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The Impact of Childhood Chronic Illness on the Family: Psychosocial Adjustment of Siblings

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The Impact of Childhood Chronic Illness on the Family: Psychosocial Adjustment of Siblings

By

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MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
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Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

Chronic illness is a multifaceted concept that significantly impacts millions of families and siblings each year. The biopsychosocial model shows that illness involves more than the biological and medical processes; it includes psychosocial implications on families as well. The purpose of this qualitative and quantitative study was to examine the effects of childhood chronic illness on families and siblings by exploring the positive and negative consequences from parents' perspectives, the extent to which families experienced illness-related stress and strain, as well as further examining the specific ways in which families adapt their lives. This study specifically sought to explore the relationship between the impact on siblings and the impact on the family. By surveying parents associated with supportive non-profit organizations, this research sought to answer those questions. This study found that illness severity and the level of stress were statistically significant in their impact on the family. This study also found a positive correlation that showed illness' impact on the family invariably impacts the siblings. The qualitative portion of this study illustrates how parents convey thoughtful, enlightening, and unique perspectives from their day-to-day lives and experiences. Social workers, Child Life Specialists, and other health care professionals need to be aware of the psychosocial implications of illness and its impact on families so that they can properly assess and provide intervention when necessary. Professionals should also be aware of and utilize a family systems perspective when working with chronically ill children and their families.

Keywords: Chronic Illness, Heart Disease, Pediatrics, Siblings, Families, Hospitalization, Medical Social Work, Child Life Specialists, Allied Health Professionals

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The Impact of Childhood Chronic Illness on the Family: Psychosocial Adjustment of Siblings

The World Health Organization (WHO) defines health as a “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (2011). In contrast, according to Eiser (1994), a chronic illness is generally long term, not curable, results in limitations in daily living, may require special assistance or adaptation in normal functioning, *and* is an ongoing health condition. Though this definition appears descriptive, chronic illness is difficult to define because it refers to multiple types of diagnoses. Chronic illness is conceptualized different ways in the research. Many studies specify the type of illness, such as cancer, heart disease, arthritis, respiratory disease, multiple sclerosis (Killian, Matschinger, & Angermeyer’s, 2001) or diabetes (Ayalon et al., 2008). Others do not specify the type of illness studied; rather, they use phrases such as acquired disabling conditions (Livneh & Antonak, 2005), having at least one chronic condition (Riley, Glasgow and Eakin, 2001), and having a health problem that lasts three months or more and affects a child’s normal activities (Compas, Jaser, Dunn, & Rodriguez, 2012, p.457). Some refer to the concept of chronicity, which is defined as an irreversible state of disease for which there is no cure (Adegbola, 2006). In general, chronic illnesses are characterized by at least three important features compiled by Compas et al. (2012). They are: illnesses are prolonged in their duration, they do not resolve spontaneously, and they are rarely cured completely (Compas et al., 2012, p.457). Because chronic illness is a widely-used and broad term that addresses many different facets of illness, the statistics show high prevalence rates.

Recent estimates indicate that approximately 16%-18% of children are classified as having special health care needs due to a chronic condition, or approximately twelve million children under the age of 18 (Bethell, Read, Blumberg & Newacheck, 2008, p.1; Kieckhefer et

al., 2005; The Child Study Center, 2001). The prevalence of specific diseases and conditions varies widely. For instance, Compas et al., (2012) states that in the United States alone, 13,000 children are diagnosed with cancer each year and another 13,000 are diagnosed with type 1 diabetes (p. 458). Furthermore, approximately 200,000 children live with either type 1 or type 2 diabetes and 9 million children suffer from asthma (Compas et al., 2012, p.458). In 2000, children and adolescents accounted for 6.3 million hospital stays and 18 percent of all stays (U.S Department of Health and Human Services, 2000). Given the high prevalence rate, it makes sense that chronic illness substantially impacts not only patients, but families and siblings (Cohen, 1999).

Improvements in the delivery of specialized care, such as better tools to diagnose chronic conditions and studies discovering successful treatments, have led to increasing survival rates for pediatric patients (Hafton & Newacheck, 2010, p. 665). Children are not only living longer with chronic conditions, but are dealing with more aggressive treatments that have harsh side effects, which often impacts their quality of life (Williams et al., 2009, p. 95). Reverting back to the WHO's definition of health, chronic illness encompasses more than simply the physical disease processes of the body; it includes the effects on individuals' and families' lives. Specifically, the presence of pediatric chronic illness can have a profound impact on the welfare of each family member, including healthy siblings (Newcom, 2004, p. 11).

The burden of having an illness in the family produces strain in all areas of life: financial, physical, emotional, social, behavioral, and personal domains (Williams et al., 2009, p. 95; Bouma & Schweitzer, 1990). Financially, as a family, lack of insurance or being underinsured can produce huge amounts of strain when medical bills are piling up. Physically, the family may not be getting enough sleep each night or not have their normal routine with all members present

in the home at a given time. Emotionally, the stress and uncertainty about the future, an upcoming procedure, or extensive worry about the ill child may dominate each member's thoughts. Socially, families may either feel isolated and alone from extended family members and friends or be overburdened by the extra attention that they are receiving. Behaviorally, family members may be pulled in different directions than normally expected, such as going to the hospital or picking up the siblings from school early and missing work. Each individual member of the family is affected in some way by childhood illness whether he or she is the patient, mother, father, grandparent, or brother or sister. Childhood chronic illness often results in worry, stress, disruptions in routine, change, financial constraints and more; these types of effects notably manifest themselves in the physical, social, financial, emotional spheres.

A childhood illness in the family can cause tremendous amounts of stress for all members. It often results in changes in family roles, relationships, and disrupts family normalcy. These changes are especially difficult because when structure is so important in early childhood development. Routine and structure gives children a sense of security, helps them develop self-discipline and boundaries, leads to clear and foreseeable expectations, creates a sense of mastery over their own lives, and ultimately allows them to handle change. Research shows well siblings of children with chronic illnesses are at an increased risk for negative psychological effects; i.e. depressive thinking and sadness in addition to anxiety and uneasiness (Sharpe & Rossiter, 2002, p. 699; Hollidge, 2000; Houtzager et al., 2004). Given the nature of their training in ecological and biopsychosocial perspectives, social workers are able to recognize that families are composed of layers of systems, and therefore are impacted by illness in a variety of spheres. Particular attention should be paid to how siblings experience differential treatment than their ill brother or sister and are often the ones who are left in the dark and are not communicated with

clearly about what is going on. In the research, this is often cited as the reasons for their experience of negative psychological effects (Sharpe & Rossiter, 2002, p. 699; Hollidge, 2000; Houtzager et al., 2004). Social workers have the skills necessary to provide comprehensive assessment, and recognize which family patterns and sources of stress are impacting siblings.

Given the literature on family functioning and childhood illness, the purpose of this study is to examine the effects of childhood chronic illness on families and siblings by exploring the positive and negative consequences from parents' perspectives, the extent to which families experience illness-related stress and strain, as well as further examining the specific ways in which families adapt their lives. This study specifically seeks to explore the relationship between the impact on siblings and the impact on the family.

Literature Review

Being diagnosed with a chronic disease can be a major upheaval in families' lives and often leads to many stressors and worries. Families with chronically ill children are fundamentally normal families forced to cope with extraordinary circumstances (Eiser, 1994). After diagnosis, families begin to experience the longevity and ongoing difficulty of managing the medical diagnoses (i.e. medication adherence, procedure and surgery recovery, doctor or hospital visits, etc.), in addition to managing "normal" family life, such as keeping up with daily household chores, schoolwork, jobs, and social activities. Often, the changes that occur after diagnosis produce stress and strain on individual family members, as well as the family as a unit (Bouma & Schweitzer, 1990; Williams, 1997). Furthermore, it is important to consider the family context in which siblings are impacted by illness, as parents are gatekeepers for their children. The gatekeeper's role include choosing to find or accept outside help such as emotional support from family members or mental health practitioners and they also choose the amount of

information to tell siblings, such as the severity of their brother or sisters illness. From a human development perspective, communication and behavioral patterns in children tend to be as a result of family communication and behavioral patterns. Family and illness factors (like lack of structure compared to maintaining normal daily routines) therefore play a role in mediating or exacerbating how siblings respond to their brother or sister's illness (Bouma & Schweitzer, 1990; Cohen, 1999; Williams, 1997). For example, open and honest communication between parents and their children can help alleviate fears and worries, thus reducing stress (Zimmerman, 1997). Though negative factors are often cited in the literature (Bouma & Schweitzer, 1990; Cohen, 1999; Williams, 1997; Zimmerman, 1997), positive effects do occur, including emotional maturity, family closeness, and a strengthening of the sibling bond (Sharpe & Rossiter, 2002; Williams, 2009).

Stress

Being diagnosed with a chronic illness places enormous demands (medical or otherwise) on children and their families, and can become the basic organizing principle of family life (Cohen, 1999). Researchers and clinicians agree that childhood chronic illness produces substantial amounts of stress on families (Cohen, 1999; Kazak, 1997; Eiser, 1997; Compas et al., 2012; Alderfer et al., 2010). As a result, the stressors faced by families are multifaceted and can include stress related to daily role functioning: disease-specific symptomology, treatment and demands, family strain, structure, function and interpersonal conflict; and stress related to uncertainty and loss (Compas et al., 2012, p. 474; Cohen, 1999; Whyte, 1995). Bouma and Schweitzer (1990) found that the degree and severity of stress was associated with the amount of care that the child required. Stress is often an ambiguous experience, unanticipated, uncontrollable, and sometimes functionally impairing for children and their parents. Stress is

ambiguous because the level and kind of stress is dependent on each individual member of the family; the coping resources to deal with the stress are both based on the individual and the family unit, as well as dependent on the level of understanding and perception of the experience. Stress can be acute, such as related to an upcoming treatment that week, or chronic and prolonged, such as related to recovery and survivorship (Compas et al., 2012, p. 457). Therefore, Compas et al. (2012) reiterate that “chronic illness presents children and families with combined acute stress and long-term chronic stress” (p. 458). To reiterate further, stressors could include: parents missing work, siblings and patients missing school, painful ongoing procedures or treatments, uncertainty related to prognosis or the future, behavioral outbursts in children, marital discord and conflict, too much or too little social support, financial constraints related to medical insurance and/or paying the bills. This is certainly not an exhaustive list of examples.

How Illness Impacts the Family as a System

It is largely accepted that families facing serious pediatric illness are fundamentally ordinary families that face extraordinary stressors and are forced to cope with unique circumstances (Kazak, 1997; Cohen, 1999; Eiser, 1994). The experience of chronic illness is a unique family *and* individual experience resulting in changes in a variety of spheres.

Impact of Parental Factors on Family. In any family, parents often wear many hats. They serve as doctors, police officers, role models, cooks and many more roles. In addition to their typical parenting roles, parents of chronically ill children also become “care coordinators, medical experts, systems advocates, personal ambassadors and representatives for their child” (Krats, Uding, Trahms, Villareale, & Kieckhefer, 2009, p. 303).

Many illness factors and caregiving burdens increase parental stress and strains; therefore, parental distress is associated with having an impact on the family, including patients

and well-siblings (Cohen, 1999; Compas et al., 2012). In general, compared to parents without an ill child, these parents report higher levels of role strain, higher stressors associated with the parental role, as well as frustration and conflict about the division of labor and expectations (Lohnberg, Howarth, and Clay, 2008). Compas et al. (2012) note that, “parents serve as resources to support and scaffold children’s coping. Parents who are ineffective in coping with the stress of their child’s illness may contribute to increased distress in their children” (p. 473). Parents also may demonstrate increased levels of anxiety and overprotectiveness; they may have lower expectations for their ill child and his or her siblings; and they may fail to provide boundaries or consistent discipline for their children (Lohnberg et al., 2008).

In her review of the literature on siblings and chronic illness, Williams (1997) frequently found that family and parent variables are present and key to adjustment to illness. For instance, absence of parental depression, good marital adjustment, and effective parent-sibling communication about illness are predictors of positive sibling adjustment, whereas high family stressors and lack of family cohesion and expressiveness were related to a number of adjustment problems of siblings (Williams, 1997, p. 319). Furthermore, Whyte (1995) and Williams (1997) reported that holding a negative perception of the experience and lacking confidence played a role in coping efforts, likewise impacting the family as a whole. For instance, Galloe et al. (1993) and Whyte (1995) found that parents who were overwhelmed with the demands of care and saw it as a burden experienced increased family stress and were less likely to have relatives offer support. All these reasons may influence how siblings respond to illness.

Moderators of Adjustment: Risk and Protective Factors Related to Illness

The ways in which siblings adjust to an illness in the family depend on several factors. Each disease has great “variability in its clinical expression, chronicity, severity, and the

associated hardships imposed on individual families” (Alderfer, 2010; Bouma & Schweitzer, 1990, p.724; Cohen et al., 1995; Terzo, 1999; Williams, 1997; Zimmerman, 1993). The availability and utilization of coping resources can impact the way in which the family and siblings adapt to the illness; if resources are unavailable, the family is more vulnerable. Lack of resources is thus a risk factor for emotional distress and maladjustment in siblings (Zimmerman, 1993, p. 301).

Terzo (1999) notes that because of the unique bond and culture that siblings share, siblings of children with cancer [chronic illness] are especially vulnerable to the stressors imposed by their brother or sister’s cancer diagnosis. Sibling variables, such as age and gender can play a role (Williams, 1997). For instance, Cohen et al., (1995) found that the younger the siblings at the time of diagnosis, the greater number of externalizing behavior problems are reported by parents on the Child Behavior Checklist, which is a widely used method of identifying problem behavior in children, not just in chronically ill families (p. 311). In contrast, Alderfer (2010) states that, “with regard to developmental stage, adolescent siblings seem to show the poorest adjustment compared to adults, school age, and preschool children” (p.799). Houtzager et al’s., (2004) findings also revealed that siblings of children with chronic illnesses aged 7-18 years old experienced more cognitive and especially more emotional problems than their peers (p. 82). In relation to gender, Alderfer (2010) found that females exhibit more distress than males (p. 799), and Houtzager et al. (2004) found that girls who had an ill sibling were particularly at risk for difficulties in social relationships (p. 82). All of these factors play a role in how families adjust to illness.

The most prevalent predictors of well-being in families with a chronically ill child include flexibility, integration into a supportive social network, balancing the demands of the

illness and family needs, clear boundaries, effective communication, active coping, and the encouragement of development and growth within the family (Lohnberg et al., 2008). Family cohesion and adaptation play the biggest role in mediating the impact of illness on healthy siblings, which may include shared affection, emotional bonding, mutual understanding, helpfulness of members etc. (Cohen et al., 1995; Williams, 1997). Cohen et al., (1995) reported that the following are significant predictors of positive sibling adjustment: absence of parental depression, good marital adjustment, high levels of neighborhood community support and family resources, and effective parent-sibling communication about illness. There are also examples of positive personal coping resources, which include: morale, beliefs, developmental understanding of siblings, previous coping experiences, parenting skills, intelligence and personality characteristics (Zimmerman, 1993, p.301).

Specific Effects of Illness on Siblings

Families are the primary socializing agents of children, and thus it is important to consider the family context, parental variable risk, and protective factors that play a role in how siblings adjust to childhood chronic illness. This section specifically addresses the ways in which siblings adjust to illness, whether it is a positive experience, negative experience, or (more often) a combination of both.

The literature on pediatric chronic illness brings light to the many ways in which siblings are impacted by their brother or sister's illness. It has already been established that the presence of childhood chronic illness in the home can lead to adjustment problems for healthy siblings (Newcom, 2004, p. 11). The majority of the research reports that siblings are at an increased risk for negative adjustment (Alderfer et al, 2010; Houtzager et al., 2004; Williams et al., 2009; Zimmerman, 1993), but many also highlight the positive factors associated with the experience

of illness, particularly long term effects after the initial crises of diagnoses and ongoing hospitalizations (Alderfer et al., 2010; Hollidge, 2000; Williams, 2007; Williams et al., 2009; Zimmerman, 1993). For instance, in reviewing more than 40 studies, Williams (1997) reported that approximately 60% included manifestations of increased risk for negative outcomes in siblings, 30% reported no increased risk, and 10% reported both negative and positive effects (p.312). Because the majority of siblings tend to adjust in negative ways, it deserves greater attention.

Negative Effects. Emotional intensity and vulnerability to negative feelings is the most commonly cited effect of a sibling's chronic illness (Alderfer et al., 2010; Hollidge, 2000). In each of their meta-analyses of the literature, Alderfer et al., (2010) and Williams (1997) report that siblings often experience feelings of intense worry, loneliness, isolation, fear, grief, helplessness, abandonment, anger, and depression (p.792; p. 318). Houtzager et al., (2004) stated that nearly 50% of the siblings in their sample of 83, reported excessive negative feelings, including anger, sadness, worry, gloom, jealousy, and fear (p. 78). To explain further, Hollidge (2000) found that siblings worry that their negative emotions could physically damage the sick child (p.58). For instance, one child commented, *"She gets whatever she wants...sometimes I get really mad at her. Sometimes I think mean thoughts. Once I didn't want her around anymore...a few days later she had an insulin reaction and ended up in the hospital. I felt like it was my fault...it made me feel like I caused it. I really felt bad"* (Hollidge, 2000, p. 58). This quote is a good example of the complexities that can occur for siblings in their thoughts and feelings from day to day, and highlights the point that "well siblings are handicapped in the race for parental attention and affection" (Hollidge, 2000, p. 59). Similarly, Alderfer et al., (2010) found that siblings often report spending less time with parents which makes them feel neglected, ignored,

and uncared for (p. 797). Parents describe the difficulty attending to needs of both their sick and healthy children, which can lead to overwhelmed, guilty and excessive feelings of worry (Alderfer et al., 2010).

Out of 65 studies, Alderfer et al's (2010) meta-analysis found that 24 studies mentioned illness' impact on siblings' school performance (p.797). Two themes emerged: a disruption in school performance and conflicts in loyalty (Alderfer et al., 2010, p. 797). School performance and behavior were impacted because healthy siblings had changes in their routine, were fatigued, experienced great amounts of worry and desired more attention from their parents. Secondly, loyalty played a factor because the sibling wanted to be with the child with cancer instead of at school (Alderfer et al., 2010, p. 797). Williams (1997) found a higher incidence of internalizing and externalizing behavior problems and among siblings (p. 318). Similarly, Cohen (1995) reported a significantly higher proportion of siblings scoring two standard deviations above the normative mean for internalizing and externalizing behavior problems on the Child Behavior Check List, as compared to the proportion expected under normal distribution (p. 307).

Positive Effects. Though the majority of research shows maladjustment problems in siblings, positive effects are cited as well. Family closeness (Zimmerman, 1993), increased responsibility, independence, maturity, increased empathy, sensitivity, compassion (Alderfer et al., 2010, p. 799; Murray, 1998), and increased family cohesion and evidence of personal growth in siblings (Williams, 1997) are positive effects shown in siblings. Hollidge (2000) reports that "well siblings are highly capable and competent in mastering their external world," which allows them to find resiliency and learn how to navigate stressful situations (p. 64), especially with guided support. Parents sometimes report that their children demonstrate increased tolerance and

maturity “beyond their years” (Kratz et al., 2009, p. 309). As shown in the literature, it is described that siblings are impacted by illness in a variety of positive and negative ways.

Gaps in the Literature

Though there appears to be an abundance of research on this topic, what seems to be missing is specific examples of the day-to-day accounts of siblings’ thoughts and behaviors, as well as how they adjust. For example, with the exception of a few researchers (see Williams, Pajariyakul, Graff & Stanton, 2010; Williams, 1997; Whyte, Baggaly, Rutter, 1995; Sartain, Clarke, & Heyman, 2000) many researchers cite effects such as jealousy and stress, but tend not to discuss how they came to that conclusion (Cohen, 1999; Cohen, 1995; Lavigne & Ryan, 1979; Zimmerman, 1995). For instance, researchers fail to say that the ill child receives more attention and gifts such as balloons, which the siblings perceive as favoritism. The child then may act out behaviorally in a negative way to get more attention, which can be perceived from families and health care professionals as maladjustment. What appears to be a negative behavior is actually quite common in siblings, and social workers can assist with normalizing the experience with parents and families.

Importance to Social Work

Assessment. A description about intervention cannot be mentioned without a word on assessment. How siblings deal with this major life stressor is dependent upon multiple factors, including illness severity, level of family functioning, level of available social support, and their own coping strategies and demographic statuses such as age and gender. Because of this variability, identifying interventions requires careful assessment. As Terzo (1999) states, simply assessing the following factors is the first step in determining intervention areas, as every family is impacted differently:

Siblings' perception of the ill child's condition, family stressors, the sibling's health, coping strategies that are and are not useful; parents' perceptions of sibling health and adjustment, including behavioral and emotional responses; the parent's mood state (e.g., anxiety, depression) and level of functioning; family conflict and functioning, including changes in roles and routines; financial resources and social support available to each family member; presence of sibling risk-taking behaviors; and health care utilization for needed problem (p. 309).

Treatment and Intervention Areas

As shown above, there are many ways in which families and siblings are impacted by illness. Because of this, the literature shows many treatment or intervention areas that have previously been helpful for alleviating the negative impact of illness. Zimmerman (1993) cited interventions that focus on coping skills in parents can invariably affect siblings. For instance, he cites talking to a spouse as a means of relieving emotional distress and deciding how to address current or further difficulties, while together focusing on positive aspects of the child were frequently reported strategies for coping (Zimmerman, 1993, p. 303). Other strategies include maintaining a lifestyle that is as normal as possible and using informal and formal support networks. Other family interventions such as providing educational or informational support that is web-based can give parents the opportunity to learn more about their children's diseases and talk through their concerns or worries with others who are going through a similar experience. By reflecting on how they are handling their situation, families of children with cancer decrease their isolation, increase connectedness, and become empowered (Svavarsdottir & Sigurdartottir, 2006, p. 989). Houtzager et al. (2004) found that siblings who were able to maintain positive expectations regarding the illness and remained optimistic (predictive cognitive coping), adjusted

more favorably to the illness. However, if a brother or sister's illness requires repeated hospitalizations (thus increasing stress and reducing positive expectations), parents should try to instill positivity or optimism.

Social workers recognize that social support is very important for well-being and adjustment. A longstanding intervention used with siblings is support groups, which promote positivity and acceptance, and allow for sharing and reflecting (Williams, 2009, p.107; Nolbris et al., 2010). In their qualitative interview design of 15 siblings who had a brother or sister with cancer, Nolbris et al., (2010) found that siblings felt a sense of belonging and comfort by being in a group, which allowed them to: talk about their situation, hear what others were feeling, recognize themselves in what others were saying, and find their inner strength to carry on. Support groups allow siblings to receive therapeutic support that gives them the tools to name and recognize their feelings, the opportunity to reflect on their situation, and receive support from peers. According to Nolbris et al's (2010) and Barrera, Fleming, and Khan's (2003) findings, siblings who had high social support had fewer symptoms of depression and anxiety and fewer behavior problems than siblings who had less support (p. 108). It appears that Nolbris et al. (2010) and Barrera, et al., (2003) reiterate that perceived emotional social support (whether it be from peers at home or a support group) plays a critical protective role in the psychological adjustment of siblings of children with chronic illness. However a family adapts to illness, interventions may be necessary by social workers and other health care professionals to ensure maladjustment is minimized in families and allow them to adapt as positively as possible.

Implications for Social Workers

As health care professionals, social workers should be assessing family factors and inquiring about how well siblings are dealing with their brother's or sister's illness. The research

shows that siblings are not only vulnerable to distress or maladjustment, but are often left in the dark during the experience. As parents are generally the gatekeeper to siblings' access to support, professionals need to familiarize parents with the effects of illness and normalize the experience as much as possible (Bellin and Kovacs, 2006, p. 209). As Zimmerman (1993) expresses, the multiplicity of factors associated with the psychosocial adjustment of children and their family requires a coordinated multidisciplinary approach (p. 304). In addition to assessment, social workers need to be aware of the psychosocial implications of disease processes, such as increased stress and strain on family roles. As a way to mediate and decrease maladjustment, social workers need to be focused on "providing holistic family-centered care, and implement strategies to enhance outcomes in all family members" (Terzo, 1999, p. 3). Because social workers are uniquely trained in the knowledge and skills related to the strengths and ecological perspectives, as well as having the understanding that if a "stressor affects the well-being of one member, it likewise influences the psychosocial outcomes of other members," clearly establishes that social workers are likely professionals to assist this population (Bellin and Kovacs, 2006, p. 213). It cannot go unmentioned the benefits of support groups among siblings that produce positivity, acceptance and belonging, and the chance to express their feelings and receive validation from others (Williams, 2009; Nolbrist et al., 2010). It is essential for healthcare professions to provide supportive interventions and educational programs to families to protect siblings' physical and emotional well-being. While treatment approaches have been created for families and siblings of chronically ill children, little to no research has sought to include their voice in what their experiences are and what they need during this time.

Specifically, the purpose of this proje is to examine the positive and negative consequences of childhood chronic illness on families and siblings from parent's perspectives,

the extent to which families experience illness-related stress and strain, as well as looking closer at the specific ways in which families adapt their lives. This research also explores the relationship between how illness impacts siblings and families alike, and seeks parents' perspectives through open-ended questions.

Conceptual Framework

There are many theoretical underpinnings one could explore to better explain and understand the interrelatedness of how illness impacts individuals and families. The research differentiates between the terms disease and illness, which is important in understanding the whole experience. Disease refers to physical processes of the body, such as a spreading cancerous cells or low insulin in a diabetes patient (Wilkman, Marklund, & Alexanderson, 2005). Illness, on the other hand, refers to the subjective experience of disease, such as being stressed over an upcoming treatment or how it impacts an ill person's self-esteem (Wilkman, et al., 2005). It is the illness experience that this research study refers to as well as how the disease process can be understood in the context of families. It has already been established that chronic illness is a multifaceted experience that affects more than the ill person or child. It is an interactive, interdependent, all-encompassing experience that has many layers. Given this, systems theory, the biopsychosocial perspective, and the ecological model are used as conceptual frameworks in this study for comprehending how illness influences the family.

Systems theory "stresses the importance of exploring the world at the level of systems made up of interdependent and interacting parts," and was originally developed by Ludwig von Bertalanffy in the 1940's (Systems Theory, 2009; Lohnberg et al., 2008, p. 2). From a systems standpoint, parents, the ill child and siblings are all part of a family unit that consists of a web of separate and unique relationships between each other. When the role of one changes, such as the

parent missing work and spending the week in the hospital with their ill child, this invariably and directly impacts the role of the other parent and siblings at home. The parent at home now has to make meals, keep up with housework, and be the sole parent figure to the other siblings. Older siblings may now need to be a babysitter to the younger siblings or take on additional roles such as keeping up the house or be forced to become more independent or self-sufficient than once before. The parents in the hospital may feel guilty or stressed about the situation they place on other members, which is added to the stress they are already experiencing. The illness places role strain on both parents as well as siblings. This demonstrates how one component of the system (absent parent) affects the other components of the system (impact on other parent and siblings), which in turn affects the initial component (guilty feelings and stress) (Ponzetti, 2003). Family systems theory conveys a more holistic viewpoint of families and recognizes that boundaries, roles, communication and family structure all influence family functioning.

Family systems theory leads one to understand the organizational complexity of families as well as the interactive patterns that guide family interactions. It is more than "who makes up a family," it is how they come together that defines that family (Ponzetti, 2003, p.644). It is also how the family as a unit responds to illness that mediates how siblings react.

Related to systems theory, one could turn to the biopsychosocial perspective to understand the complexity and interrelatedness of how illness impacts a family. As described by Engel (1977) the biopsychosocial model is a "holistic perspective for understanding and explaining the interfacing biological, psychological, and social forces that influence health, illness, and well-being" (p. 132). Understanding health as a biopsychosocial experience further exemplifies the subjective experience of illness, not just the objective physical disease processes of the body. Thus, an illness in a child impacts many other domains of life, including jobs,

schools, friends, family members, financial stability, sense of the future, etc. For example, parents may take many days off of work, thus resulting in less pay potentially placing financial constraints on the family. Another example is that siblings may experience a whole host of feelings, including jealousy and worry over their ill sibling, causing them to perform lower than normal in school. Recognizing that childhood chronic illness influences other domains of life, in addition to understanding the ways in which siblings react, is imperative to keep in mind when assessing the subjective experiences of families.

When there is a health crisis, it often impacts other domains of life. This is especially true for parents and their children. Family systems theory and the biopsychosocial perspective align with the assumption that illness is a family experience. Given that social workers are trained to assess the whole client, and that clients impact and are impacted by their environment, it is appropriate to use family systems and the biopsychosocial model as theoretical orientations.

Method

Research Design

To answer the research questions, a pre-designed survey was created for this cross-sectional, mixed-methods study (see Appendix A). The survey was given to parents who have a child with a chronic illness and at least one healthy child in the home. Because this study was explanatory in nature, a pre-designed survey allowed the researcher to gain specific examples of the many ways in which families are impacted by illness, not just how many siblings in a sample, for example, experience anxiety during hospitalization. A survey with both open and closed ended questions, filled out by parents, allowed for richer data, as it was from the “individuals’ [parents’] own perceptions and subjective apprehensions” (Berg, 2009, p. 16). A survey was appropriate for this study because it can be sent electronically or through the mail to a greater

number of participants compared to interviewing one-on-one (Berg, 2009). A survey allowed participants to complete it on their own time, gave them time to think about the questions before answering, and permitted participants to be truthful because their answers were anonymous. Limitations on using a survey were the potential for a reduced response rate and the potential for participants to skip questions.

Sample

Purposive sampling was used for this research study because the population had very specific attributes. Forty-six respondents completed the survey (N=46). Holden et al., (1997), Kazak (1997) and Whyte, Baggaley, and Rutter (1995) all agree that using a noncategorical approach (as compared to a categorical approach) to the study of chronic illness in childhood is appropriate because stressors are salient across all disease indicators; many commonalities emerge across diseases in terms of general distress, caretaking duties, and family reorganization; and relevant predictors of adjustment outcomes are noted as suitable compared to looking at individual illness categories. Therefore, one of the criteria for this study was that the family must have at least one child who has been diagnosed with a chronic disease, whether asthma, diabetes, heart disease, cancer, or juvenile arthritis, which are among the most common chronic diagnoses in childhood. The ill child needed to have been diagnosed for at least six months with one of the above diagnoses. The six-month time period was to ensure that families were over the immediate crisis of diagnosis and had already established, changed, or redefined unique family patterns. If a child was recently diagnosed, parents may not yet have been aware of how the family had changed. The ill child's diagnosis may not be terminal, because of the possible presence of anticipatory grieving, in which the family may be dealing with different stressors. Therefore, there needed to be an absence of issues related to death and dying. The ill child may not have

been in the hospital at the time of the survey because families are more vulnerable at that time, and the primary concern and focus would be on the ill child. By bringing up the siblings, it may have caused more stress. Families must have had at least two children, one ill child and at least one healthy sibling. Eligible families could have been composed of single parents (male or female headed), divorced and/or separated parents, gay and lesbian families, and multi-generational families. Siblings must have been at least three years old and no older than 18, because siblings must have the ability to vocalize thoughts and feelings (even if they are rudimentary) and have noticeable behavior that can be connected as a response to the ill child.

Protection of Human Subjects

Recruitment Process. By using purposive and snowball sampling, research participants were attained by locating parental, sibling, or disease-specific non-profit organizations related to this topic in Minnesota. It is appropriate to gather information from parents connected with non-profit organizations because they are more likely in a place of emotional willingness to communicate about their situation and are able to reflect on the impact of illness on the family.

The researcher contacted the director and/or an employee of the non-profit organizations first, who upon agreement to forward the survey to their parents associated with the organization, were asked to sign an agency consent form electronically (see Appendix B). After the agency signed the consent form, they in turn forwarded the email with a link to the survey to their parents to ensure confidentiality.

Measures to Ensure Confidentiality and Anonymity. Anonymity was assured in the creation of this research study, as the survey did not ask identifying information such as name and address. Rather, it asked basic demographic information such as age, gender, and illness diagnosis. By completing the survey online, research participants were automatically consenting

to complete a survey without the need to provide a name or a signature. The survey results online cannot be traced back to the original participant; therefore, their identity is unknown.

The agencies from which participants were sought will not be published in the final publication to further protect the anonymity and confidentiality of research participants. The researcher, research chair, committee members, class members, and IRB members were the only ones who knew which agencies agreed to forwarding the survey to parents.

Protocol for Ensuring Informed Consent. Informed consent was obtained from participants prior to completing the online version of the survey. A script was written and placed prior to the survey items, which were followed by “I understand what is written above and agree to continue”. Participants were unable to continue unless they accepted. Please see the script prior to the survey located in Appendix A.

Data Collection Process and Instrument

The survey was given to participants electronically via email with a link to the survey in the body of the text. The agencies were responsible for forwarding the survey to participants, to ensure confidentiality was not broken. Qualtrics was the internet-based program that was used for sending out surveys and collecting the data.

The survey was comprised of a total of 27 questions, 12 of which were demographic questions. Eight of the questions were open-ended, allowing parents to type or write their responses. The remaining 19 were closed ended questions, with 8 being Likert scale questions. The questions were developed as a result of questions that arose from the literature and addressed various aspects of family responses to a child with chronic illness. The questions were written to explore the relationship between the impact of chronic illness on the family and siblings. The specific questions were discussed further in the methods portion of the paper.

Data Analysis Plan

Data were received from completed surveys and were analyzed two ways, as the survey instrument asked both open and closed-ended questions, resulting in qualitative and quantitative data analysis. For the qualitative questions, the data was transcribed into a separate document of paper and analyzed for themes based on grounded theory methodology. SPSS statistical package was used to analyze the quantitative questions. Both methods are described in more detail below.

Qualitative Data Analysis. The survey includes eight open-ended questions, intended to allow parents the opportunity to share individual illness-related experiences. This benefited this research study by allowing for more subjective and meaningful data to be uncovered, such as the day-to-day occurrences on how families are impacted by illness. Data analysis for the qualitative portions was based on a grounded theory methodology perspective, so named because it is “grounded” in the raw data so as to ensure that the data analyzed are as close to the respondent’s message as possible (Berg & Lune, 2012).

Accordingly, the process of analyzing the data was the same for each open-ended question. The data drawn from the survey was transcribed and analyzed for concepts, potential codes, and essentially emerging themes. Recurring codes and concepts were grouped into themes and the transcript of survey responses were reviewed again to ensure that codes corresponded to the research question.

The following open-ended questions were analyzed by grounded theory methodology. The first was, “Briefly describe your child’s limitation related to his/her illness.” The second was “Please share any comments or stories related to how your child’s illness has impacted the family as a whole and/or the ways in which your family experiences stress/strain related to the illness. Specific answers are appreciated, such as the cost of medication as being difficult or ‘I

experience a lot of stress because I need to administer my child's medication three times a day.”

The third question was “Please comment on or share a few examples of how you feel your healthy child has been impacted negatively by your child's illness.” The fourth question was, “It is not uncommon for families and siblings to share a few positive examples of how their child's illness has impacted them. For example, sometimes families note increased family closeness and cohesion, maturity in siblings, increased empathy and compassion and evidence of personal growth. Please comment on or share a couple examples of how you feel your healthy child has been affected positively by your child's illness.” The fifth question was “When thinking about how your healthy child has responded to their sibling's illness, what changes or adjustments have you noticed?” Please comment on any behavioral, physical, and/or emotional responses.” The sixth question was, “What advice or suggestions would you give to other parents who are in a similar position to yours?” The seventh question was, “Name the biggest thing that has helped the family adjust to the illness:” The eighth question was, “Is there anything that comes to mind that wasn't covered in this survey? Do you have any thoughts, comments, or stories you'd like to share?”

Quantitative Data Analysis. The quantitative data analysis was used to correlate several statistics related to the closed ended questions and variables. Several nominal and ordinal variables were analyzed.

This variable was operationalized with the question: “Please choose one of the following that best describes your child's diagnosis.” The response options were heart disease, cancer, diabetes, arthritis, cystic fibrosis, asthma, developmental disability including ADHD and autism spectrum, mental illness, and other: please specify.

The ordinal variable “age of ill child” measured the respondents’ ill child’s age. This variable was operationalized with the question, “What is the age of your ill child”? The response options were 0-3, 4-7, 8-11, 12-15, 16-19, 20+.

The nominal variable “sex of ill child” measured the respondent’s ill child’s sex. This variable was operationalized with the question: “What is sex of your ill child?” The response options were male, female, and other.

The ordinal variable “age of healthy child” measured the respondents healthy child’s age. This variable was operationalized with the question: “What is the age of your healthy child?” The response options were 0-3, 4-7, 8-11, 12-15, 16-19, and 20+.

The nominal variable “sex of healthy child” measured the respondents’ healthy child’s sex. This variable was operationalized with the question: “What is sex of your healthy child?” The response options were male, female, and other.

The nominal variable “respondent’s current marital status” measured parents’ relationship status. This variable was operationalized with the question: “What is your current marital status?” The response options were divorced, married, separated, single, and widowed.

The nominal variable “health insurance” measured whether or not the family had health insurance. This variable was operationalized with the question: “Does the family have health insurance?” The response options were yes, no, and other: please specify.

The nominal variable “sibling impact” measured whether or not the parent felt that their ill child’s illness impacted their healthy sibling. This variable was operationalized with the question: “Do you feel your ill child’s illness has impacted their sibling?” with response options as yes or no.

Some variables were analyzed using measures of central tendency and dispersion. The variable “severity of illness” was interpreted as an interval-level variable; it measured the respondent’s perception of how severe their ill child’s illness is. This variable was operationalized with the question: “On a scale from 1 to 10, what is the severity of your child’s illness?” The response options ranged from 1 being not severe to 10 being very severe.

The ordinal variable “time since diagnosis” measured the length of diagnosis of the respondents’ ill child. This variable was operationalized with the question: “How long has it been since your ill child was diagnosed with their illness?” The response options were 6 months, 1 year, 2 years, 3 years, 4 years, 5 years or more

The ratio variable “number of children” measured the amount of children in the household. This variable was operationalized with the question: “How many children are in the household?” The response options were 0, 1, 2, 3, and 4+.

Correlation for severity of illness and family life domains. A correlation was run to determine if there is a relationship between the severity of illness and the extent to which it impacts family domains of life. The first interval variable in this study measured the respondents’ perception on the severity of the chronic illness. The severity of illness variable was operationalized with the item: “On a scale from 1 to 10 (1 being not severe 10 being very severe), what is the severity of your child’s illness?” The response options ranged from 1 to 10.

The second interval variable in this study measured the extent to which the respondent felt the illness impacted family domains. The family domains variable was operationalized with the question, “To what extent has your family been impacted by your child’s illness within the following domains: physical, financial, emotional, social, behavioral, personal?” The response options for each domain range from 1 (“no impact”) to 3 (“moderate impact”) to 5 (“great

impact”) along a Likert scale. SPSS statistical software was used to combine the responses into a total scale score, ranging from 6 (little impact) to 21 (moderate impact) to 36 (great impact).

The research question for this study was: What is the relationship between the severity of illness and the extent to which it impacts family domains of life? The hypothesis for this study was: There is a relationship between the severity of illness and each family domain of life. The null hypothesis for this study was: There is no relationship between the severity of illness and each family domain of life.

Correlation for the severity of illness and positive impact. A correlation for severity of illness (defined above) and perceived positive impact on siblings was run to determine if there is a relationship. The interval variable, “positive impact” was operationalized with the item “on a scale from 1 to 10 (1 being not at all positive, 10 being very positive) please rate how much your child’s illness has impacted your healthy child positively,” with responses ranging from 1 to 10 along a Likert scale.

The research question for this study was: is there is a relationship between the severity of illness and the perceived positive impact of illness on siblings? The hypothesis for this study was: there is a relationship between the severity of illness and the perceived positive impact of illness on siblings. The null hypothesis of this study was: there is no relationship between the severity of illness and the perceived positive impact of illness on siblings.

Correlation for the severity of illness and negative impact. A correlation was run for the severity of illness (described above) and perceived negative impact on siblings variables. The interval variable, “negative impact” was operationalized with the item “on a scale from 1 to 10 (1 being not at all negative, 10 being very negative) please rate how much your child’s illness has impacted your healthy child negatively”, with responses ranging from 1 to 10 on a Likert scale.

The research question for this study was: What is the relationship between the severity of illness and the perceived negative impact of illness on siblings. The hypothesis for this study was: there is a relationship between the severity of illness and the perceived negative impact of illness on siblings. The null hypothesis of this study was: there is no relationship between the severity of illness and the perceived negative impact of illness on sibling.

Correlation for the impact on siblings and impact on family. A correlation was run for the relationship between impact on siblings and impact on family domains (described above). The first interval variable in this study measured the extent to which the respondent felt the illness impacts the family. The second interval variable in this study measured the extent to which the respondent felt the illness impacts the siblings. The impact on sibling variable was operationalized with the question, “To what extent is your healthy child impacted in the following ways: disrupted in normal routines such as missing school; vulnerability to negative feelings such as jealousy, worry or loneliness; less family cohesion; decreased maturity; increased dependence ; behavioral disruptions such as acting out. The response options for each impact ranged from 1 (“no impact”) to 3 (“moderate impact”) to 5 (“great impact”) along a Likert scale. A scale was created to measure this variable, ranging from 6 (little impact) to 21 (moderate impact) to 36 (great impact). Higher scores indicated a negative impact.

The research question for this study was: What is the relationship between respondent’s perception about how childhood chronic illness impacts the family and its’ impact on siblings. The research hypothesis for this study was: There is a relationship between respondent’s perception about how childhood chronic illness impacts the family and its’ impact on siblings. The null hypothesis was: There is no relationship between respondents perception about how childhood chronic illness impacts the family and its’ impact on siblings.

Correlation for severity of illness and amount of stress. A correlation was run for the severity of illness (described above) and amount of stress. The second interval variable in this study measures the respondent's perception of the level of stress their family and sibling experiences. The level of stress variable was operationalized with the following three questions that were combined to create a scale score.

The first question was "on a scale from 1 to 5, please rate the amount of stress/strain you experience as a family because of your child's illness." The second question was "on a scale from 1 to 5, please rate the amount of stress/strain your healthy child experiences because of your child's illness." The third question was "in the following areas, to what extent has your child's illness caused stress for the family?" listing "daily roles of family members, disease-specific symptoms, treatment, and demands, family strain, missing work, children missing school, change in family structure and normalcy, hospitalizations, interpersonal conflict, uncertainty, and losses." Each option for the third question had a scale from 1 to 5. The response options for each ranged from 1 being no stress and 5 being great stress. SPSS statistical software was used to recode and create a new variable called "level of stress", by adding up each of the three questions created a scale score ranging from 12 (little stress) to 36 (moderate stress) to 60 (great stress).

The research question for this study was: What is the relationship between the severity of illness and level of stress? The research hypothesis for the study was: There is a relationship between the severity of illness and level of stress. The null hypothesis for the study was: There is no relationship between the severity of illness and level of stress.

Correlation for level of stress and impact on family. A correlation was run for the interval level variables level of stress (described above) and impact on family (described above).

The research question for this study was: What is the relationship between the level of stress and perceived impact on the family? The research hypothesis for the study was: There is a relationship between the level of stress and perceived impact on the family. The null hypothesis for the study was: There is no relationship between the level of stress and perceived impact on the family.

Correlation for level of stress and impact on siblings. A correlation was run for the interval level variables level of stress (described above) and impact on siblings (described above). The research question for this study was: What is the relationship between the level of stress and perceived impact on the sibling? The research hypothesis for the study was: There is a relationship between the level of stress and perceived impact on the sibling. The null hypothesis for the study was: There is no relationship between the level of stress and perceived impact on the sibling.

Results

Qualitative Analysis

The results of the qualitative portion of this research study give a good illustration of the day-to-day experiences of ill children and their families, as parents responded to many of the open-ended questions. Forty-one of forty-six parents wrote something in the survey about what kind of limitations their ill children have due to their illness or simply noted their children had no limitations at all.

The majority of parents wrote about the physical limitations holding their children back, many due to fatigue and some due to restrictions in contact sports. For example, one parent responded, *his limitations are self-imposed, which means he'll play until he's tired and can't keep up.* Several other parents used terms such as *losing energy quickly, shortness of breath,*

fatigues easily, limited in activity due to being worn out, over-exertion, and reduced stamina and endurance. For instance, one parent noted her child *was limited in playground and gym activities; she would get cold very easily and would get tired.*

Several parents also commented on the risks and impact involved in being immunosuppressant. For example, one parent expressed this well by saying, *by choice he does not go to daycare (..or on an airplane or the Children's Museum) due to all the illnesses (and germs) that run around there... he may end up in the hospital.* The parent continues: *this is a chance we don't want to take.* Others used terms such as *prone to illness, sick often, and picks up everything and lasts 3 times longer than "normal" child,* and, *immune system varies.*

Some parents specified the type of illness and its direct impact on their child, such as *complex cardiovascular disease, has had open heart surgery five times, developmental delay, congestive heart failure, deaf, mobility issues and feeding issues.*

Impact on family including stress-related experiences. Twenty-six parents of forty-six wrote about their stories and comments related to how their child's illness has impacted their family and why they experience stress. Several parents wrote about the financial difficulties of illness causing great amounts of worry and stress. For example, one parent wrote, *financially it has been tough* and continues, *even though insurance covers the major hospital expenses, there are many other personal expenses [like] travel, motel stays, and meals.* Many parents commented on the fear they experience if they lose their health insurance, including *without insurance we would not be able to handle the costs of her care.* One profound statement made by a parent was *we can't afford the treatments without Medicaid and are limited to poverty level income to keep it.* A few parents commented on needing to miss work or quit due to

hospitalizations and treatments having *strained* [their] *finances*, and needing to *fight with* [their] *insurance companies to help pay for the bills*.

A few parents wrote about the constant need to manage medications as being stressful. One parent noted, *our lives revolve around dosing times of medications* and another stated the *regular regimen of medications initially* [involving a] *PICC line that required dosages every six hours on top of other medications*, became stressful.

Numerous parents wrote about the uncertainty they feel and the difficulty with the unknown as being stressful, both in general terms such as, *I worry about the future* and the *wait and see* about prognosis, procedures, and treatment options to more specific concerns such as *had I done something wrong as a parent?* and *will my baby die?* *Not knowing what is ahead of us is very difficult*, explained one parent. Another parent wrote, *we've been fortunate as our child has been extraordinarily healthy despite his complex condition. The unknowns associated with his disease and the toll this takes on us as his parents have been profound*.

Though not explicitly stated, several parents identified it being difficult to maintain a balance when managing their family and child's illness. One parent's statement exemplified this theme: *emotional well-being and balance are very hard* and gave several examples. For instance *hard to keep emotional control as a parent in order to protect children from worries... very hard to navigate social situations when trying to keep child well but not [be] over protected and isolated...wonderful and difficult to be a part of the heart community- fellow heart friends pass away and it is a reality that is difficult to navigate your heart child through when friends from support group don't make it*.

Negative impact on healthy siblings. Twenty-eight of the forty-six parents shared their thoughts on how they feel their healthy sibling is impacted negatively by their other child's

illness. Emotional feelings, attention on the ill child, behavioral disruptions, caretaking, and missing out on life experiences were all themes within their writings.

Emotional feelings was the most apparent negative impact parents wrote about. Numerous parents wrote about jealousy and worry as common feelings felt by healthy siblings, such as *jealous of the attention on his little brother and anxiety about his ill brothers sickness*. Many parents wrote about separation anxiety impacting healthy siblings, particularly related to hospital stays, such as *she was consistently separated from me while I was in the hospital caring for her sister and has had anxiety about separation ever since*; and another wrote, *he has anxiety over having to be apart from us for overnight hospital stays to the point where I can't go out to check the mail without him getting upset*.

One parent noted her son tends to feel alone and isolated, yet also expressed *anger towards the loss of normalcy for our family*. Another noted her daughter sometimes expresses confusion and is *overly concerned for anyone ill since her sister's illness*.

Related to feelings of jealousy, several parents commented on the amount of attention the healthy sibling receives compared to the ill child. Some explained that the ill child *takes up a lot of my time, needs to go to doctor appointments, needing extra help with school, and no matter what we are doing, if the baby is having trouble (coughing, food pumps going off, etc) we have to stop what we are doing to solve the problem*. One parent admitted, *they maybe feel like sometimes you may seem a little more in-tune to the other siblings sometimes*. At times this can even get to the point where a sibling may feel like *we don't love her as much because she doesn't get as much attention at times*.

One of the realities of having a chronically ill child is the disruption in normal family routine, which no doubt impacts siblings. One parent illustrated this *missing out on life* fact by

saying *we make family plans that the healthy child is looking forward to then the sick sibling has a health issue and the outing and plans are cancelled*. Another stated, *I worry often that he is not being exposed to valuable life experiences as a result of our family situation*.

Related to missing out on life experiences, one parent observed her healthy child as being unable to *handle any disruption to her normal regimen*. Behaviors are not an uncommon way for children to express themselves and react to family stressors. Several parents mentioned that after some time away from their parents, the healthy child exhibited *acting out* behavior and one further stated, *in some ways it's hard to know how much this has affected her*. Other quotes from parents as concerns include: *acted out with drugs and drinking, impacted her schooling, and regressed with toilet training, behavioral issues, anger displays, and clinginess*.

Though these themes are separated for the purpose of the dissemination of the results of this research study, it is important to note these issues tend to go hand in hand together, as one parent stated: *he also expresses great worry for his sister. But also expresses jealousy over her extra attention, and then acts out rebelliously*.

Positive impact on siblings. Twenty-six of forty-six shared positive examples of how their child's illness has impacted their healthy sibling. Greater compassion, protectiveness, giving back and sticking together, and independence and maturity were all themes apparent within what parents wrote.

Fourteen of those who responded to this question wrote about the increased compassion in their healthy sibling exemplified in different ways. Parents noticed their sons or daughters *being very nice to the special needs kids at his high school, being much more understanding with friends who are sick, more compassion for people who are different*. One further stated: *will go out of their way to include them in their play, looking out for each other a little more, increased*

empathy for others, he is very compassionate toward others who are hurting or sad, a greater appreciation for each other and our strengths and weaknesses and I think it has made him a very caring person.

Protectiveness is another theme that emerged from parents responses. Several wrote about how the healthy sibling is protective of their sibling and how *it has made him a strong person*. A couple parents spoke of this theme well: *he is affectionate and even though he is younger, acts as the protector, and he 'watches his back' and has his best interests in mind as a big brother*. Interestingly, two parents spoke of how the healthy sibling *kept the family in check*. For instance, one wrote: *if anything kept our family normal, it was his brother being a brother by playing with him, talking to him and keeping him accountable so we wouldn't spoil or favor him*. And another explained: *I see true compassion in the siblings and a concern for their sister but not 'hovering' over her. I think there is some agreement between the two older siblings that maybe we 'coddle' the heart child a bit more and that [because of her siblings] she 'flies by the seat of her pants and comes out standing on all 4's'*.

A few parents noticed independence and maturity in their healthy child. One parent stated: *he is very independent and only 3 years older and at times is too independent*, which sometimes makes this parent sad. Two parents noted the ease at which the siblings respond to upcoming medical procedures and doctor visits and related this to maturity by sharing that, *she learned that doctors can be good and help, and, I think that comes from those things being common in our family*.

Though this question asked about positive impact on healthy siblings, several parents made note of the positive impact their child's illness had on the family system, including family closeness and the philanthropic events they participated in. *We have a lot of family closeness, as*

well as a keen understanding of the value of time we have together. Several parents involve their entire family and give back during activities such as: support the children's hospital by collecting toys. One sibling at age two wanted to: give back to others in the same situation as our family and has brought gifts to other children in the hospital where we stayed because of her sister. One family stated they are: much more aware of and dedicated to raising awareness, fundraising for heart causes, and sharing their story. Simply stated, we stick together as a family to get through the tough times.

Sibling adjustment to illness. Twenty-three of forty-six respondents commented on any changes or adjustments they saw in their children. Many of parents' responses were similar to the way they described the positive and negative impacts illness had on siblings. They described anxiety, behavioral outbursts and jealousy but also compassion and maturity, as common reactions to their siblings' illness. A few parents reiterated these further by sharing additional insight. For example, *my healthy son has a unique style and tenderness that he displays when it comes to his brother. It's very beautiful to see as a parent. Another sibling: acts like he doesn't care at all about his sister's health issues and will actually tease her about them.*

The following parent's statement exemplified the mixed emotions and behaviors that sometimes occur after illness is identified, as *he [the healthy sibling] gets really angry and impulsively aggressive with his siblings at times, but other times is very vulnerable and loving. Before illness, he was consistently loving and not at all angry. Another parent wrote about allowing her daughter to adjust during the time of crisis: our daughter was more defiant after staying with family for two weeks during our son's surgery. She was an angel for our family and she needed to let off steam when we returned home. Similarly, one mother described a situation during which her son, when she came home, yelled in a heated argument when you were gone I*

needed you and you weren't there, and she comments further, I reassured him that I loved him and missed him every day. He had held in those feelings for 10 years and needed to get it off his chest and it was cleansing for him. The following two parents wrote about unique ways the siblings explain to their parents how they are feeling, both positively and negatively: *my son is worried the sun isn't going to come back up.... He's worried about his sister not waking up, and another: she talks about her sister's heart and her own heart, in terms of where it is and can feel it beating, that it pumps blood, etc. So much more knowledge than 'I love you with all my heart' like is more common with kids her age.*

Family adjustment. Thirty-one parents responded to the question of *name the biggest thing that has helped the family adjust to the illness.* The majority of the parents named the support they receive from their family, whether it was extended family like their parents or the support of their spouse and strength of family unit as key to adjustment. For example, one parent revealed: *The strength and commitment we've made to each other in our marriage has created a very strong family bond that sustains our children. It's rewarding to see how they relish the time spent together as a family.* Another called upon the support of her mother, who stated: *My mother's advice. When I told her that I was worried about what this would do to our older son, she said to think about what it would do FOR our older son. It would make him a better person showing kindness, patience, love, etc.*

Many parents looked outside the family for support and adjustment, such as their faith, community, other parents who also have kids with medical issues, or a support group. One parent expressed appreciation *for how big the heart community is, you find others with the same experiences, and sometimes, see exactly how lucky you are that your child has one illness and not another.* This parent was able to find perspective by reaching out to others. Related to this,

one parent felt that holding the following perspective was helpful to remember: *LOVE...knowing that they are loved no matter what....that everyone has challenges in life and theirs are just coming sooner rather than later...*

Several parents commented that having a good health care team behind you was comforting in the time of illness. One parent explained: *we were at the mercy of the staff at the hospital and they were wonderful in teaching, explaining and supporting us through each decision necessary.* Another cited the importance of *finding good specialists.*

A few others noted: *therapy, knowing we have to have fun every day, because you never know what life has to throw your way, having tolerance, understanding, patience, and humor.* One created a blog to help others and found it to be: *more cathartic for us to let go of the anger.*

Advice and suggestions for other parents. Twenty six respondents wrote their own advice and suggestions they would give to parents who are in a similar position to theirs. The themes centered around the importance of self-care, finding support, and being meticulous about making time for each child. Self-care is often overlooked when parents are experiencing a medical crisis while balancing between the responsibilities of raising a family. One parent advised to: *take time for yourself, when possible. Understand this is a marathon, and you need to be your best version of yourself to make it through. That means making investments in yourself through exercise, hobbies, work, friends, etc.* Another wrote about the emotional heaviness of the experience: *it is so easy to let worry and fear take hold of your life after experiencing near death trauma and surgeries with your children-it affects your mood-your marriage-how you see the world. It is only recently that I realize how much I have changed and I am trying hard to take back control of my emotions and live in the moment and not be so fearful of the future.*

Several parents also advised that other parents to find support. One parent recommended: *find other families with a child like yours (health issue), accept help when offered--people don't offer if they don't mean it or don't care!* And another suggested similarly: *reach out to your community, family and friends for support. Lean on others, it will lighten the load.*

The majority of parents discussed maintaining a balance, keeping routines as much as possible and taking time to be with each child as helpful for adjustment to illness. Parents suggested to *keep routines as much as possible, treat all children normally, and try to do normal activities when your child isn't experiencing a medical challenge or crisis.* Others note it is important to take time out of your day to pay attention to your healthy kids as exemplified by: *make individual time for them on a daily basis even if it is just minutes to read a book or sit in the bathroom with them while they bath to listen to their day, and, even though it seems that your ill child needs more attention & caring for, you need to give the healthy child the same attention if not more.*

Another theme that emerged was parents appreciated open communication with their family and providers. Several parents commented on the importance of honesty in talking with siblings *no matter what people tell you, the kids are NOT too young to remember or be impacted. I personally think as a parent you need to explain often what happened to them and their sibling so it's always been something that they are not embarrassed of or feel strange about.* Another parent explained everything their child's sister was going through, including the scars and devices. He/she recognized early on that: *she is very perceptive so we had to tell her in advance what was going on to be prepared.* They continued stating that involving the child in the process helped her: *we tried to involve her in her sister's care like getting syringes or diapers or her own medical kit for her babies.* Related to communication, two other parents reiterated that it was

really important to convey: *reassurance and lots of love* while being willing to talk about “*normal feelings that each child can be having*, and concluded with: *kids just want to know that they are normal*.

Other words of wisdom parents stated that helped get them through was to: *look for the blessings that accompanied the illness - for us that was great insurance, supportive family, fabulous MDs and a tolerance for the ‘minor’ irritants that can overwhelm new parents that don't phase us at all*. Others note to continue to *keep advocating and fight for your child*. They stated: *You know your child the best. We all know that children develop at their own rates, but if you notice that something is just not right then continue to fight till you get the answers and the help that you need. You are your child's best advocate*.

Illness perspective. Fourteen parents chose to answer the last question, which asked *is there anything that comes to mind that wasn't covered in this survey? Do you have any thoughts, comments, or stories you'd like to share?* Many parents chose to use this option to reflect back on how they were impacted by their child's illness and others used it as a way to convey their own perspective of what it has taught them. It is here that many profound statements were said to convey their unique trials, tribulations and challenges, in addition to the strengths and positives that related to their own illness experience and perspective. Their words were conveyed in a thoughtful and enlightening manner.

This parent clued in to the individualistic manner in dealing with illness: *every family is different and each one has to find their way of dealing with the illness that is within the family*.

Several spoke of the importance of social support from others. One articulated it well with: *looking back, it is really important to stay strong. They say that it takes a whole village to raise a child. It certainly takes a whole village to raise a chronically ill child. We depended on*

our church, our faith in God, our family, our friends and our community. Somewhat related, this parent keyed into finding a helpful support, as not everyone will understand: A lot of people will avoid you or dismiss the reality of the illness b/c they are uncomfortable in dealing with it. This includes family and close friends. Finding support from people who understand is crucial.

Sometimes, this support may need to be from someone in the community who shares and understands your experience. *It has been important to me and I think it might be important to my daughter to stay connected with other people who have gone through similar circumstances.*

Others spoke about the difficulties they had along the way. One parent described the stress of the child's father moving out, and that when the diagnosis came soon after: *having a child with a broken heart helped heal our broken hearts.* Another parent commented: *it's hard to deal with illness day in and day out. There is no easy answer on how to handle it - but doing the best you can is the best answer.* One parent finished with *personally I feel more open and understanding to the pain and struggles of others after going through this difficult time.*

Quantitative

Demographics Distribution of Ill Child and Healthy Child Characteristics. The demographic distribution of ill child and healthy child characteristics are located in Table 1. The findings of this survey study in Table 1 show that the majority of respondents' (N=35, 76.1%) ill child had heart disease with the rest falling under other (N=11, 24.4%) diagnoses. A few of the other written responses were: *heart birth defect, heart transplant, pulmonary hypertension, childhood apraxia of speech, ARPKD Kidney Disease, and Vacterl's (congenital scoliosis/kyphosis, tethered spinal cord, heart defect, kidney reflux).* Table 1 also shows that the majority of respondents' children were diagnosed with a mean of 3 years ago, with 25 respondents' (54.3%) children diagnosed 5 years ago or more. Table # show that the large majority of the sample's (N=32) ill children were 7 or younger (69.5%), which was similar to the

sample's healthy children (N=21, 45.6%) at age 7 or younger. The breakdown of gender for both ill children and healthy children were proportionate. Lastly, Table 1 also shows the demographic variable "number of children", which the majority of the sample (N=37, 80.4%) reported two or more children in the household.

Table 1

Demographics Distribution of Ill Child and Healthy Child Characteristics

Variable	Options	Frequency	Percent
Ill Child's Diagnosis	Heart Disease	35	76.1%
	Other Diagnoses	11	24.4%
Time Since Diagnosis	6 months	3	6.5%
	1 year	2	4.3%
	2 years	6	13%
	3 years	7	15.2%
	4 years	3	6.5%
	5 years or more	25	54.3%
Ill Child's Age	0-3	18	39.1 %
	4-7	14	30.4 %
	8+	14	30.4%
Ill Child's Sex	Male	24	52.2 %
	Female	22	47.8 %
Healthy Child's Age	0-3	10	21.7%
	4-7	11	23.9%
	8+	21	45.7%
Healthy Child's Sex	Male	22	47.8%
	Female	19	41.3%
Number of Children in the Household	1	5	10.9%
	2	22	47.8%
	3	12	26.1%
	4+	3	6.5%

Demographic Distribution of Other Characteristics. Table 2 shows the demographic distribution of other sample characteristics, including current marital status and health insurance.

The findings of this study in Table 2 show that 8 respondents (17.4%) were divorced, 35

respondents (76.1%) were married, 2 respondents (4.3%) were single, and 1 respondent (2.2%) was widowed. The findings in Table # also show that 40 respondents (87%) had health insurance and 1 respondent (2.2%) did not.

Table 2

Demographics Distribution of Other Characteristics

Variable	Options	Frequency	Percent
Marital Status	Divorced	8	17.4%
	Married	35	76.1%
	Single	2	4.3%
	Widowed	1	2.2%
Health Insurance	Yes	40	95.2%
	No	1	2.4%

Sibling impact. The nominal variable “sibling impact” measured whether or not the parent felt that their ill child’s illness impacted their healthy sibling. The findings of this study show in Table 3 that 29 respondents (63%) felt that their child’s illness impacted their siblings whereas 9 respondents (19.6%) felt that it did not have an impact.

Table 3

Demographics Distribution of Sibling Impact

Variable	Options	Frequency	Percent
Sibling Impact	Yes	29	63%
	No	9	19.6%

Inferential Statistics

Correlation for severity of illness and family life domains. Table 4 and Table 5 show the inferential statistics of the relationship between the two variables, illness severity and family domains including financial, physical, emotional, social, behavioral, and personal domains

combined into a scale score ranging from 6 to 36. Table # shows that, of the 46 respondents, the mean illness severity from 1 to 10 was 7.22 with a standard deviation of 2.19. Table 4 also shows that, of the 40 respondents, the mean impact on the family domains scale from 6 to 36 was 25.5 with a standard deviation of 5.98.

The calculated Pearson correlation ($r = .386$, $p < .014$) indicates a moderate, positive correlation. Therefore, the greater the severity of the child’s illness the bigger impact it has on family life. Since the p-value ($p < .014$) is less than .05, this researcher rejects the null hypothesis. Therefore, the results of this portion of the study support the hypothesis that there is a statistically significant relationship between the severity of illness and each domain of family life. The results of the study indicate that parents’ perceived severity of their child’s illness correlates positively with the illness’ impact on the family. The greater perceived severity of illness, the bigger perceived impact on the family domains as a whole.

Table 4

Descriptive Statistics for Illness Severity and Family Domains Scale

Variable	N	Mean	Std Dev
Illness Severity	46	7.22	2.118
Family Domains Scale	40	25.5	5.987

Table 5

Correlation for Illness Severity and Family Domains Scale

		Illness Severity	Family Domains Scale
Illness Severity	Pearson Correlation	1	
	Sig. (2-tailed)		.386*
	N	46	.014 40

Family Domains Scale	Pearson Correlation	.386*	
	Sig. (2-tailed)	.014	1
	N	40	
			40

*. Correlation is significant at the 0.05 level (2-tailed).

Correlation for the severity of illness and positive impact. Table 6 and Table 7 shows the inferential statistics of the relationship between the two variables, illness severity and positive impact on siblings. Table 6 shows that, of the 46 respondents, the mean illness severity from 1 to 10 was 7.22 with a standard deviation of 2.19. Table 7 shows that, of the 35 respondents who answered the question, the mean positive impact on siblings score (ranging from 1 to 10) was 5.03 with a standard deviation of 2.31.

The calculated correlation ($r = .042$, $p < .809$) indicates a weak, positive correlation. Therefore, as respondents' perception of the severity of their child's illness increases, their belief about a positive impact on healthy siblings also increases. Since the p-value ($p < .809$) is not less than .05, this researcher cannot reject the null hypothesis. Therefore, the results of this study do not support the hypothesis that there is a significant relationship between respondents' perception of their child's severity of illness and the positive impact on healthy siblings. The results of this study do not indicate that there is a strong correlation or statistically significant relationship between the severity of illness and its positive impact on siblings.

Table 6

Descriptive Statistics for Illness Severity and Positive Impact

Variable	N	Mean	Std Dev
Illness Severity	46	7.22	2.118
Positive Impact	35	5.03	2.307

Table 7

Correlation for Illness Severity and Positive Impact

		Illness Severity	Positive Impact
Illness Severity	Pearson Correlation	1	.042
	Sig. (2-tailed)		.809
	N	46	35
Positive Impact	Pearson Correlation	.042	1
	Sig. (2-tailed)	.809	
	N	35	35

Correlation for the severity of illness and negative impact. Table 8 and Table 9 show the inferential statistics of the relationship between the two variables, illness severity and negative impact on healthy siblings. Table 8 shows that, of the 46 respondents, the mean illness severity from 1 to 10 was 7.22 with a standard deviation of 2.19. Table 8 shows that, of the 35 responses, the mean negative impact on siblings was 4.71 on a scale from 1 to 10 with a standard deviation of 2.72.

The calculated correlation ($r = .308$, $p < .072$) indicates a moderate, positive correlation. Therefore, as respondents' perception of the severity of their child's illness increases, their belief about a negative impact on healthy siblings also increases. Since the p-value ($p < .072$) is greater than .05, this researcher cannot reject the null hypothesis. Therefore, the results of this study do not support the hypothesis that there is a significant relationship between the perceived severity of their child's illness and the perceived negative impact on healthy siblings.

Table 8

Descriptive Statistics for Illness Severity and Negative Impact

Variable	N	Mean	Std Dev
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Illness Severity	46	7.22	2.118
Negative Impact	35	4.71	2.718

Table 9

Correlation for Illness Severity and Negative Impact

		Illness Severity	Negative Impact
Illness Severity	Pearson Correlation	1	.308
	Sig. (2-tailed)		.072
	N	46	35
Negative Impact	Pearson Correlation	.308	1
	Sig. (2-tailed)	.072	
	N	35	35

Correlation for the impact on siblings and impact on family. Table 10 and Table 11 show the inferential statistics of the relationship between the two variables, impact on family domains and impact on siblings. Table 10 shows that, of the 40 respondents, the mean impact on family domain was 25.5, ranging from 6 to 36, with a standard deviation of 5.98. Table 10 also shows that, of the 35 respondents, the mean impact on siblings scale score was 16.6, ranging from 6 to 36, with a standard deviation of 8.34.

The calculated correlation ($r = .450$, $p < .008$) indicates a moderate, positive correlation. Therefore, as parents perceive the impact of their child's illness on the family increases, their perception on its' impact on the healthy sibling also increases. Since the p-value ($p < .008$) is less than .05, this researcher rejects the null hypothesis. Therefore, the results of this study support the hypothesis that there is a significant relationship between respondents' perception about the child's illness impact on the family and respondents' perception about the child's illness' impact on the healthy siblings. The results of this study indicate that when parent's perceive their child's

illness impacts family domains of life, including physical, emotional, social, etc, it positively correlates with its' impact on the siblings.

Table 10

Descriptive Statistics for Family Domains Scale and Sibling Impact Scale

Variable	N	Mean	Std Dev
Family Domains Scale	40	25.5	5.987
Sibling Impact Scale	35	16.62	8.342

Table 11

Correlation for Sibling Impact Scale and Family Domains Scale

		Family Domains Scale	Sibling Impact Scale
Family Domains Scale	Pearson Correlation	1	.450**
	Sig. (2-tailed)		.008
	N	40	34
Sibling Impact Scale	Pearson Correlation	.450**	1
	Sig. (2-tailed)	.008	
	N	34	35

** . Correlation is significant at the 0.01 level (2-tailed).

Correlation for severity of illness and amount of stress. Table 12 and Table 13 show the inferential statistics of the relationship between the two variables, illness severity and level of stress. Table 12 shows that, of the 34 respondents, the mean level of stress scale score was 41.5 ranging from 2 to 60, with a standard deviation of 8.82.

The calculated correlation ($r = .326$, $p < .06$) indicates a moderate, positive correlation. Therefore, as the parents' perception of the severity of the child's illness increases, the level of stress the parent and family experience increases. Since the p-value ($p < .06$) is not less than .05, we fail to reject the null hypothesis. Therefore, the results of this study do not support the

hypothesis that there is a statistically significant relationship between the parents perception of the severity of their child's illness and the level of stress they experience.

Table 12

Descriptive Statistics for Illness Severity and Level of Stress Scale

Variable	N	Mean	Std Dev
Illness Severity	46	7.22	2.118
Level of Stress Scale	34	41.52	8.829

Table 13

Correlation for Illness Severity and Level of Stress Scale

		Illness Severity	Level of Stress Scale
Illness Severity	Pearson Correlation	1	.326
	Sig. (2-tailed)		.060
	N	46	34
Level of Stress Scale	Pearson Correlation	.326	1
	Sig. (2-tailed)	.060	
	N	34	34

Correlation for level of stress and impact on family domains. Table 14 and Table 15 show the inferential statistics of the relationship between the two variables, level of stress and impact on family domain.

The calculated correlation ($r = .656$, $p < .000$) indicates a strong, positive correlation. Therefore, as the level of stress increases, the perceived impact of their child's illness on family domains increases. Since the p-value ($p < .000$) is less than .01, this researcher rejects the null hypothesis. Therefore, the results of this study support the hypothesis that there is a statistically significant relationship between the level of stress parents experience because of their child's illness and the perceived impact on family domains. The results of this study indicate that when

parents experience increased levels of stress, they are more likely to perceive their child's illness as having a greater impact on the family.

Table 14

Descriptive Statistics for Level of Stress Scale and Family Domains Scale

Variable	N	Mean	Std Dev
Level of Stress Scale	34	41.52	8.829
Family Domains Scale	25.5	5.98	40

Table 15

Correlation for Level of Stress Scale and Family Domains Scale

		Level of Stress Scale	Family Domains Scale
Level of Stress Scale	Pearson Correlation	1	.656**
	Sig. (2-tailed)		.000
	N	34	33
Family Domains Scale	Pearson Correlation	.656**	1
	Sig. (2-tailed)	.000	
	N	33	40

** . Correlation is significant at the 0.01 level (2-tailed)

Correlation for level of stress and impact on siblings. Table 16 and Table 17 show the inferential statistics of the relationship between the two variables, level of stress and impact on siblings.

The calculated correlation ($r = .475$, $p < .007$) indicates a moderate, positive correlation. Therefore, as the level of stress increases, the impact of their child's illness on the healthy siblings increases. Since the p-value ($p < .007$) is less than .05, this researcher rejects the null hypothesis. Therefore, the results of this study support the hypothesis that there is a statistically

significant relationship between the level of stress parents and families experience because of their child's illness and the impact on healthy siblings.

Table 16

Descriptive Statistics for Level of Stress Scale and Sibling Impact Scale

Variable	N	Mean	Std Dev
Level of Stress Scale	34	41.52	8.829
Sibling Impact Scale	35	16.62	8.342

Table 17

Correlation for Level of Stress Scale and Sibling Impact Scale

		Level of Stress Scale	Sibling Impact Scale
Level of Stress Scale	Pearson Correlation	1	.478**
	Sig. (2-tailed)		.007
	N	34	31
Sibling Impact Scale	Pearson Correlation	.475**	1
	Sig. (2-tailed)	.007	
	N	31	35

** . Correlation is significant at the 0.01 level (2-tailed)

Discussion

Forty-six parents who have a chronically ill child and a healthy child responded to the electronic survey from the non-profit support organizations they were involved in. The results of the study indicate that childhood chronic illness does impact the family in many ways. It first showed that there was a positive correlation of illness between its impact on the family and the impact on siblings, showing the interrelated effect of family systems. This finding is consistent with previous literature, recognizing that the changes that occur after diagnosis produce stress

and strain on both individuals themselves as well as the family as a unit (Bouma & Schweitzer, 1990; Williams, 1997). It is important to consider the family context, as parents are gatekeepers for their children

This relates to the second significant finding of this research: the greater perceived severity of their child's illness, the more likely parents were to report it impacts the family, but not necessarily on either end of the positive or negative spectrum. This research showed that families are impacted in a multi-faceted and all-encompassing way and in some ways could be considered positive or negative manner. Illness severity may be just one of many factors that plays a role in whether or not families adjust in an adaptive manner. This finding was consistent with prior research, in that disease characteristics like "variability in clinical expression, chronicity, severity, and the associated hardships imposed on individual families" all combine as a risk factor for family maladjustment (Alderfer, 2010; Bouma & Schweitzer, 1990, p.724; Cohen et al., 1995; Terzo, 1999; Williams, 1997; Zimmerman, 1993).

The biggest takeaway from this research should be the significant finding of the relationship between perceived level of stress and its impact on both families and siblings. The stress scale score was quantified by three questions, two specifically about the family and healthy siblings, and the third about nine particular events that may cause stress, such as hospitalizations or change in normalcy. It is not surprising that there were significant correlations for both the siblings and families, as it has been shown that what impacts the family invariably affects the siblings. This shows that, healthy siblings are more impacted by their brother or sisters' illness if stress is a present variable and may lead to further problems with adjusting to the illness.

Though this relationship was significant, there was no significance between the variables of illness severity and stress suggesting there may be outside influences separate that may mediate the effects on siblings and families. This validates Cohen (1999), Eiser (1994), and Kazak's (1997) thought that families facing serious pediatric illness are fundamentally ordinary families that face extraordinary stressors and are forced to cope with unique circumstances. Simply knowing that stress, whatever the source, is significant in families experiencing childhood chronic illness is something social workers and other allied health professions should key into.

The results of the qualitative portion of this research study exemplified the day-to-day experiences of ill children and their families, as parents responded to many of the open-ended questions with careful thought and consideration. Parents explained the kinds of physical limitations on their children which help add substance of how their daily lives are impacted, such as the management of medications and being immunosuppressant. The physical limitations of ill children may place a higher demand of care on parents and families, thus creating more stress. When working with ill children and their families, social workers and other health professions should assess physical limitations and care needs in children and thereby work with families to adapt in the most beneficial way possible. The financial toll illness places on parents was stressed highly, in addition to the uncertainty and the unknown. Social workers should recognize that this a major source of concern and stress for parents and help support them by providing psychoeducation and resources when available. Parents acknowledged many of the impacts on siblings, as the research does both in a positive and negative manner, including emotional influences, the disparity of attention giving, how the disruption in normal routines invariably impacts siblings compared to the increased compassion and empathy towards others who are

different, the protectiveness, independence, and maturity siblings exhibit, and how the family itself has gotten closer, thus improving the sibling relationship. Given that most social workers utilize the strengths perspective, it is important for families to hear the things they are doing well and the positive attributes siblings are exhibiting.

Though they described many of similar attributes as above, parents also made note of the adjustments they have noticed in both siblings and the family as a whole, including accepting help and looking for support both within the family and in the community and having a good health care team behind you. When asked to give advice, parents keyed into self-care, maintaining balance and routine, having open communication, and always paying attention to the healthy sibling. These are all variables that could be researched more to ensure positive wellbeing in families who are impacted by illness. Several parents wrote in the last question where they exhibited an illness perspective of thoughtful reflection and wisdom of what they were taught because of the experience.

All of the findings in this study suggest that illness impacts more than the physical and biological processes of the body; it spans the psychological, emotional and mental domains as well, confirming the all-compassing influence of health and illness. These findings show that it may be beneficial to utilize a bio psychosocial and family systems approach when working with chronically ill children, their parents, and families.

The qualitative and quantitative portions of this research were consistent with Williams et al (2009), and Bouma & Schweitzer's (1990) research, in that the impact of illness was shown to produce strain in all areas of life including financial, physical, emotional, social, behavioral, and personal domains. The qualitative results of this study were also consistent with previous research in identifying both the negative (Bouma & Schweitzer, 1990; Cohen, 1999; Williams,

1997; Zimmerman, 1997) and positive effects of childhood chronic illness (Sharpe & Rossiter, 2002; Williams, 2009). Alderfer et al., (2010) Murray (1998), Sharpe & Rossiter (2002), and Williams, (1997) all noted family closeness as a positive effect of childhood illness. This research did not find family closeness as a positive effect, but this is likely related to the focus of the question on siblings specifically.

The overall findings of this study demonstrate that it is important to consider family systems in the delivery of care in pediatrics, as there was a positive correlation between the impact of siblings and the family. Social workers and other allied health professionals should be meticulous in assessing for sources of stress, both illness and non-illness related.

Strengths and Limitations

There are several strengths of this research. The study was broader in nature and included many different variables to paint an overall picture of the daily lives of parents and families experiencing illness. This study found several positive, statistically significant correlations that may provide some insight to this topic and could be a focus of future research. Most importantly, this study was able to give a voice to the experts on childhood chronic illness; the *parents*. Despite the small sample size, many parents who responded to the survey put time and effort into writing about their experiences. This researcher credits this to their involvement and relationship with the supportive non-profit organizations in which they are involved.

This research was broader in nature exploring several variables that may play a role in families; however, this is both a strength and limitation, because although it gives breadth and provides a perspective related to childhood chronic illness, it does not specifically explore one issue in its entirety. There are always limitations with using survey-based research, such as the availability to skip questions or not being honest in responses. This study was primarily limited

by its small sample size of 46. The sample size could have been expanded by having more time to make connections with other organizations. Ideally, the sample should have been more evenly distributed among disease categories, with this sample being primarily ill children with heart related illnesses and defects.

Implications for Research

The literature suggests that open and honest communication between parents and well siblings can alleviate fears and stress (Zimmerman, 1997). This study did not explicitly ask about communication between parents and well siblings, but this may be another factor that impacts family and sibling adjustment and should be explored further by future research. Previous research emphasizes the impact of caring for an ill child places enormous amounts of stress on parents, which then in turn impacts the family system (Cohen, 1999; Compas et al., 2012, Lohnberg et al., 2008). In this study, illness severity was found to correlate with its impact on families; and, furthermore, parents described their sources of stress that sometimes included caregiving demands such as medication management, but it did not ask specifically about the correlation between caregiving and how the family is impacted. Future research should explore this relationship between the severity of illness, care needs, and demands on parents on how that relates to the family system.

Practice Implications

Social workers and other allied health professionals that are assessing and working with chronically ill children and their families should be inquiring about parents' understandings of illness severity, the level and sources of stress they are experiencing, and overall the functioning of the family and siblings. Professionals should listen carefully when talking with parents and take note of some of these themes and others found in prior research. For example, social

workers could work with families to reduce stress in the household by encouraging families to reach out to alternative caregivers, knowing that illness demands, severity and stress impact families. Social workers could also normalize and provide education to parents about the acting-out behavior in healthy siblings and urge parents to maintain routine and structure, which may reduce the stress that is experienced. This is not to downplay other influences separate from the illness experience that may likely be causes of stress, such as marital conflict or job loss. Social workers should key into these other, non-illness related variables, like family structure, living situation, lack of trust in physicians and others that may also be interceding the experience.

Furthermore, this research found that many parents exhibited an “illness perspective” and outlook on life, particularly demonstrated in their responses on advice to other parents and written comments on what their experience has taught them. Their thoughtful reflection and wisdom should not be understated nor missed. Social workers and other health care professionals can assist in facilitating this process of reflection in parents and help connect parents to support organizations. All parents in this survey study were involved in supportive non-profit organizations, where their connection with others experiencing similar circumstances is focused within a family systems approach.

Social workers and other allied health professionals are in a *human* profession that cannot always be defined by correlation or statistics. Though there appears to be an abundance of research on this topic, previous literature tended to miss the day-to-day accounts of how families and siblings adjust to illness. This study expanded prior research by including parent’s perspectives and voices in the effects that previous researchers cite (Cohen, 1999; Cohen, 1995; Lavigne & Ryan, 1979; Zimmerman, 1995). We need to continue to recognize the impacts of illness on individuals and family systems and how overall health encompasses more than the

physical processes of the body (WHO, 2011). This researcher found that many parents convey unique perspectives from going through the circumstances of their experience. As quoted by an anonymous social worker at a local acute care children's hospital, who echo's that walking through the journey with parents and families can be rewarding: *they're going through it, whether I'm a part of it or not. If I can help make their journeys easier, then what greater reward is there?* One parent confirmed that: *we are grateful for our son's life. It has changed us in many ways, many of them very positive ones. We have come to value human life as the most precious thing there is. Life is a gift.*

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Appendix A

Survey

Childhood Chronic Illness' Impact on the Family

You been asked to complete a 27 question survey because you are a parent of a chronically ill child and are involved in either a non-profit organization or affiliated with a support group. The purpose of this survey research study is to examine the impact of childhood chronic illness on the family, with a specific focus on its' impact on siblings. The survey asks 12 non-identifying demographic questions, with 15 closed-ended questions and 8 open-ended questions and will take approximately 15-45 minutes to complete, depending on the thoroughness of your answers. There are no known risks or benefits by participating in this study. Your valuable perspective and the sharing of your experiences about the day-to-day life of your family is very appreciated. When the survey asks about how illness impacts siblings, please think of one sibling that is most impacted by the illness. By checking the box below and filling out the survey, you are automatically assuming informed consent. This means you understand that you can skip questions, not finish the survey, and once the survey is complete, you cannot change nor withdrawal your responses.”

Demographics:

Child with Illness Characteristics:

1. Please choose one of the following that best describes your child's diagnosis:

Heart Disease Cancer Diabetes Arthritis Cystic fibrosis
 Asthma Developmental Disability including ADHD and Autism Spectrum
 Mental Illness Other: Please Specify

2. What is the age of your ill child? 0-3 4-7 8-11 12-15

_____16-19 _____20+

3. What is sex of your ill child? _____Male _____Female _____Other

4. How long has it been since your ill child was diagnosed with their illness?

_____6 months _____1 year _____2 years _____3 years _____4 years _____5 years or more

5. On a scale from 1 to 10 (1 being not severe 10 being very severe), what is the severity of your child’s illness:

1 2 3 4 5 6 7 8 9 10

6. Briefly describe your child’s limitations related to his/her illness:

Healthy Child/Sibling Characteristics:

7. If there is more than one sibling in the home, please think of the **one** who has been **most impacted** by the illness

8. What is the sex of your healthy child? _____Male _____Female _____Other

9. What is the age of your healthy child? _____0-3 _____4-7 _____8-11 _____12-15

_____16-19 _____20+

Parental/Family Characteristics:

10. What is your current marital status? _____ Divorced _____ Married _____

Separated _____ Single _____ Widowed

11. How many children are in the household? _____0 _____1 _____2 _____3 _____4+

12. Does the family have health insurance? _____ Yes _____ No _____ Other: Please Specify

Impact/Effect on Family

13. To what extent has your family been impacted by your child’s illness within the following domains:

No impact moderate impact great impact

1 2 3 4 5 6

- Financial 1 2 3 4 5 6
- Physical 1 2 3 4 5 6
- Emotional 1 2 3 4 5 6

- Social 1 2 3 4 5 6
- Behavioral 1 2 3 4 5 6
- Personal 1 2 3 4 5 6

14. On a scale from 1 to 5, please rate the amount of stress/strain you experience as a **family** because of your child’s illness. (1 being no stress, 5 being great stress)

1 2 3 4 5

15. In the following areas, to what extent has your child’s illness caused stress for the family?

No stress moderate stress great stress
1 2 3 4 5

- Daily roles of family members
1 2 3 4 5
- Disease-specific symptoms, treatment, and demands
1 2 3 4 5
- Family strain
1 2 3 4 5
- Missing work
1 2 3 4 5
- Children missing school
1 2 3 4 5
- Change in family structure and normalcy
1 2 3 4 5
- Hospitalizations
1 2 3 4 5
- Interpersonal conflict
1 2 3 4 5
- Uncertainty
1 2 3 4 5
- Losses
1 2 3 4 5

16. Please share any comments or stories related to how your child’s illness has impacted the family as a whole and/or the ways in which your family experiences stress/strain related to the illness. Specific examples would be appreciated, such as the cost of medication as being difficult needing to administer child’s medication multiple times a day, etc.

Impact/Effects on Siblings:

17. Do you feel your ill child’s illness has impacted his/her sibling? _____Yes_____No

18. On a scale from 1 to 5, please rate the amount of stress/strain your **healthy child** experiences because of your child’s illness. (1 being no stress, 5 being great stress).

- 1 2 3 4 5

19. On a scale from 1 to 10 (1 being not at all negative, 10 being very negative) please rate how much your child’s illness has impacted your healthy child negatively:

1 2 3 4 5 6 7 8 9 10

20. To what extent is your healthy child impacted in the following ways:

No impact	moderate impact	great impact
1	2	3
4	5	6

- Disrupted in normal routines such as missing school

1 2 3 4 5 6

- Vulnerability to negative feelings such as jealousy, worry or loneliness

1 2 3 4 5 6

- Less family cohesion

1 2 3 4 5 6

- Decreased maturity

1 2 3 4 5 6

- increased dependence

1 2 3 4 5 6

- behavioral disruptions such as acting out

1 2 3 4 5 6

21. Please comment on or share a couple examples of how you feel your healthy child has been impacted negatively by your child’s illness.

22. On a scale from 1 to 10 (1 being not at all positive, 10 being very positive) please rate how much your child’s illness has impacted your healthy child positively:

1 2 3 4 5 6 7 8 9 10

23. It is not uncommon for families and siblings to share a few positive examples of how their child’s illness has impacted them. For example, sometimes families note increased family closeness and cohesion, maturity in siblings, increased empathy and compassion and evidence of personal growth. Please comment on or share a couple examples of how you feel your healthy child has been affected positively by your child’s illness.

Adjustment to Illness

24. When thinking about how your healthy child has responded to his/her sibling’s illness, what changes or adjustments have you noticed? Please comment on any behavioral, physical, and/or emotional responses.

25. What advice or suggestions would you give to other parents who are in a similar position to yours?

26. Name the biggest thing that has helped the family adjust to the illness:

27. Is there anything that comes to mind that wasn't covered in this survey? Do you have any thoughts, comments, or stories you'd like to share?

Appendix B

“Non-profit organization name”

December 15th, 2012
University of St. Thomas
2115 Summit Avenue
St. Paul, MN 55105

Dear Institutional Review Board Committee:

As the Vice President of “non-profit organization”, I am writing to give my support to Heather La Clare, Graduate Student in the Masters of Social Work Program at University of St. Thomas and St. Catherine University in her survey research study.

I understand Heather will be doing an original, graduate-level research study on the effects of childhood chronic illness on families and siblings. I am aware that her survey comprises of both open and closed ended questions and is approximately 27 questions long and will take about 15-45 minutes long to complete. Upon written consent from “non-profit organization” we will be forwarding an email with a link to her online survey to the families in our database. I recognize that parents will receiving the survey but may choose to participate or decline. The parents associated with our non-profit organization have children with cardiovascular disease, therefore, our organization is appropriate for her study.

Heather has provided “non-profit organization” with the necessary forms to explain the confidentiality protocols she will be adhering to as well as the risks and benefits of the study. Parents will understand that the surveys will be anonymous. We recognize that her research project will be published and presented in a public forum. This “non-profit organization” is graciously inviting Heather to conduct her study.

Sincerely,

*Signature deleted to provide confidentiality

Print Name and Title: