters. And, like age, girls who are already experiencing depressive symptoms may experience the stress of a sick sibling differently than girls or boys who are not depressed. Again, future research should examine how different types of depressed girls deal with the strains of a chronically ill sibling differently.

Neither birth order nor family size were significant predictors of depressive symptoms across all of the models. Birth order was initially significant, but once mother's marital status was added to the model it was no longer a significant predictor of depressive symptoms. Family size was never a significant predictor of depressive symptoms. Both of these findings are relevant for parents to be aware of,

in that they should provide equal attention to preventing depressive symptoms in their children regardless of birth order or the number of children that they have living in their household.

Hypothesis 2, that older siblings will experience more depressive symptoms due to role strain and role overload and thus that age and birth order will moderate the effect size of having a chronically ill sibling, was not supported. However, findings did show that older children in general show more depressive symptoms. One possible explanation for this finding is that all older children may experience role strain and role overload simply by growing up, and thus show more signs of depressive symptoms. It is also possible that there is a three-way interaction between age, birth order, and having a chronically ill sibling. That is, birth order might moderate the impact of having a chronically ill sibling, but only for older siblings (e.g. only older, first born children are asked to assume new and additional roles). With a larger sample, it might be possible to test for more complicated interactions.

Hypothesis 3, that female siblings will experience more depressive symptoms due to role strain and role overload and thus that gender will moderate the effect size of having a chronically ill sibling, was not supported. A possible explanation is that female children in general face role transitions and role overload as they are expected to take on new duties and responsibilities more so than male children – whether or not they have sick siblings. The addition of a sick sibling should add extra strain on girls, but it is possible that they are better prepared, given their experiences, to deal with the burden of additional roles and family obligations.

Hypothesis 4, that siblings from larger families will experience fewer depressive symptoms and thus that number of children in the family will reduce the effect size of having a chronically ill sibling, was not supported. The explanation for this hypothesis was that children from larger families will experience more social support, and thus will be protected from depressive symptoms. No significant relationship was found between family size and depressive symptoms in any of the multivariate models or in the bivariate results. This may suggest that children from all family sizes receive equal social support, with smaller families either seeking support from outside sources or more consciously relying on one another to get through the trials and tribulations of family illness.

Thus no conclusion can be drawn about social support for children with chronically ill siblings.

### ***Other Findings***

One other interesting finding emerged through my analyses. Three other variables, race, mother's marital status and household income, were significant across many of the models and in the bivariate results as well. Although I did not include any of these three variables in my hypotheses, I would be interested to see the results of interactions between any of these three variables and having a chronically ill sibling in terms of predicting depressive symptoms. While race is a demographic variable that cannot be changed or controlled, both mother's marital status and household income are things that could be changed, or better compensated for, to help ensure better outcomes for children with chronically ill siblings.

## **CHAPTER 6 - CONCLUSION**

### ***Overview***

The central question of this research study is whether or not siblings of children with chronic illness face higher levels of depressive symptoms than those children who do not have chronically ill siblings. Because so much research attention has been focused on the chronically ill children themselves, often siblings become left-behind and forgotten by both researchers and parents alike. However, the chronic illness of a child affects the family unit as a whole, in ways that are both complex and difficult to ascertain.

In the past two chapters I have presented the main findings of my research: having a chronically ill sibling is in fact correlated with having more depressive symptoms. This meshes well with previous research that found that children who have a chronically ill sibling face more role transitions, leading to role strain and role overload, and receive less emotional support (Bluebond-Langer 1996; Bellan and Kovacs 2006; Taylor et al 2008). Hence, it is no surprise that children with chronically ill siblings also display more depressive symptoms. They are faced with a tumultuous life event, one that changes every aspect of their childhood and upbringing. My findings only further confirm the research that says that special attention needs to be paid not only to the chronically ill child, but to their well siblings also.

When I first approached my research with the stress process model, I was hoping to find variables that would mediate or reduce the effect of having a

chronically ill sibling on childhood depressive symptoms. Although I was not able to determine a variable that reduces the effect of having a chronically ill sibling on depressive symptoms, I did discover some interesting findings about childhood depressive symptoms in general. In my sample, older children and girls showed more depressive symptoms than younger children and boys. These are important findings for both parents and professionals to keep in mind when dealing with siblings of chronically ill sibling. Because older children and girls are more prone to depression in general, special attention should be paid to these children in the context of a chronic illness.

Chronic illness is something that more children than ever have to cope with, due in part to the increases in medical technology that lead to children surviving illnesses that in the past would have proven fatal (Hollidge 2001). No longer a simple life event, chronic illness presents itself as a chronic life strain on all families that are affected by it. Although the sick child is obviously greatly impacted, their siblings are affected as well. This research will help both parents and professionals alike to see the importance of studying the impact of chronic illness on siblings, and on other family members as well.

### ***Methodological Limitations***

My research has a few key advantages over previous research on siblings of children with chronic illnesses. First, I have a larger sample size than many prior studies. I also account for many more types of illness, ranging from cancer to less fatal but still threatening illnesses like autism. However, there are limits to my study that can (and should) be improved upon through further research. Because I did not control for length of time since diagnosis, I was unable to compare siblings of children who were recently diagnosed with a chronic illness to those siblings who have been coping with illness for years already. I also did not control for severity of illness, and possibility of fatality, both of which might impact the level of depressive symptoms displayed by siblings.

There were other important variables that I was unable to measure as well, which have been shown to directly impact childhood depression and depressive symptoms. These include mother's mental health and occurrence of depression, as well as other life strains and stressful life events that a child may be

facing. Finally, I had no measure of sibling closeness in the model; it is to be assumed that children who are closer to their sibling who is ill will probably demonstrate more depressive symptoms and signs of poor mental health.

While the BPI is a reliable measure of depressive symptoms, it is still only one measure of overall mental health. Further research into childhood depressive symptoms using more measures, as well as other measures of overall mental health, would only strengthen my findings that having a chronically ill sibling is bad for a child's mental health. Such information would make it possible to apply these findings not only to depressive symptoms, but to a child's overall mental health in general.

### ***Implications for Interventions and Further Research***

Overall, my findings that having a chronically ill sibling predicts higher levels of depressive symptoms in children fit with the research on chronic illness as a stressful life event. They provide numerous important implications for both parents and professionals to consider. The field of *child life* is growing, and is focused on healing children holistically and treating the whole person rather than just treating the illness. One component of the role of child life specialists in hospitals is to work with patients' families and siblings. The findings from this study only further support the movement towards treating not only pediatric patients, but their families as well. Because families are such crucial support structures, it is important to ensure that all members are functioning in a positive manner. By tailoring interventions to suit both patients and their siblings, child life specialists can make sure that each family unit is effectively treated as a whole.

These findings are important for parents to note as well. Often, it is easy for parents to become consumed by treating their sick child and forget about the needs of their other children in the process. However, well children may need their parents' love and support as much if not more than their chronically ill counterparts. Parents need to be aware that a chronic illness impacts all family members; by providing special attention to their well children as well as to their sick child, they can help counteract the detrimental effects that illness has on their children's mental health.

Further research is needed still to determine which children, if any, are most impacted by the

chronic illness of a sibling. By determining certain risk factors, as well as potential moderating factors, on the outcomes of siblings of chronically ill children, parents and professionals can learn to allocate their time most efficiently to the children who need them most. Not all children are equally impacted by having a chronically ill sibling. In fact, research shows that there can be both good and bad outcomes for these children (Bluebond-Langer 1996; Bellan and Kovacs 2006; Fleitas 2006). However, it is important for researchers to be able to predict which children will be adversely affected versus which children may be better prepared to cope or thrive under the stresses of a family illness

Pediatric chronic illness can be a terrible thing for families to deal with, and its impact stretches far past the sick child only. Chronic illness changes relationships between parents, between parents and their children, and between siblings themselves. It is a major event for families to cope with, and is potentially harmful for everyone involved. My research findings reported here fit into a larger body of research that shows the negative impacts of chronic illness on siblings. While more research is needed to determine which siblings are most affected by chronic illness, parents and professionals should be aware of the basic findings: children who have chronically ill siblings need special care and attention to have the best mental health outcomes possible. No longer can we forget about the siblings when a child gets sick – they need our love and attention more than ever.

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