SIBLINGS OF CHRONICALLY ILL CHILDREN

by

Samantha Suzanne Newcom

A Masters Report Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements
For the Degree of

MASTER OF SCIENCE

In the Graduate College

THE UNIVERSITY OF ARIZONA

2004
STATEMENT BY THE AUTHOR

This master’s report has been submitted in partial fulfillment of the requirements for an advanced degree at The University of Arizona and is on reserve in the Arizona Health Sciences Center to be made available to borrowers under the rules of the library.

Brief quotations from this report are allowable without special permission, provided that accurate acknowledgement of the source is documented. Requests for permission for extended quotation from or reproduction of this manuscript in whole or in part may be granted by the head of the major department or the Dean of the Graduate College when in his or her judgment the proposed use of this material is in the interests of scholarship. In all other instances permission must be obtained from the author.

SIGNED: Samantha S. Newcom

APPROVAL BY MASTERS REPORT DIRECTOR

This has been approved on the date shown below:

Ida M. (Ki) Moore  
Professor of Nursing  
2/25/05  
Date
ACKNOWLEDGMENTS

I would like to thank the two members of my report committee Dr. Ki Moore and Connie Trice for their feedback and support. I would also like to thank my twin sister Tami Odom and my friend Kelly Foster for believing in me and for encouraging me as I wrote this paper. Finally, I am extremely grateful to my husband Jon, for the continuous love and support he has shown me during the pursuit of my master’s degree.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>STATEMENT BY THE AUTHOR</td>
<td>2</td>
</tr>
<tr>
<td>ACKNOWLEDGMENTS</td>
<td>3</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>4</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>5</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>6</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>7</td>
</tr>
<tr>
<td>CHAPTER I. INTRODUCTION</td>
<td>8</td>
</tr>
<tr>
<td>Introduction</td>
<td>8</td>
</tr>
<tr>
<td>Purpose Statement</td>
<td>10</td>
</tr>
<tr>
<td>Background</td>
<td>11</td>
</tr>
<tr>
<td>Significance of Sibling Relationships</td>
<td>13</td>
</tr>
<tr>
<td>Significance to Nursing</td>
<td>14</td>
</tr>
<tr>
<td>Theoretical Framework</td>
<td>15</td>
</tr>
<tr>
<td>Summary</td>
<td>18</td>
</tr>
<tr>
<td>CHAPTER II. LITERATURE REVIEW</td>
<td>20</td>
</tr>
<tr>
<td>Introduction</td>
<td>20</td>
</tr>
<tr>
<td>Review Articles Relevant to Siblings of Children with Chronic Illnesses</td>
<td>20</td>
</tr>
<tr>
<td>Articles Specific to Siblings of Children with Illnesses in Different Disease Categories</td>
<td>29</td>
</tr>
<tr>
<td>Siblings of Children with Chronic Life-threatening Diseases</td>
<td>29</td>
</tr>
<tr>
<td>Siblings of Children with Progressive Fatal Illnesses</td>
<td>35</td>
</tr>
<tr>
<td>Articles Relevant to Siblings of Children with Neurological Illnesses</td>
<td>37</td>
</tr>
<tr>
<td>Articles Analyzing the Variables that Impact Healthy Sibling Outcomes</td>
<td>47</td>
</tr>
<tr>
<td>Intervention Studies Relevant to Siblings of Chronically Ill Children</td>
<td>53</td>
</tr>
<tr>
<td>Summary</td>
<td>60</td>
</tr>
<tr>
<td>CHAPTER III. IMPLICATIONS FOR NURSING PRACTICE</td>
<td>62</td>
</tr>
<tr>
<td>Knowledgeable Research Consumers</td>
<td>62</td>
</tr>
<tr>
<td>Assessing Before Intervening</td>
<td>62</td>
</tr>
<tr>
<td>Social Support</td>
<td>65</td>
</tr>
<tr>
<td>Recommended Interventions</td>
<td>66</td>
</tr>
<tr>
<td>Summary</td>
<td>71</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>72</td>
</tr>
</tbody>
</table>
LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1.1</td>
<td>A Family Ecosystem</td>
<td>17</td>
</tr>
<tr>
<td>Figure 1.2</td>
<td>The Family Adjustment and Adaptation Response (FAAR) Model</td>
<td>18</td>
</tr>
</tbody>
</table>
### LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 2.1</td>
<td>Review Articles Relevant to Siblings of Children with Chronic Illnesses</td>
<td>26</td>
</tr>
<tr>
<td>Table 2.2</td>
<td>Articles Relevant to Siblings of Children with Specific Diseases</td>
<td>41</td>
</tr>
<tr>
<td>Table 2.3</td>
<td>Articles Analyzing the Variables that Impact Healthy Sibling Outcomes</td>
<td>51</td>
</tr>
<tr>
<td>Table 2.4</td>
<td>Intervention Studies Relevant to Siblings of Chronically Ill Children</td>
<td>57</td>
</tr>
</tbody>
</table>
ABSTRACT

The purpose of this report is to summarize the current state of knowledge pertaining to how siblings of chronically ill children are impacted by their brother or sister’s illness and what can be done to improve their outcomes. Recent, relevant literature was reviewed, and implications for nursing practice were addressed. Although multiple factors affect sibling adjustment, most articles reviewed did indicate that the presence of a pediatric chronic illness in the home does predispose healthy siblings to the development of psychosocial problems. Evidence-based interventions to support siblings were recommended when possible. The theoretical framework was Family Systems Theory with its main premise being what happens to one family member will in turn affect every other family member. Although the body of knowledge specific to siblings of chronically ill children has grown significantly over the last 10-15 years, the impact of the multiple variables involved is still not completely understood.
CHAPTER I
INTRODUCTION

Having a chronically ill child in the family can have a profound impact on the welfare of each family member, including the healthy siblings (Derouin & Jessee, 1996). Research focused specifically on healthy siblings of children with chronic illnesses has been escalating since the 1970’s (Van Riper, 2003). According to a meta-analysis that included more than 50 different studies, more reports concerning siblings of children with chronic illnesses were published in the 1990’s than in all of the previous decades combined (Sharpe & Rossiter, 2002). Research in this area has recently moved toward testing interventions that are aimed at helping healthy siblings adapt to life with a chronically ill brother or sister (Williams et al., 1997). It is important for health care providers to keep updated concerning new research so that their clinical practice is consistent with and incorporates current knowledge.

In 1994, 12 percent of U.S. children had a chronic physical, developmental, behavioral, or emotional condition that required health or health-related services beyond those routinely used by the average child (Newacheck et al., 1998). Other sources estimate that 15 to 18 percent of children in the United States will experience a chronic illness or disability at some point during their childhood (Chernoff, Ireys, DeVet, & Kim 2002). In the United States one million chronically ill children are severely impaired and an estimated three million family members are significantly impacted by the numerous responsibilities of providing for their care (Williams, 1997). In a comprehensive review of more than 40 studies, Williams reported that 60 percent of the studies demonstrated
that siblings of chronically ill children are at an increased risk for developing adverse psychosocial outcomes (Williams). Other sources indicate that siblings of children with chronic illnesses or developmental disabilities are two to three times more likely to develop adverse psychological problems than siblings of non-ill children (Lobato & Kao, 2002). This may be due to the acknowledged fact that healthy siblings tend to be the most emotionally neglected and unhappy of all family members when another child in the family has a serious illness (Murray, 1998). In addition, parents are sometimes less tolerant of their healthy children in comparison to their children that are chronically ill (Foster et. al, 2001).

Multiple definitions of chronic illness exist and are commonly used. The presentation and course of a chronic illness can also vary greatly. While some chronic illnesses are irreversible, serious and obvious others may be temporary, insignificant and obscure (Brady, 2004). According to Mosby’s Medical, Nursing and Allied Health Dictionary fourth edition, a chronic illness is defined as “any illness that persists over a long period of time and affects the person’s physical, emotional, intellectual, social or spiritual functioning”. Another definition of chronic illness is that it is a medically diagnosed condition with a duration of six months or longer, which demonstrates little change or slow progression (Williams, 1997). Furthermore, a chronic illness has also been defined as a condition that interferes with daily functioning for more than three months in one year, causes hospitalization of more than one month in any given year or is likely to cause either of these in the future (Wong, Hoockenberry-Eaton, Winkelstein, Wilson, Ahmann & DiVito-Thomas, 1999).
Some of the most prevalent chronic illness statistics among children in the United States are listed in this paragraph. In 1996, 23.6 out of 1000 children under the age of 18 were estimated to have some form of heart disease and four out of 1000 children were estimated to have some form of epilepsy (Center for Disease Control, 2004). One out of every 500 African-American babies and one out of every 1,000 to 1,400 Hispanic American babies will receive a diagnosis of sickle cell anemia (American Sickle Cell Anemia Association, 2004). It is estimated that during the year 2002 approximately 9,100 children age 0-14 years in the United States received a new diagnosis of cancer (American Cancer Society, 2004). Thirty thousand Americans have cystic fibrosis (CF) and 80 percent of those with CF were diagnosed by the time they were three years old (Cystic Fibrosis Foundation, 2004). In addition, it is estimated that 206,000 people living in the U.S. that are under the age of 20 have diabetes (American Diabetes Association, 2004). Finally, 8.7 percent of children in the U.S. have been diagnosed as having some form of asthma (National Center for Health Statistics, 2004).

Purpose Statement

The purpose of this master’s report is to summarize the state of knowledge currently available regarding siblings of chronically ill children. The three questions to be answered are: 1) How are healthy children affected by their sibling’s chronic illness? 2) What are some of the disease specific issues that affect these healthy siblings? and 3) What interventions have demonstrated effectiveness in improving healthy sibling outcomes? In order to address the above, a review of current literature will be completed
and summarized in chapter two. In addition, chapter three will focus on the implications for nursing practice.

Background

The presence of pediatric chronic illness in the home can lead to adjustment problems for healthy siblings. Some researchers speculate that this is because pediatric chronic illness often causes parents to have less time for interacting with their healthy children. In addition, when interactions do occur, they are often negative due to the stress the family faces on a daily basis (Gallo & Szychlinski, 2003). Furthermore, when a child is chronically ill, changes occur in the family routine. Healthy brothers and sisters often become responsible for more housekeeping activities and/or childcare. This increased contribution in the home is often associated with a decrease in school and social activities (Cox, Marshall, Mandleco & Olsen, 2003). Adjustment problems that these healthy siblings develop are evidenced by poor academic achievement, impaired social interactions, aggressiveness, social isolation and withdrawal. In addition, these healthy siblings often experience and display feelings of anger, anxiety, confusion, depression, fear, guilt, jealousy and resentment (Fleitas, 2000; Murray, 1998; Sahler et al., 1997; Thibodeau, 1988 & Williams, 1997). The following quote, written by a 14-year-old female whose younger sister was diagnosed with cancer, clearly reveals the turmoil that a sibling of a chronically ill child can experience (Murray, 1998).

As her illness became the focal point in our lives, jealousy, anger, and confusion jumbled in my mind. I wondered if our family would ever be the same. I began to feel hatred for my sister. I often thought if I got sick, maybe I too would
receive presents and sympathy. My sister stood bathed in the spotlight, and I’d been thrown into the corner. I resented her. I thought everyone was totally insensitive to me. People would always ask me how she was doing, never how I was doing. I was suffering just as much as she was – not physically, but emotionally. I became very tough on the outside, but I was dying on the inside. (p. 62).

However, some research studies have demonstrated that healthy siblings of chronically ill children will not necessarily develop negative psychosocial outcomes, but may actually experience positive outcomes. A few of the positive outcomes that have been identified are personal maturation, increased appreciation for life, increased sensitivity, enhanced family closeness and empathy for others (Murray, 1998). The potential for both positive and negative outcomes are thought to be due, in part, to the numerous non-illness and illness related variables that may be involved.

Some of the non-illness related variables that have been recognized as influencing healthy siblings’ psychosocial outcome are age, developmental level, sex, birth order, birth spacing and type of illness (Thibodeau, 1988). These factors affect healthy sibling outcomes because they influence a person’s understanding of the illness as well as impact sibling relationships. Generally, closer age spacing between the ill child and healthy sibling has been associated with an increased risk for healthy sibling adjustment problems. Also, sisters that are older than the chronically ill child and brothers that are younger have demonstrated higher levels of behavioral problems (Gallo & Szychlinski, 2003). Additional factors that can potentially affect healthy siblings’ adjustment are
family dynamics such as the quality of marital relationships, sibling relationships (prior
to and during the illness), family communication and problem-solving skills (Drotor &
Crawford, 1985). Furthermore, the absence or presence of parental depression, the
mother’s perspective concerning her child’s illness, the level of community support, the
available family resources, the family’s social class and the time elapsed since diagnosis
have also been shown to impact sibling adjustment (Williams, 1997).

Two illness related variables that can influence a healthy sibling’s adaptation are
the type of chronic illness and the duration of the illness (Patterson & Garwick, 1994).
For example, a healthy sibling is more likely to be influenced by his or her sibling’s
illness if the prognosis is bad, if the disability is severe or if the illness will be prolonged.
In addition, whether or not the illness is progressive or relapsing are also illness related
variables that can affect how a healthy sibling adapts. The amount of care provided in
the home verses the amount of care provided in a hospital setting as well as whether the
care is needed daily, weekly, monthly, or intermittently are other factors that can affect a
healthy sibling’s adjustment (Patterson & Garwick). In summary, pediatric chronic
illness is a stressor, which in combination with multiple other variables has the potential
to increase a healthy sibling’s risk for developing adverse psychosocial outcomes (Drotor
& Crawford, 1985).

Significance of Sibling Relationships

Due to longevity and shared growing experiences, sibling relationships are
usually the strongest of all family bonds (Thibodeau, 1988). Siblings often share their
thoughts, feelings and secrets with each other, and this can lead to a supportive
relationship in which they can mature (Thibodeau). Even competition between siblings can be useful by teaching children about conflict resolution and interaction (Thibodeau). Not surprisingly then, the sibling relationship has been shown to have a considerable effect on the development and social adjustment of children (Mancuso, 2003). Children’s initial social interactions are usually with their siblings. Because of these interactions, they become each other’s instructors, role models, counselors and mediators. Siblings usually spend twice as much time interacting together as they do with their mother or father. In addition, the lifespan of the siblings usually extends beyond that of their parents (Mancuso). For these reasons, it seems that siblings significantly influence one another while growing up and into adulthood. Therefore, it seems reasonable to conclude that one child’s chronic illness can have a dramatic impact on his or her healthy siblings. Unfortunately, there is minimal information available describing how sibling relationships are affected by pediatric chronic illnesses (Derouin & Jessee, 1996).

Significance to Nursing

Nurses should provide family centered care which involves recognizing that the family is the constant in each child’s life (Wong et al., 1999). Family centered care is based on two different concepts, enabling and empowering. Nurses can enable families by providing opportunities for each family member to use their abilities and by helping them to develop new ones. In addition, nurses can also empower families by allowing the mother and father to have equal partnership with health care providers. This allows the parents to acquire and maintain a sense of control over their lives which then impacts the entire families’ sense of control, including the healthy siblings (Wong et al.).
The Family Systems Theory, which is discussed in the following section, helps to clarify why healthy siblings of children with chronic illnesses need consideration by the nursing profession. The presence of chronic illness influences everyone in our society ranging from close family members of the ill person to every person in the community. This is due to the fact that chronic illness increases the cost of health care and reduces productivity (Patterson & Garwick, 1994). Every single family member is impacted by a chronic illness and this is why nurses must promote healthy adaptation for each and every family member, including the healthy siblings. In order to accomplish this, nurses need to know what interventions have demonstrated effectiveness in helping healthy siblings adapt. Armed with this knowledge, nurses can then promote interventions that have been proven effective (evidence based practice) and influence the entire family in a positive way. Those interventions will then, in turn, influence their community and our society as a whole.

Theoretical Framework

The theoretical framework that will be used as a foundation for this report is the Family Systems Theory. According to Family Systems Theory, family members are interdependent in relation to one another and have regular interactions with one another (Morgaine, 2002). Family members also have boundaries that range from open to closed. Family members also function on the premise that the whole is more than the sum of its parts. In addition, family members have spoken and unspoken agreements that prescribe or limit their actions and they exhibit logical behavior patterns (Morgaine). The family is a system made up of interrelated and interdependent people that are arranged into a single
unit. Each family member (subsystem) directly affects other family members (subsystems) (Morgaine). Based on this information, the conclusion can be drawn that the demands of caring for a child with a chronic illness can potentially disrupt each subsystem or family member, including the well siblings. This is because stress is generated directly by the child that is ill and then indirectly placed on that child’s family members. This stress often affects marital and parental functioning as well as sibling relationships which can lead to recurring psychological problems for healthy siblings (Fisman, Wolf, Ellison & Freeman, 2000). Despite evidence regarding the above, healthy siblings are rarely included in research that is based on family system theory (Laufersweiler-Plass, Rudnik-Schoneborn, Zerres, Backes, Lehmkuhl, & Gontard, 2003).

A family ecosystem includes the environment that supports a particular family system. A diagram of a family ecosystem is shown in Figure 1.1 on page 18. The family itself is shown as being in the center of this ecosystem and includes the parents and their children. Other relatives are shown as being on the fringe of both this family system and the community. The community is then made up of the various people and institutions that are within a certain geographical area that impact the family on a recurring basis. The society in this ecosystem is then made up of a broad group of people that have particular aims and beliefs as well as certain standards of living and behavior. This society influences the community which influences the family and vice versa.
Families, like all social systems, try to maintain homeostasis by using the various skills, resources and coping mechanisms that they possess. The numerous meanings that family members personally give to the new demands placed on them in caring for an ill child and the ability that they have to cope with those demands are crucial factors that will determine whether or not the family can obtain and preserve a functional balance (Patterson & Garwick, 1994). The Family Adjustment and Adaptation Response (FAAR) Model, shown in Figure 1.2 on page 19, consists of two different phases that clearly demonstrate how a family might try to maintain a balance in the midst of caring for a chronically ill child.

The adjustment phase occurs when a family attempts to resist major changes and tries to meet the new demands with the capabilities that they currently possess. The adaptation phase occurs when a family is able to restore homeostasis either when the
demands placed on them are decreased, when they acquire new resources or when they develop better coping skills. The family often develops better coping skills when their worldview is altered regarding what they think about themselves and their situation (Patterson & Garwick, 1994). A crisis occurs when the demands consistently outweigh the capabilities in a prolonged manner. Based on Family Systems Theory each family member influences every other family member and that is why it is important to remember that healthy siblings are also impacted when their families experience the phases described by this response model.

![Figure 1.2 The Family Adjustment and Adaptation Response (FAAR) Model. Adapted from Patterson & Garwick (1994).](image)

Summary

Because pediatric chronic illness affects over three million family members in the United States alone, it is important for nurses to understand its many potential
repercussions. Nurses can help these needy families develop the necessary coping skills that will help them meet the strenuous demands placed on them when there is a chronically ill child to care for within their family. As new research focused on the well siblings is conducted and becomes available, it is important for nurses to keep abreast of these new findings. The Family Systems Theory clearly demonstrates how each family member impacts other family members in multiple ways. As nurses develop a better understanding of how the healthy siblings are affected and how they can help these siblings adjust, more appropriate and effective interventions will be implemented to the benefit of everyone.
CHAPTER II

LITERATURE REVIEW

Introduction

This chapter will review journal articles published during the last ten years (1994 to present) that are applicable to the siblings of chronically ill children. Concerted efforts to study the effects that pediatric chronic illness has on healthy siblings have only been occurring since the early 1970’s (Faux, 1993). Literature reviews are useful because of the following: what is known and unknown about a subject is established, new practice interventions are discovered or current ones are supported, research questions are generated, whether or not studies need to be replicated or refined is determined and the strengths and weaknesses of existing studies are synthesized (Krainovich-Miller, 2002). The articles that will be summarized and discussed in this review will be divided into one of the following categories: articles that are literature reviews, articles relevant to siblings of children with different types of illnesses, articles that discuss the variables that impact healthy sibling outcomes and articles that summarize intervention studies. Chapter three will conclude this report by summarizing current nursing practice implications that pertain to the siblings of chronically ill children.

Review Articles Relevant to Siblings of Children with Chronic Illnesses

A meta-analysis of 51 articles published between 1976 and 2000 that pertained to siblings of children with chronic illnesses was published by Sharpe and Rossiter. Each study was categorized according to the method of data collection, the type of chronic illness, the age of the healthy siblings and the number of healthy siblings vs. the number
of comparison participants. In addition, seven different dependent measure categories were included in the analysis. Those seven categories were psychological functions, self-concept, caretaking, sibling relationship, peer activities, cognitive functioning and cognitive development (Sharpe & Rossiter, 2002).

This meta-analysis which is summarized in Table 2.1, found that a child’s chronic illness has a statistically significant and negative general effect on his or her healthy sibling(s). Parental reports were found to be more negative than child self-reports. Surprisingly, this meta-analysis indicated that siblings of children with severe chronic illnesses (based on life-expectancy) were no more at risk than siblings of children with less severe chronic illnesses. However, siblings of children with chronic illnesses that affected their day-to-day functioning were more negatively impacted than siblings of children who did not require daily assistance. Internalizing behaviors such as anxiety and depression were found to be more common in healthy siblings than externalizing behaviors such as problems in school and interactions with peers. In addition, fewer negative outcomes for the healthy siblings were reported in the more recent studies when compared to the older studies (Sharpe & Rossiter, 2002).

Murray performed a literature review of 18 articles specific to siblings of children with cancer (Murray, 1999a). According to Murray, the majority of articles specific to this topic have been written by people from other disciplines such as medicine, psychology and sociology. The article emphasized the need for more nursing research to be conducted specific to this topic. The articles reviewed were divided into different sections based on its subject or its findings. The first three articles Murray reviewed
examined sibling responses after a patient death and are not relevant to the focus of my report. The other subdivisions were effects on healthy siblings during cancer illness, positive effects of the cancer experience on healthy siblings, minimal effects of the cancer experience on siblings, predictors of sibling adjustment, sibling coping strategies, sibling facilitative behaviors and nursing interventions that provide social support to the healthy siblings. This review article is also summarized in Table 2.1.

Increased levels of anxiety and depression were the main negative effects identified by this review regarding healthy siblings during the cancer experience (Murray, 1999a). In addition, it was determined that healthy siblings often feel isolated from others. It was also concluded that the sibling’s emotional needs are met at a significantly lower levels than that of other family members. Dissimilar to other studies, one study found that the majority of siblings reported no change in their overall experiences following their sibling’s cancer diagnosis (Koch-Hattem, 1986). Some of the studies included in this review revealed that healthy siblings sometimes experience positive outcomes. Some of the positive outcomes identified by the literature review were personal maturation, increased sympathy for others and an increased appreciation for life.

One review article focused specifically on how siblings of children with chronic fatigue syndrome (CFS) are affected by their sibling’s illness (Jackson, 1999). CFS is a poorly understood condition that has an unknown etiology and is debilitating. CFS often fluctuates and is characterized by extreme fatigue that worsens with exertion. Obtaining a diagnosis of CFS is a lengthy process and opinions on how to treat CFS often differ. This is because most medical professionals are unsure whether CFS is a disease caused
by physiological or psychological factors (Jackson). In comparison to other illnesses, CFS does not cause visible physical disabilities. Because of this, others often do not accept CFS as a genuine illness including the healthy siblings. When a sibling’s health fluctuates on a daily basis, the healthy siblings may become resentful of their impact on the family routine (Jackson).

The author was unable to find any articles specific to how families or how healthy siblings with CFS are affected. Because of this, a parallel review of studies was performed and it focused on healthy sibling reactions to other types of pediatric illnesses (Jackson, 1999). The author reviewed articles that spanned a 25 year time frame and found that for the most part, study results varied. The most consistent finding was that families and healthy siblings adapt in many different ways. In addition, the author found that most evidence of psychosocial problems in these healthy siblings was gathered by parental report (Jackson). According to Jackson, more recent studies have shown that parental and healthy sibling reports can differ by up to 44 percent. Other studies have demonstrated that healthy siblings are more likely to experience maladjustment if the ill child cannot adapt to his or her circumstance (Jackson). The author emphasized the need for research to be conducted specific to how CFS impacts the family in comparison to other pediatric chronic illness. This article is also summarized in Table 2.1.

A comprehensive literature review of over 40 studies written between 1970 and 1995 that focused on siblings of a wide variety of chronic illnesses was also conducted (Williams, 1997). The purpose of her literature review was to identify the types and extent of risks these healthy siblings face and what factors increase or decrease those
risks. The results of this literature review are summarized in Table 2.1. The studies were divided into the following categories based on their findings: increased risk, no risk and positive and negative outcomes. Twenty-six of the studies reported an increased sibling risk, twelve reported no increased sibling risk and five of the studies reported both positive and negative outcomes for the healthy siblings.

Healthy siblings were identified as being at risk for the following externalizing behavior problems, lower social competence, low self-esteem, withdrawal or shyness, somatic complaints and feelings of loneliness, isolation, anxiety, depression and anger (Williams, 1997). Some family and parental variables recognized by the review as negatively affecting sibling outcome were parental depression, parental marriage problems, negative parental attitudes toward the illness, low levels of community support, financial difficulties and ineffective parent-sibling communication. Sibling variables such as birth order, age of the children at the time of diagnosis and gender are some additional factors that were identified by the review as influencing healthy sibling outcomes (Williams). Children aged six to eleven years old were more likely to develop externalizing behavior problems than their adolescent counterparts. In addition, older sisters tended to experience higher levels of anxiety and depression compared to younger brothers who demonstrated more aggression and delinquency. This review article also found that even though illness characteristics have been hypothesized as effecting healthy sibling outcomes, they have rarely been included in studies (Williams).

An integrative review of the literature was performed in order to summarize the existing nursing research pertaining to the siblings of chronically ill or disabled children.
(Van Riper, 2003). Forty out of the 86 published articles she identified as relevant this topic were either co-authored or authored by nurses. The articles that were written by nurses were divided into three groups: early research 1972-1992, recent research 1992-present and four main programs of research dedicated to this subject matter (Van Riper). Early research was mainly descriptive and qualitative. Semi-structured interviews were the main method of data collection. In addition, according to Van Riper early research results were contradictory and inconclusive and had limited generalizability. This limited generalizability is due to convenience sampling and lack of control groups. The main method of data collection used in the more recent studies was self-report questionnaires. Much of the recent research also included control or comparison groups. Unfortunately, studies will longitudinal designs still remain uncommon (Van Riper). See Table 2.1 for a summary of this article.

There were four programs of research that focus specifically on sibling response to illness and disability were identified as being headed up by the following nurse researchers: Craft, Gallo, Murray & Williams (Van Riper, 2003). Van Riper concluded this review article by presenting these recommendations for future research studies: study samples need to include siblings and families that are from diverse cultural and socioeconomic backgrounds, the outcomes need to continue to be evaluated at multiple levels and more emphasis needs to be placed on the identification of modifiable variables. Modifiable variables need to be identified in order to develop nursing interventions that will promote healthy adaptation and functioning. In addition, she recommended that intervention studies need to have longitudinal study designs (Van Riper).
### Table 2.1

**Review Articles Relevant to Siblings of Children with Chronic Illnesses**

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Sample</th>
<th>Methods</th>
<th>Findings</th>
<th>+ or - attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Murray J.S. 1999</td>
<td>Review of the literature</td>
<td>This article presented an appraisal of 18 different studies specific to siblings of children with cancer.</td>
<td>The articles were divided into sections based on its focus or its findings. The subdivisions pertinent to my report were effects on healthy siblings during cancer illness, positive effects of the cancer experience on healthy siblings, minimal effects of the cancer experience on siblings, predictors of sibling adjustment, sibling coping strategies, sibling facilitative behaviors and nursing interventions that provide social support to the well siblings.</td>
<td>+ attribute: Data presented clearly. A chronological table summarizing the 18 articles reviewed was included.</td>
</tr>
<tr>
<td>Jackson 1999</td>
<td>Review article and discussion of Chronic Fatigue Syndrome’s (CFS) impact on the healthy siblings.</td>
<td>Review article that summarized previous research concerning healthy sibling adjustment to childhood chronic illness.</td>
<td>The indecision and skepticism on the part of the medical providers when diagnosing pediatric CFS often causes additional stress on the family unit. Siblings are often protective of their ill sibling especially when they return to school. It can be difficult for the healthy siblings to stand up for their sick sibling when others do not view him or her as actually being sick.</td>
<td>+attribute: new topic -attribute: CFS and its impact on the family only presented from the authors perspective.</td>
</tr>
</tbody>
</table>

**Research Recommendations**

Further research specific to how the numerous variables impact one another needs to be performed. In addition, nurse researchers need to conduct research specific to this body of knowledge.

Future research should address how skeptical medical professionals can impact adjustment. In addition, research specific to how CFS impacts the family needs to be conducted.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Type of Review</th>
<th>Methodology</th>
<th>Findings</th>
<th>Attributes</th>
<th>Future Study Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharpe &amp; Rossiter, 2002</td>
<td>Review of literature: A meta-analysis</td>
<td>Fifty-one studies concerning siblings of chronically ill children published between 1976 &amp; the year 2000 were analyzed.</td>
<td>Overall, this meta-analysis found that there is a statistically significant and general negative effect on having a sibling with a chronic illness. Siblings of children with chronic illnesses that affect their day-to-day functioning are more negatively impacted than siblings of children who do not require daily assistance. Fewer negative outcomes for the well siblings were reported in the more recent studies in comparison to the older ones.</td>
<td>+attribute: Comprehensive, many variables taken into consideration. -attribute: Answers to the hypotheses the authors presented were not easy to find.</td>
<td>More studies involving direct observation and child self-report need to be conducted. In addition, improved matching of comparison groups is recommended as well as longitudinal studies designs.</td>
</tr>
<tr>
<td>Williams 1997</td>
<td>Review of literature</td>
<td>This literature review categorized the studies as follows: ones that showed an increased risk for siblings, ones that showed no risk and ones that showed both positive and negative outcomes.</td>
<td>Sixty percent of the studies reported an increased sibling risk, 30 percent reported no increased sibling risk and 10 percent reported both positive and negative outcomes for the siblings. The author found that in general, most of the studies that reported no increased sibling risk and the studies that reported both positive and negative outcomes did not have good study designs. On the other hand, most of the studies that did show that the healthy siblings were at an increased risk had better study designs.</td>
<td>+ attributes: Comprehensive review that included a table which summarized the articles reviewed.</td>
<td>More studies need to be longitudinal in design. In addition, studies need to use standardized data collection tools, control groups and larger sample sizes. More studies need to focus on the numerous variables that effect healthy sibling outcomes.</td>
</tr>
<tr>
<td>Van Riper 2003</td>
<td>Integrative review</td>
<td>Summarization of existing nursing</td>
<td>Forty out of 86 articles pertinent to this topic were either co-authored or authored by nurses. The articles</td>
<td>+ attributes: Focused specifically on</td>
<td>Future study samples need to be more diverse and</td>
</tr>
<tr>
<td>Research that pertains to the siblings of chronically ill or disabled children.</td>
<td>Authored by nurses were divided into three groups: early research 1972-1992, recent research 1992-now and the four programs of nursing research (Craft, Gallo, Murray &amp; Williams).</td>
<td>Nursing research. Research trends now and in the past discussed.</td>
<td>Intervention studies also need to have longitudinal study designs.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Articles Specific to Siblings of Children with Illnesses in Different Disease Categories

Siblings of Children with Chronic Life-threatening Diseases

A study that investigated whether or not adolescent siblings of cancer survivors experience post-traumatic stress (PTS) and to what extent was published in 2003 (Alderfer, Labay & Kazak, 2003). Cancer is a disease mainly characterized by uncontrolled cell growth that can take many forms and has numerous prognoses. According to the authors, the long-term adjustment of siblings of children with cancer has rarely been investigated. Self-report measures on anxiety, PTS and perceptions of the cancer experience were collected and analyzed. There were 134 children included in the study who did not have a family member with chronic medical or psychiatric condition used as a comparison group. In general, the control group’s socio-economic status differed a little, included more minorities and was one year younger on average (Alderfer et al.)

The study found that nearly half of the siblings of childhood cancer survivors had at least mild PTS reactions and almost one-third of them had moderate to severe PTS reactions. Female siblings and siblings that were older than the age of six years at the time their sibling was diagnosed tended to have higher PTS symptoms when compared to the others in the study (Alderfer et al., 2003). The researchers felt this finding may be explained by the fact that female siblings are more likely to have increased family responsibilities when a family member is diagnosed with cancer. In addition, children that are six years or older at the time their sibling is diagnosed are able to remember more
and have a better understanding of what it means for someone to be diagnosed with cancer (Alderfer et al.). The main findings of this article are summarized in Table 2.2.

The demands of childhood cancer on the ill child and his or her family have been researched since the late 1950’s (Murray, 1998). However, research focused on how the healthy siblings of these children are impacted is scarce in comparison (Murray). The purpose of a study conducted by Murray, also summarized in Table 2.2, was to gain a better understanding of the lived experience of how one 14-year-old healthy sibling (J.S.) was impacted by her sister’s (C.S.) cancer diagnosis and treatment. J.S. was 12 years old when C.S was diagnosed with cancer at age 9. J.S. wrote her experiences down and then her writings were analyzed line by line for recurring themes. The main themes identified were emotional intensity (feelings of fear, anger, hate, jealousy and isolation) followed by increased empathy for others, personal growth, the need for support and a desire to help others (Murray).

According to Sloper and While, much of the empirical research on healthy sibling adjustment to childhood illness has been dependant upon parental report (Sloper & While, 1996). This is troubling because the research that does include input from the healthy siblings indicates a general disagreement between parental and sibling reports of what the healthy sibling’s concerns actually are (Sloper & While). Some researchers believe that there has been a lack of healthy sibling appraisal due to the fact that there is a lack of standardized instruments (Sloper & Whiles). A study conducted during the last decade by Sloper and Whiles focused on discovering which factors separated healthy siblings of children with cancer at risk for negative psycho-social outcomes from those
who are not (Sloper & While). The researchers wanted to discover the above in order that areas for intervention could be identified.

Semi-structured interviews and surveys were completed six months after a child in the family was diagnosed with cancer. The interviews were conducted separately with the healthy siblings and then with their parents. In addition, each healthy sibling’s teacher completed a questionnaire specific to any behavior changes noted since that child’s sibling received a cancer diagnosis (Sloper & While, 1996). Siblings in the poor adjustment group were more likely to be from manual social class families, from families that reported having monetary problems due to the illness and from families that did not own a vehicle. The main illness variable to impact the poor adjustment groups was the number of nights the ill sibling spent in the hospital with more hospital nights correlating with a poorer adjustment for the healthy sibling (Sloper & While). Mothers of siblings in the poor adjustment group were more likely to have a higher level of dissatisfaction with their own level of social support than the mothers of the children not in the poor adjustment group. Another variable found during the analysis was that if the ill sibling’s perception of the effects of the illness was negative, the healthy siblings would have higher levels of negative behavior (Sloper & While). For a summary of this article’s main findings see Table 2.2.

Hematopoietic stem cell transplantation (HSCT) is a therapy used for several life-threatening pediatric disorders. A recent study examined the psychosocial impact of HSCT on the healthy siblings of pediatric HSCT patients (Packman, Gong, VanZutphen, Shaffer & Crittenden, 2004) and is also summarized in Table 2.2. The study used
Erikson’s developmental theory as a basis for understanding human development and Posttraumatic Stress as its psychosocial model. HSCT is different than other pediatric chronic illnesses because the majority of children that have a HSCT receive the marrow used in the procedure from one of their own siblings (Packman et al.). In addition, the impact on the family is greater because now two family members have to go through medical procedures. Furthermore, once the ill child receives the transplant he or she is placed in isolation until their hematological system recovers. This study conducted by Packman and associates used both quantitative and qualitative methods of data collection. The healthy siblings current psychosocial functioning was collected by behavior rating scales completed by parents and teachers as well as by child self-report and drawings. In addition, background questionnaires and interviews were conducted (Packman et al.).

HSCT effect on the siblings who provided the bone marrow for their sibling’s procedure (donors) were compared to HSCT effect on the siblings who did not provide the marrow for their sibling’s procedure (non-donors). The final sample for the study included 21 donor siblings and 23 non-donor siblings aged 6 to 18 years (Packman et al., 2004). The donor group had statistically significant higher levels of low self-esteem compared to the non-donor group. In addition, donors were reported as having higher levels of depression and withdrawal. Sibling donors often felt that they were not included in the decision-making-process in which it was determined that they would donate their bone marrow (Packman et al.). The article suggests that the family’s involvement with the donor sibling before surgery is high, but the focus of the family quickly returns to the ill child once the procedure is over. This often leaves the donor
sibling feeling isolated and forgotten (Packman et al.). Contrary to the donor group, non-donors experienced more externalizing behaviors such as problems in school. Close to 33 percent of the siblings from both groups experienced moderate to severe levels of posttraumatic stress reactions. The article recommends that the donor sibling be included more in the decision making process as well as be provided more information about HSCT (Packman et al.).

Sickle Cell Anemia (SCA) is a recessive genetic disorder that affects a person’s hemoglobin and red blood cells. It most often occurs in people of African, Mediterranean, Indian and Middle Eastern heritage. People that have SCA display a wide variety of symptoms that range from unanticipated incidents of pain, to strokes, lung disease, growth retardation, organ deterioration and early death (Noll, Yosua, Vannatta, Kalinyak, Bukowski & Davis, 1995). The body of research that concerns the psychosocial problems these children and their families face is beginning to recognize the impact that SCA may also have on the healthy siblings (Noll et al.) A report focused on the social competence of siblings of children with SCA was published by Noll and associates in 1995. The purpose of the study was to assess the level of social competence of the healthy siblings of children with SCA. The sample for this study consisted of 37 healthy siblings of children with SCA and a control group that also had 37 age and race matched children. All healthy siblings included in the study were of African American descent with approximately 70 percent of them living in single parent homes (Noll et al.).

Four outcome measures were used to collect data for this study: 1) the Revised Class Play (RCP), which measures social reputation, 2) Three Best Friends, the children
in each class were asked to choose three people in their class that they considered as their best friends. 3) Liking Rating Scale, all classmates answered a 5-point scale about each person in the class where they rated each other from someone they don’t like, to someone they like a lot and finally the 4) Assessment of Illness Severity was used. The child with SCA had his or her chart reviewed by a pediatric hematologist who assigned each of them an interim severity (Noll et al., 1995). Two hypotheses were tested: a) healthy siblings of children with SCA would be experiencing difficulties with peer relationships; and b) greater disease severity of the child with SCA would be associated with more problems with peer relationships for the healthy sibling (Noll et al.). Contradictory to other reports, none of the anticipated problems with peer relationships for the healthy siblings were detected. In addition, the disease severity did not correlate with the peer relationships for the non-affected siblings (Noll et al.). See Table 2.2 for details.

An additional study relevant to the siblings of children with SCA was carried out by Lee and associates (Lee, Phoenix, Brown, & Jackson, 1997). Lee’s study focused on how much hopelessness and self-perception of competence were associated with depression among children with SCA in comparison to their healthy siblings. This study used a general systems theory to describe depression as a phenomenon that can impact the whole family in many different ways and not just one individual (Lee et al.). This study’s data collection methods were interviews, the Depression Self-Rating Scale (DSRS) questionnaire and the Perceived Competence Scale (PCS) questionnaire. The PCS has four subscales that assess self-worth, cognitive competence, social competence and physical competence (Lee et al.).
The study randomly selected the children with SCA and their healthy siblings from the L.D. Barksdale Sickle Cell Anemia Foundation which serves South Carolina’s upstate area. All study participants were African American. The only two areas with significant statistical differences in scores between the siblings with SCA and those without were depression and perceived physical competence (Lee et al., 1997). The healthy siblings were the ones with higher rates of depression and the siblings with SCA had lower scores on their perceived physical competence scores. This study included recommendations for nursing practice such as screening the entire family for depression and providing education and support when needed (Lee et al.). For a summary of this article see Table 2.2.

Siblings of Children with Progressive Fatal Illnesses

A study conducted by the Department of Psychological Medicine, University of Sheffield in the United Kingdom, investigated what impact caring for a child with cystic fibrosis (CF) had on the family (Foster et al., 2001). CF is a genetically inherited disease that reduces life expectancy and has no known cure. CF primarily affects the respiratory and digestive systems causing a person’s exocrine glands to produce abnormally thick mucous (Foster et al.). The data analyzed during this study was based on patient, parent and healthy sibling accounts. Interviews that focused on the management of the illness and the impact of the illness on the family were conducted individually with each of the above family members. Treatments for CF have become more and more demanding and are mainly performed in the home setting. Much of the treatment that these ill children need intrudes upon the family routine as it can be time-consuming and tiring (Foster et
Adherence to the treatment routine is very important for those with CF because a positive correlation does exist between treatment adherence and health status (Foster et al.).

The levels of parental involvement of caring for their child with CF were influenced by the patients’ age and whether or not the patient was experiencing an exacerbation (Foster et al., 2001). Parents often described the healthy siblings as being resentful of the extra attention the patients received. The patients themselves also described the healthy siblings as being resentful towards the amount of attention the patients received. Much of the differential treatment was described as being unintentional. A patient’s poor adherence was found to be associated with poor maternal well being as by negative behavior when it came to sibling relationships (Foster et al.).

This article was very family focused because it included the viewpoints of the patient, the parent and the healthy sibling. However, the research recommendations focused more on investigating ways to improve patient adherence rather than on ways to lessen sibling resentment secondary to the differential treatment that they feel their ill siblings receive. This article is also summarized in Table 2.2.

A recent study was conducted that investigated the behavioral adjustment of children with Spinal Muscular Atrophy (SMA). SMA is an autosomal recessive disorder that causes a progressive loss of motor function that is eventually lethal (Laufersweiler-Plass et al., 2003). SMA has various forms from mild (which slightly reduce a person’s life-span) to severe (which usually causes death before the individual turns two). Even though the focus of this study was on the children with SMA, the healthy siblings of
these children as well as children who did not have a sibling with SMA were used as control groups (Laufersweiler-Plass et al.). All of the participants in the study completed a Child Behavior Checklist (CBCL) questionnaire and the children with SMA also participated in a structured interview. The results of this study demonstrated that even with a severely disabling condition such as SMA, the patients themselves do not necessarily show a high level of adjustment problems. On the other hand, the healthy siblings of children with SMA did demonstrate a high percentage of behavior problems at a rate two to three times that of the normal population (Laufersweiler-Plass et al.) See Table 2.2 for the CBCL results for each group.

Articles Relevant to Siblings of Children with Neurological Illnesses

Although past studies have focused on families of children with mental retardation, few have focused exclusively on children with specific genetic defects (Hodapp, Wijma & Mosino, 1997). Recent research conducted by faculty from the college of education at University California Los Angeles (UCLA) focused specifically on families that had a child with 5p- (Cri du Chat) syndrome. People with 5p- are born with a missing part of the short arm of chromosome 5. Although only a small percentage of these children are born with serious organ defects or have other life threatening medical conditions, most of them do have severe to profound mental retardation (Hodapp et al.).

Questionnaires for this study were completed by 99 parents of children with 5p- and 44 of the healthy siblings from the same families completed the Sibling Perception Questionnaire (SPQ). The study, which is also included in Table 2.2, found that family
stress was lower if the family had high levels of social support. The study also found that families with higher incomes and families where the parents were not divorced tended to have higher communication scores compared to those that with a lower socio economic status (SES) or included parents that were divorced (Hodapp et al., 1997). In addition, parents and healthy siblings tended to disagree on the amount interpersonal concerns the healthy siblings had which is a finding that has been replicated by other studies. Finally, the study found that the best predictor of familial stress was the affected child’s level of maladaptive behavior. The higher the affected child’s maladaptive behavior, the higher the families stress level (Hodapp et al.). See Table 2.2 for a synopsis of this article.

Epilepsy is a neurologic disorder in which a person has recurrent seizures, sensory disturbances, abnormal behavior, loss of consciousness or a combination of these (Mims, 1997). Minimal information exists that pertains to the effect of epilepsy on healthy siblings. In 1997, a comparative study was conducted where 20 children whose siblings had frequent seizures (average eight or more per month) or infrequent seizures (less than one per month and at least one per year) where matched according to age, gender and birth order to subjects whose siblings had no chronic illnesses (Mims). Three outcome measures were used, the Piers-Harris Children’s Self-Concept Scale was used to measure their self-esteem, the Family Inventory of Life Events and Changes (FILES) questionnaire was used to measure the level of family stress and the Child Behavior Checklist (CBC) was used to evaluate their social and behavioral functioning. Children in the seizure groups were also given the Sibling Concerns about Seizure Scale. In addition, a demographic survey was completed by each child’s mother (Mims).
Overall, there was no statistical difference among the three groups in regard to self-esteem or social functioning (Mims, 1997). Higher stress levels were reported by the families that had children with frequent seizures than was reported by the families of children with infrequent seizures. There was no difference in the stress levels of the families of children with infrequent seizures when compared to families with children that do not have chronic illnesses. The frequent seizure group had a trend toward increased levels of externalizing behaviors as well as a trend towards having more concerns than the children in the other groups. Interestingly, the siblings of children with infrequent seizures had a higher number of children that reported being concerned about being made fun of due to their siblings’ disorder. The families of these children were similar demographically and educationally (Mims). The results of this study are also summarized in Table 2.2.

In 1994, a study was published that focused specifically on the siblings of children with myelomeningocele (Kiburz, 1994). Myelomeningocele, also known as spina bifida, is a congenital birth defect that affects the neural tube. This defect can leave a person with sensory and motor deficits that can cause problems with elimination and mobility. In addition, people with spina bifida are often hospitalized due to shunt revisions, infections and orthopedic procedures (Kiburz). This study was descriptive and analyzed the perceptions and concerns of 15 school-aged children that had a sibling who was born with spina bifida. These healthy siblings participated in interviews that consisted of 20 open-ended questions. The children’s mothers also completed a questionnaire (Sibling Inventory of Behavior) that evaluated their perceptions of their
healthy child’s behavior. The children’s responses were categorized according to themes and were then compared to the maternal questionnaire responses (Kiburz).

Contrary to other studies, maternal and healthy sibling responses were similar instead of the parental report being more negative. Additionally, the age, birth order and the gender of the siblings did not significantly affect the responses. The researcher explained that this could be due to the small sample size as well as the unequal age and gender representation (Kiburz, 1994). Overall, the healthy siblings reported positive feelings toward their sibling with myelomeningocele as well as toward their parents. Responses regarding jealousy were for the most part evenly divided with seven of the children describing their affected siblings as receiving extra attention, money or presents. None of the healthy siblings indicated feelings of embarrassment and all of them verbalized empathy toward their brother or sister with spina bifida. Eighty percent of the healthy siblings responded that they would wish that their brother or sister did not have spina bifida if they had three wishes that would come true (Kiburz). See Table 2.2 for details.
Table 2.2

Articles Relevant to Siblings of Children with Specific Diseases

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Sample</th>
<th>Methods</th>
<th>Findings</th>
<th>+ or - attributes</th>
<th>Research Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alderfer, Labay &amp; Kazak, 2003</td>
<td>Comparative study of 78 adolescent siblings of childhood cancer survivors and a group of 134 children with no illness in the family.</td>
<td>The purpose of this study was to discover whether or not siblings of childhood cancer survivors experience PTS and to what extent. Self-report measures on anxiety, PTS and their perceptions of the cancer experience were collected and analyzed.</td>
<td>Approximately half of the siblings of childhood cancer survivors had mild PTS reactions and 32% had moderate to severe PTS reactions. Although there were significant levels of PTS were found in these siblings, their levels of anxiety were not found to be elevated when compared to the control group. The comparison group had a larger representation of minorities and was one year younger on average.</td>
<td>+ attribute: PTS is area previously not researched in regard to healthy siblings. -attribute: demographic differences existed between the two comparison groups.</td>
<td>Future research should use structured clinical interviews and not just self-report measures. Future research should have control groups that are better matched.</td>
</tr>
<tr>
<td>Foster et al., 2001</td>
<td>Nine parents of children with CF, eight of their children that have CF and eight of those</td>
<td>This was a cross-sectional qualitative study in which in-depth semi-structured interviews were conducted. The interviews were tape-recorded and</td>
<td>The main themes identified were adherence, level of parental involvement, and differential treatment. Three forms of lack of adherence were identified: unintentional, intentional, and imposed (influenced by external forces). The level of parental involvement was dependent on the</td>
<td>+ attribute: Family focused. -attribute: small sample size and study focused more on pt.</td>
<td>Research recommendations focused mostly on studying patient compliance and not on interventions directed toward the well sibling's feelings of</td>
</tr>
</tbody>
</table>
children’s healthy siblings each participated individually in interviews. Patient’s age and whether or not the child was ill. Patients were described as receiving differential treatment due to the many treatment demands, ill health and special treatments. Differential treatment was attributed as being the cause of the healthy sibling’s resentment.

| Hodapp et al., 1997 | The first study included 99 parents of children with 5p-. The second study included 44 healthy siblings from the families in the first study and one of each of their parents. | Questionnaires and interviews concerning the affected child measured demographics, resources, stress, family support, functioning level and aberrant behavior. Healthy siblings completed the Sibling Perception Questionnaire (SPQ). | Study 1: The level of stress was found to be higher when the child with 5p- had high levels of maladaptive behavior. Study 2: The parents indicated that there was also poorer communication when the affected child had more maladaptive behavior patterns. Similar to other studies, the parents tended to indicate that the healthy siblings had higher levels of interpersonal concerns than the healthy siblings reported themselves. | + attribute: Family focused. -attributes: 5p- most-likely considered a disability (mental retardation) and not a chronic illness. | Future studies need to include more minorities and those with lower SES. Future research needs to determine why parental and sibling reports differ in regard to the healthy sibling’s interpersonal concerns scores. |

| Kiburz 1994 | 15 siblings of children with spina bifida and | Descriptive study in which the children participated in | Overall, the healthy siblings reported positive feelings toward their sibling with myelomeningocele as well as | + attribute: Not many other studies specific to | Larger and more diverse sample. Use instruments with established |
their mothers interviews and the mothers answered the Sibling Inventory of Behavior questionnaire. toward their parents. The age, birth order and gender of the siblings did not significantly affect the participant’s responses. Feelings of jealousy were reported by about half of the participants. spina bifida
-attribute: small sample used and a direct comparison not applicable.

<table>
<thead>
<tr>
<th>Laufer-sweiler-Plass et al., 2003</th>
<th>Ninety-six children and adolescents with spinal muscular atrophy (SMA), 45 of their non-affected siblings and 59 non-affected children and adolescents without a sibling with SMA. The non-affected children were matched to the SMA children according to age, sex and SES. The SMA group was assessed using a structured interview as well as by the parental Child Behavior Checklist (CBCL). The two control groups were assessed only by the CBCL. Non-affected siblings of children with SMA had the highest percentages of all on all three CBCL subscales (total score, internalizing behaviors and externalizing behaviors). The score percentages for each group are listed below.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td><strong>Internalizing</strong></td>
</tr>
<tr>
<td><strong>Externalizing</strong></td>
<td><strong>%</strong></td>
</tr>
<tr>
<td>SMA</td>
<td>11.5%</td>
</tr>
<tr>
<td>Sibling</td>
<td>20%</td>
</tr>
<tr>
<td>No Sibling with SMA</td>
<td>11.9%</td>
</tr>
<tr>
<td>11.5%</td>
<td></td>
</tr>
<tr>
<td>+attribute: Decent sample size with well matched control groups.</td>
<td></td>
</tr>
<tr>
<td>-attribute: Main focus of the study on the child with SMA. The CBCL was the only measurement tool used for healthy sibling.</td>
<td></td>
</tr>
<tr>
<td>Future research should include more information from the well siblings’ perspectives. Use same measurement tools for all three groups.</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Sample Description</td>
</tr>
<tr>
<td>-------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Lee et al., 1997</td>
<td>Fourteen children with Sickle Cell Anemia (SCA) and 14 of their healthy siblings.</td>
</tr>
<tr>
<td>Mims, J. 1997</td>
<td>Ten siblings of children who had frequent seizures. Ten siblings of children who have infrequent seizures and a control group of 11 children with no ill siblings.</td>
</tr>
<tr>
<td>Murray J.S. 1998</td>
<td>One 14-year-old healthy sibling of a child with cancer</td>
</tr>
<tr>
<td>Noll et al., 1995</td>
<td>Thirty-seven healthy siblings of children with Sickle Cell Anemia (SCA) and a control group that consisted of 37 age &amp; race matched children.</td>
</tr>
</tbody>
</table>
and 4) Illness Severity.

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Study Design</th>
<th>Participants</th>
<th>Methods</th>
<th>Results</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Packman, et al., 2004</td>
<td>Twenty-one donor siblings and 23 non-donor siblings of pediatric HSCT patients.</td>
<td>The study conducted by Packman and associates used both quantitative and qualitative methods of data collection. Behavior rating scales, self-reports, drawings and interviews.</td>
<td>The donor group had statistically significant higher levels of low self-esteem, depression and withdrawal. Non-donors exhibited more externalizing behaviors. Close to 33 percent of the siblings from both groups experienced moderate to severe levels of posttraumatic stress reactions. A few nursing implications were included, such as including the donor sibling more in the decision-making-process.</td>
<td>+attribute: multiple measures. Qualitative and quantitative.</td>
<td>Longitudinal study designs. Larger &amp; more diverse samples. Better gender matched comparison groups.</td>
</tr>
<tr>
<td>Sloper &amp; While, 1996</td>
<td>Ninety-nine healthy siblings of children with cancer (between the ages of eight &amp; 16) and their parents.</td>
<td>Semi-structured interviews and surveys were conducted. In addition, the healthy siblings’ teacher completed a behavior questionnaire. Diagnosis and prognosis were the illness parameters included for the analysis.</td>
<td>Almost 10 percent of the 99 siblings had borderline behavioral problem scores and one-fifth had scores that were regarded as being in the clinical range. The logistic regression analysis indicated that poor adjustment was related to the degree of family life disruption secondary to the illness and the available resources the family had. In addition, the sibling’s perception of the negative interpersonal effects of their sibling’s cancer on their lives was another indicator of adjustment.</td>
<td>+attributes: Sample size descent. Several different tools used to measure the variables.</td>
<td>Future research should investigate what role extended family plays in compensating for the decrease in parental support that is available to healthy siblings.</td>
</tr>
</tbody>
</table>
Articles Analyzing the Variables that Impact Healthy Sibling Outcomes

A study was conducted in which the perceptions of healthy siblings of children with asthma were compared to the perceptions of healthy siblings of children with Cystic Fibrosis (CF) (Derouin & Jessee, 1996). The researchers chose to focus on the siblings of children with these two types of illnesses due to there being minimal data about healthy siblings of children with illnesses that are on opposite ends of the disease continuum (Derouin & Jessee). The study included the perceptions of 15 healthy siblings of children with either CF or asthma. The healthy siblings participated in telephone interviews that used semi-structured, open-ended questions. In addition, the healthy siblings answered questionnaires regarding their self-esteem. The parents of these children completed demographic surveys. These three general categories were included in the interview: knowledge of the illness and its impact on the ill sibling, effect of the illness on the family and effect of the illness on the respondent (Derouin & Jessee).

Sixty percent of the siblings in the CF group thought that their brother or sister received special treatment compared to 22 percent of the siblings in the asthma group. Siblings of children with CF also reported more sharing of the medical care among family members than siblings of children with asthma. The siblings of children with CF also reported having to give up more things due to their siblings’ illness (outings, vacations and time with their parents) in comparison to the siblings of children with asthma (Derouin & Jessee, 1996). In addition, the siblings of children with CF reported feeling more worried and jealous than the siblings of children with asthma. Unfortunately, only the data from the sibling interviews was presented in this article and
not any data from the demographic or self-esteem questionnaires. The author acknowledged that the efficacy of telephone interviews with children respondents still needs to be established (Derouin & Jessee). See Table 2.3 for the main points of this article.

The interrelationships among some of the variables found to influence the outcomes of healthy siblings of children with chronic illnesses were summarized in recent data-based journal article (Williams et al., 2002). Discovering how these variables impact one another is essential so that appropriate nursing interventions can be developed. The article presented a structural equation model in order to demonstrate the interrelationships involved. Six different outcome measures were used in an intervention study that was conducted by Williams and associates. The six outcomes measured were sibling knowledge about illness, sibling behavior problems, sibling social support, sibling self-esteem, sibling attitude toward illness and sibling mood. The covariates evaluated for possible relationships were the age of the well sibling, the study group they were assigned to (full participation, partial participation or control group), the diagnoses of the ill child, the socio-economic status of the family, family cohesion and parental mood (Williams et al.). See Table 2.3 for the relationships discovered by the analysis.

Upon analysis of the outcome measures and covariates, socioeconomic status was found to have a direct effect on parental mood. In addition, healthy sibling behavior was directly influenced by these five variables: family cohesion, age of the well sibling, sibling social support, socioeconomic status, and sibling knowledge about illness (Williams et al., 2002). Sibling knowledge about illness also directly affected sibling
attitude toward illness, which was influenced by sibling mood, which was influenced by sibling self-esteem. Sibling social support had a significant direct effect on sibling self-esteem. Paternal mood directly affected family cohesion but did not impact sibling behavior problems or sibling social support. Family cohesion had direct effects on sibling behavior problems, sibling attitude toward illness and sibling social support (Williams et al.). Sibling knowledge about illness was affected mostly by diagnosis as well as by the age of the well sibling. Family cohesion had a large effect on sibling attitude toward illness, but the age of the well sibling had the strongest total effect on sibling attitude toward illness. The effects of the family’s socio-economic status had the strongest impact on all other variables. This study helps demonstrate that there are numerous interrelated variables that influence healthy sibling adaptation when there is a pediatric chronic illness in the family (Williams et al.).

An article published recently in the Journal of Family Nursing focused on how healthy siblings’ self-perceptions are impacted by their satisfaction with family functioning (Gallo & Szychlinski, 2003). Previous research focusing on the effect of a chronic illness on the family was mainly studied from the parental point of view. The sample for this study consisted of three groups of 45 families each. Each group consisted of school-aged children, one group included healthy siblings of children with asthma, one group included healthy siblings of children with Type 1 diabetes and one group had no children in the family with a chronic condition (Gallo & Szychlinski). Other variables evaluated as to whether or not they had an effect on healthy siblings were sociodemographics, parental functioning, family functioning and illness characteristics.
Two measures were used in this study: the Self-Perception Profile for Children (SPPC) and the Family APGAR for Children (FAC). All three groups completed those two measures while their mothers completed the demographic information (Gallo & Szychlinski).

When the scores for self-perception were analyzed, significant differences were found to exist between the three groups. The siblings of children with diabetes were found to have lower self-worth scores than both the asthma and healthy groups (Gallo & Szychlinski, 2003). Interestingly, the siblings of children with asthma were found to have higher scores on the social acceptance scale than the siblings of children with diabetes as well as the siblings of healthy children. Scores for satisfaction with family functioning were found to be the lowest in the siblings of children with diabetes group. The authors speculated that the above may be due to the fact that diabetes influences each family member on a daily basis more so than asthma. Female sibling pairs in the group with diabetes and the group with asthma were found to score lower on family functioning when compared to other gender combinations. Overall, the study found that definite relationships existed between the children’s self-perception of themselves and their family functioning scores (Gallo & Szychlinski). See Table 2.3 for the main findings from the article.
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Sample</th>
<th>Methods</th>
<th>Findings</th>
<th>+ or - attributes</th>
<th>Research Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Derouin &amp; Jessee, 1996.</td>
<td>Compared healthy siblings of children with asthma to healthy siblings of children with CF. Sample size, 15 healthy siblings.</td>
<td>Telephone interviews used semi-structured, open-ended questions. Questionnaires regarding sibling self-esteem levels &amp; demographic surveys were completed.</td>
<td>Sixty percent of the siblings in the CF group compared to 22 percent of the siblings in the asthma group thought that their brother or sister received special treatment. The siblings of children with CF reported having to give up more things due to their siblings’ illness in comparison to the siblings of children with asthma. The siblings of children with CF also reported feeling more worried and jealous in comparison to the siblings of children with asthma.</td>
<td>+attribute: The focus was on the well siblings’ perspectives. -attribute: Demographic and control data were not included. Small sample size.</td>
<td>More varieties of illnesses should be studied in order to provide disease specific interventions. Continue studying diseases on various places of the disease spectrum.</td>
</tr>
<tr>
<td>Gallo &amp; Szychlinski, 2003.</td>
<td>Three groups of 45 families. One group had siblings of children with asthma, one group had siblings of children with Type 1 diabetes.</td>
<td>Two measures were used: the Self-Perception Profile for Children (SPPC) and the Family APGAR for Children (FAC). Mothers completed</td>
<td>Focused on how healthy siblings’ self-perceptions are impacted by their satisfaction with family functioning. The siblings of children with diabetes were found to have lower self-worth scores than the other two groups. In addition, their satisfaction with family functioning was found to be the lowest. Interestingly, siblings of children with asthma were found to have higher self-worth scores than the other two groups.</td>
<td>+attribute: Several non-illness related variables also analyzed. Not from parental viewpoint. Larger sample. -attribute:</td>
<td>Use qualitative and quantitative measures. More diversity in sample, include more minorities and those from lower social classes. Perform intervention studies to improve family functioning and self-</td>
</tr>
<tr>
<td>Study</td>
<td>Description</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>-------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes and one group had no ill siblings.</td>
<td>have the highest scores on the social acceptance scale. Female sibling pairs in the group with diabetes and the group with asthma were found to score lower on family functioning when compared to other gender combinations.</td>
<td>Sample not diverse, no qualitative measures.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Williams et al., 2002</td>
<td>The interrelationships between variables (obtained from an intervention study) were analyzed.</td>
<td>SES was found to have a direct and strong affect on MMOOD. MMOOD directly effected COHES and SSELF which affected SATT. MMOOD did not impact SBEHV or SSUP. AGE had the strongest total effect on SATT. COHES had a direct effect on SBEHV, SATT and SSUP. SBEHV was found to be directly affected by 5 variables COHES, AGE, SSUP, SES and SNOW. SKNOW also directly affected SATT. SSUP had a significant direct effect on SSELF. SKNOW was affected the most by DX as well as by AGE. The effects of SES had the strongest impact on all other variables.</td>
<td>The SEM needs validation that can only come from future studies. Future studies should include more minorities, more families with lower incomes and healthy siblings from single-parent homes.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Intervention Studies Relevant to Siblings of Chronically Ill Children

Intervention studies aimed at helping well siblings adjust to life with a chronically ill sibling are scarce and mostly qualitative in design (Houtzager, Grootenhuis & Last, 2001; Williams et al., 1997). In addition, even though educational programs exist for the ill child and his or her parents, only a few resources address the specific needs of these siblings (Williams, et al). Furthermore, even though evidence supports the concept that sibling and parental adjustment are intertwined, few studies actually incorporate parents into the sibling intervention programs that do exist (Lobato & Kao, 2002). Four studies that focus specifically on interventions for healthy siblings and their families are summarized next and additional information regarding these studies is provided in Table 2.4.

An intervention study was conducted that focused specifically on lowering the anxiety levels of siblings of children with cancer (Houtzager, Grootenhuis & Last, 2001). This study divided 38 well siblings into six different support groups that met on five separate occasions. The purpose of the support groups was to provide information and social support so that they could better cope with their brother or sisters’ cancer. Prior to the intervention three-fourths of the well siblings had anxiety scores that were above the 80th percentile. Upon completion of the support group, less than half of the well siblings had anxiety levels above the 80th percentile. The type of cancer the sibling was diagnosed with, the age of the well sibling and whether or not the well sibling was a boy or a girl were variables that seemed to have an effect on the level of anxiety they experienced (Houtzager et al.).
An additional intervention study was conducted in 2002 and included 54 healthy siblings of children with a variety of physical, developmental, medical and psychiatric disabilities (Lobato & Kao, 2002). One parent for each child was also included in the intervention program entitled “SibLink”. The intervention consisted of six 90 minute psycho-educational sessions. The outcomes measured in this study were sibling knowledge of illness, sibling adjustment to illness, sibling connectedness, sibling behavioral functioning and parental satisfaction with the program. There were no control groups and no difference in the amount of interventions offered to each family. Parental reports verses sibling reports differed when it came to the sibling adjustment to illness scale with parental reports being more negative than the sibling reports (Lobato & Kao).

The results of a pilot intervention study that focused on the siblings of chronically ill children were published in 1997 (Williams et al., 1997). The purpose of the study was to evaluate the effectiveness of the nursing interventions and to describe the insights that healthy siblings and their parents had regarding day-to-day life with a chronically ill child. Educational sessions were held in order to provide information to the well siblings regarding their brother’s or sister’s illness. Psycho-social and recreational activities were also included in the program (Williams et al.). These sessions included scenarios that involved common sibling experiences and allowed for group discussion. Parents also attended a session that involved discussing sibling needs and how they could help their non-ill children psychosocially. The outcomes measured were knowledge of the illness, sibling perceptions of the illness, parental perceptions of the illness and parental evaluations of the program (Williams, et al.).
A thorough intervention study aimed at helping the siblings of chronically ill children was recently conducted and used a randomized three-group repeated measures design (Williams et al.). This study had a significant sample size consisting of 252 well siblings and at least one parent for each child. The full intervention included a five day residential camp (for the healthy siblings) that focused on social support and self-esteem. The full intervention camp also had structured teaching regarding the siblings’ illnesses and also included psychosocial sessions. In addition, the full intervention group also received two booster sessions for the healthy siblings and their parent(s) after the five day camp was over. The partial intervention consisted of the five day residential camp without the structured teaching, psychosocial sessions or the follow-up booster sessions (Williams et al.).

The outcomes measured in the above study were sibling knowledge about illness (SKNOW), sibling behavior problems (SBEHV), sibling social support (SSUP), sibling self-esteem (SSELF), sibling attitudes (SATT) and sibling mood (SMOOD). The cost of the full intervention was estimated to be $500 per sibling-parent dyad (Williams et al., 2003). The above cost could be either a positive or negative attribute depending on the sustainability of the intervention. Surprisingly, the control group also showed improvement on two of the outcome measures. The researchers’ analysis of the study suggested that because the well sibling and parent traveled together to the data collection sites, the communication between them may have been improved (Williams et al.).

A study that focused mainly on improving outcomes for chronically ill children instead of the outcomes for the healthy siblings was also reviewed (Chernoff, Ireys,
DeVet, & Kim, 2002). This study was included in the literature review because other family members were included in some of the intervention activities such as community based lunches and parties. In addition, the mothers of these children were also assigned a trained “Network Mother”. These network mothers had previous experience taking care of a child with the same diagnosis as the child participating in the study. The children in the experimental group demonstrated an increased level of self-esteem when compared to those in the control group. Because the outcomes for children with several different types of chronic illnesses were similar, it is possible that this type of intervention could be effective for families with other types of pediatric chronic illness (Chernoff et al.). Although all nuclear family members were invited to participate in some of the community based activities, unfortunately only outcomes specific to the chronically ill children were measured. See Table 2.4 for a summary of this article.
### Table 2.4

Intervention Studies Relevant to Siblings of Chronically Ill Children

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Sample</th>
<th>Methods</th>
<th>Findings</th>
<th>+ or - attributes</th>
<th>Research Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chernoff, et al., 2002</td>
<td>Mothers and 136 of their chronically ill children (age 7-11) that had DM, sickle-cell anemia, asthma or CF.</td>
<td>Randomized controlled clinical trial with four different mental health measures. Child and parental reports were taken 12 months apart. The community based, family support intervention program lasted for 15 months.</td>
<td>The “dose” of the intervention was measured in contact minutes. Mean time spent participating in program activities was 23 hours per family. Psychosocial adjustment, depressive symptoms, anxiety and self-esteem were the outcomes measures taken before the intervention and at the end of 12 months. In addition to increases in self esteem levels, the experimental group also had decreases in the number of children whose scores rated as maladjusted.</td>
<td>+ attributes: well funded, lots of contact hours, decent sample size, several outcome measures. -attributes: No outcome measures for non-ill family members.</td>
<td>Future community based, family centered intervention studies need outcome measures for each family member not just for the chronically ill child. In addition, randomized control groups are needed.</td>
</tr>
<tr>
<td>Houtzager et. al, 2001</td>
<td>Thirty-eight siblings (ages seven to 18) of children with cancer participated in one of six</td>
<td>Non-experimental in design. Pre and post-treatment intervention questionnaires were completed by the healthy</td>
<td>Seventy-five percent of the well siblings experienced high anxiety scores before attending the support groups. After the intervention was over, only 46 percent of the children had high anxiety levels. These anxiety scores were found to be high</td>
<td>+attribute(s): Intervention study. -attribute(s): Small sample size. Socio-economic</td>
<td>Future studies should have a follow-up to evaluate the long-term effect on anxiety reduction as well as multiple outcome measures. In addition, there should be a larger</td>
</tr>
<tr>
<td>Study</td>
<td>Sample Description</td>
<td>Intervention Details</td>
<td>Findings</td>
<td>Attributes</td>
<td>Additional Comments</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Lobato, 2002</td>
<td>The sample consisted of 54 healthy siblings of children with various disorders and disabilities and one parent.</td>
<td>Non-experimental design. Pre and post-treatment evaluations were performed. Twenty families also completed an evaluation three months after the intervention. Parental ratings of the program were high and the siblings’ ability to name the illness or disability correctly improved from pre-treatment to post-treatment. Scores on the negative adjustment scale (sibling report) indicated improvement, whereas results from the negative adjustment scale (parental report) were not significant. Internalizing and externalizing behavior scores were also decreased.</td>
<td>Status not included and only one outcome measure.</td>
<td>+attribute(s): Family focused -attribute(s): Smaller number of participants &amp; most were Caucasian and from middle class families.</td>
<td>Randomized controls are needed as well as evaluations 6 months to 1 year after the intervention. The disparity between sibling versus parental report regarding the negative adjustment scale deserves further investigation.</td>
</tr>
<tr>
<td>Williams, et al., 1997</td>
<td>Twenty-two siblings of children with chronic illnesses (CF, DM, Spina bifida and cancer) and one of</td>
<td>Pilot study that used a pretest-posttest, pre-experimental design. Knowledge of the illness test, the sibling perception Knowledge of siblings’ illness test scores went up 20%. Sibling Perception Questionnaire (SPQ) results supported prior research that suggested that healthy siblings’ experience feelings of isolation. In addition, the study also supported the concept that families are interrelated.</td>
<td>+ attribute(s): Family focused and several outcome measures -attribute(s): Small sample</td>
<td>+attribute(s): Family focused -attribute(s): Smaller sample</td>
<td>Replicate study using larger sample, control groups and random assignments.</td>
</tr>
<tr>
<td>Williams et al., 2003</td>
<td>Two-hundred-twenty five siblings (ages seven to 15) of children with CF, spina-bifida, cancer, diabetes or a developmental disability.</td>
<td>A randomized three-group repeated-measure design. N=79 full intervention, N=71 partial intervention, N=102 no intervention. Data was collected at baseline, after the intervention at 5 days, 4 months, 9 months and 12 months.</td>
<td>The full treatment group showed improvements on all six outcome measures (five to 25 percent over baseline). The partial treatment group showed improvement on 3 of 6 outcomes measured and the control group also showed improvement on two of the outcomes measured. A dose-response relationship to the interventions was found and the treatment gains were maintained over a 12 month time-period.</td>
<td>+ attribute(s): Randomized study with multiple outcome measures. Large sample size, longevity of study -attribute(s): Sample not very diverse socioeconomically and few minorities.</td>
<td>Dependent variables and covariates should be further examined for manipulation suitability and treatment/intervention in health care settings. Further studies are needed that include more minorities and those with lower socioeconomic status.</td>
</tr>
</tbody>
</table>
Summary of the Literature Reviewed

In conclusion, the majority of articles included in this literature review gave the impression that the siblings of children with chronic illnesses experience negative psychosocial effects secondary to their siblings’ illnesses. These healthy siblings often exhibit internalizing and externalizing behavior problems. On the other hand, a few of the articles did indicate that siblings of children with chronic illnesses can experience both positive and negative psychosocial outcomes. More importantly is the fact that the presence of a pediatric chronic illness in the family, in combination with multiple other variables, does have an impact on the psychosocial development of healthy siblings. This impact can be explained by the Family Systems Theory as it is based on the premise that what happens to one family member has an influence on every other family member.

Although many of the studies reviewed for this report focused on how healthy siblings are impacted by their siblings’ chronic illnesses, only some of them actually analyzed the relationships between the variables involved. Researchers need to continue studying these relationships in order to determine which ones positively and which ones negatively impact healthy sibling outcomes. Once significant relationships between the variables are identified, new and effective interventions can be developed and implemented. The majority of the studies reviewed for this report had limited generalizability due to small samples and inadequate minority or socio-demographic representation. In order to be statistically significant, studies need to have randomized matched control groups in addition to larger sample sizes.
Based on findings from the literature reviewed, the following recommendations are made for future studies relevant to siblings of children with chronic illnesses: 1) more studies need to have longitudinal designs, 2) multiple and standardized data collection tools need to be used (new tools need to be developed and/or validated for use with children), 3) study samples need to be more diverse (with respect to ethnicity, socioeconomic status and single-parent homes), 4) more emphasis needs to be placed on identifying modifiable variables and 5) intervention studies need to be replicated in order that their effectiveness can be validated. Obtaining funding for these types of comprehensive research studies is a recognized issue considering the amount of contact hours required and number of participants necessary to conduct a thorough study. Although the body of knowledge specific to siblings of children with chronic illnesses has grown significantly over the last 10-15 years, the impact of the multiple variables involved is even now not completely understood.
CHAPTER III
IMPLICATIONS FOR NURSING PRACTICE

Knowledgeable Research Consumers

Nurses need to be knowledgeable research consumers. This means that nurses need to have an understanding of current knowledge pertaining to the area of interest. The nurse consumer also needs to be able to separate and evaluate information rationally, as well as have the ability to apply the knowledge that he or she has gained (LoBiondo-Wood & Haber, 2002). According to the above criteria, the first step in improving healthy sibling outcomes would be to learn about the various effects that chronic pediatric illnesses have on healthy siblings and what can be done to improve those outcomes. If nurses do not know how and why they are performing nursing interventions, the interventions they provide are not likely to be as effective as they could. Therefore, it is important for nurses to keep abreast of current research and practice implications. Once nurses have obtained the necessary knowledge, they can then disseminate that knowledge to the parents of these chronically ill children. In addition, nurses should become involved in committees or other pro-active teams that are dedicated to dispersing information and bringing about beneficial change (LoBiondo-Wood & Haber).

Assessing Before Intervening

The next step in providing valuable nursing interventions for the siblings of children with chronic illnesses is to perform a comprehensive family assessment. This is because familial patterns of adjustment need to be evaluated in order to develop effective
family-based interventions (Alderfer et al., 2003). Additionally, performing a comprehensive family assessment will allow the nurse to identify which illness related variables and which non-illness related variables are affecting the healthy siblings on a daily basis. An assessment of this type will also reveal which resources are available to help the healthy siblings adapt as well as identify areas that could use intervention. Family relationships, stressors, coping strategies, strengths, weaknesses, behavior changes, levels of functioning and familial values all need to be assessed before effective interventions can be implemented (Mims, 1997). Recognizing various coping responses is an essential step when one wants to provide effective interventions for these families (Cox et al., 2003). Furthermore, it is important for nurses to evaluate the healthy siblings’ understanding of their sibling’s illness in addition to evaluating the understanding of the ill child and his or her parent(s) (Wong, et al., 1999).

An additional area that is important to assess in these families is how often family members are communicating and what is the quality of that communication. A major concern reported by siblings of chronically ill children was not being able to share their thoughts and feelings with anyone (Murray, 2002). Parents should be encouraged to communicate frequently about the ill child as a way to keep the healthy siblings informed and as a way to encourage the healthy siblings to express how they feel (Gallo & Szychlinski, 2003). Additionally, nurses need to assess whether or not healthy siblings have demonstrated any internalizing or externalizing behavior problems such as depression or changes in peer relationships and behaviors. Nurses need to have an understanding of the numerous illness related variables that can affect healthy sibling
adaptation so that they can identify which healthy siblings are at a higher risk for developing psychosocial problems. For example, we know from the literature review that an illness that impacts the family routine on a daily basis is more likely to have an impact on the healthy siblings than illnesses that do not impact the daily routine of families (Gallow & Szychlinski).

Furthermore, it is equally important for nurses to assess for the non-illness related variables known to impact healthy sibling outcomes. For example, if a nurse is aware that a family with a chronically ill child is also experiencing financial difficulties or that the parents are experiencing marital problems he or she will know that the healthy siblings in that family are even more at risk for developing adverse psychosocial problems. This is because multiple aspects in their family system are undergoing strain and according to Family Systems Theory, families are interactive and what impacts one family member will impact every other family member (Morgaine, 2002). Some sources suggest that a non-categorical approach to intervention and treatment for healthy siblings be used as several research studies have indicated that siblings of children with various chronic illnesses and cognitive disabilities share common psychosocial problems (Williams et al., 2003; Faux, 1993). However, how each family member is dealing with the diagnosis is important to assess as studies have shown that the meanings and significance that each family member places on the ill child’s condition will then influence how the entire family adapts as well as how they individually adapt (Patterson & Garwick, 1994).
Social Support

Past research has demonstrated that the presence or absence of social support effects an entire family’s adjustment to an illness experience (Murray, 2000). The concept of social support is subjective, multifaceted and difficult to define. Nurses need to have an understanding of exactly what social support is comprised of so they can assess for the presence or absence of it in the families of the children for which they care. The four types of social support were defined as 1) Emotional support which includes empathy, encouragement, understanding, caring, love and trust. Siblings of children with chronic illnesses need to have someone with whom they can share and discuss their problems and feelings. 2) Instrumental support is behavior that directly helps the person in need. This could involve helping the healthy siblings maintain daily routines through assistance in areas such as transportation and homework. 3) Informational support is when someone is given advice, directives or provided with specifics. From the sibling’s perspective this is receiving advice, direction and information about the illness affecting his or her brother or sister. 4) Appraisal support is communicating in a way that helps the healthy siblings assess how their siblings’ illness affects his or her own life. This includes asking the healthy siblings what their views of the illness experience are so that they can interpret it more appropriately (Murray).

Studies have indicated that nurses and parents view emotional and informational support as being the most important aspects of social support for siblings of chronically ill children (Williams, 1992). Unfortunately, very little research exists that indicates what healthy siblings view as the most valuable aspects of social support (Murray, 2000).
According to one study, healthy siblings of children with cancer identified emotional and instrumental support as being the most helpful aspects of social support (Murray, 2002). It is important for nurses to recognize and focus on the aspects of social support that healthy siblings have identified as being the most helpful because those areas are most likely to have a greater impact on the outcome of healthy siblings (Murray, 2002).

Another study confirmed that a lack of instrumental support is another major factor negatively affecting healthy sibling outcomes (Sloper & While, 1996). Not surprisingly, the presence of an external support system was identified by the same study as a protective factor for the siblings of children with chronic illnesses. A lack of instrumental support for these healthy siblings is not an uncommon occurrence due to the fact that parents of these children are often overly burdened with caring for the ill child to be able to provide the instrumental support that their healthy children need (Patterson & Garwick, 1994; Gallo & Szychlinski, 2003). Nurses can help families obtain the instrumental support they need by informing them about services offered in their community by various organizations and volunteer groups. In addition, nurses can encourage these families to accept assistance from others when it is offered and to not be reluctant to ask for it when it is needed (Murray, 2000).

Recommended Interventions

One of the comprehensive literature reviews that was summarized in chapter 2 identified three areas as being responsible for healthy sibling adjustment problems 1) they are not given enough information about the situation, 2) they feel physically and emotionally isolated from their parents and 3) there is an insufficient amount of resources
available to provide these siblings with the information and support that they require (Williams et al., 1997). Fortunately, according to one study, two of the most commonly used interventions already address some of the issues identified above. The two most frequently used interventions that nurses from that study used when trying to help the siblings of children with chronic illnesses were: 1) providing honest answers to the questions healthy siblings ask and 2) encouraging parents to spend time with their healthy children (Murray, 2002).

Knowing which interventions nurses should focus on is especially important given the fact that one study identified time constraints as the biggest obstacle to providing interventions for these healthy siblings (Murray, 1999b). Other areas nurses identified as barriers to implementing interventions for healthy siblings were staffing shortages, lack of access to healthy siblings and institutional or role constraints (Murray). Additionally, it is important that nurses focus on the risk factors that are potentially modifiable. For example, nurses are unable to change a family’s socio-economic status or the ill child’s diagnosis. However, areas that can be influenced by health related interventions are family cohesion, sibling mood, as well as feelings of support and self-esteem (Williams et al., 2002). In addition to evaluating which areas require attention and which factors are modifiable, it is important that interventions directed toward these families be provided in a timely fashion. This is because there is a better chance of preventing negative psychosocial outcomes for the siblings of chronically ill children when interventions are provided early on (Williams, et al., 1997).
Nurses can address the lack of information that healthy siblings experience by providing age-appropriate explanations when they accompany their ill brother or sister to the hospital or clinic setting (Houtzager et al., 2001; Spinetta et al., 1999 & Wong et al., 1999). In addition, nurses can help further meet the needs of these healthy siblings by distributing age-appropriate educational material concerning their sibling’s illness as well as its treatment. These types of brochures and pamphlets can be obtained from child life departments at local hospitals, various disease specific organizations or they can be developed by nurses if adequate ones are unavailable. These types of materials should help healthy siblings obtain a better understanding of their sibling’s disease, its treatment, as well as help them develop realistic expectations of how their sibling’s disease will impact their family life. If children are given enough information about their sibling’s illness and progress then they are most likely not going to wonder or fantasize as often about what is happening to their sibling as well as to themselves.

Nurses can initiate a discussion concerning healthy sibling adjustment by asking the parents how their healthy children are adapting to their brother or sisters illness. If the parents seem open to discussing how their healthy children are being impacted, the nurse can then provide them with information and suggestions that are pertinent to the topic. Parents need to be aware of the various responses that healthy siblings may have towards the illness such as social withdrawal or attention seeking behaviors. Parents should also be encouraged to let their children express their feelings, whether or not they are positive (Gallo & Szychlinski, 2003). In addition, it is important for parents to know how important it is for them to share their time and energy with all of their children and
not just the one that is ill. Because of this, parents should be encouraged to spend time with their healthy children and to remain as involved as possible in their daily activities (Kiburz, 1994). Remaining involved will help the healthy siblings to feel cared for and important (Sloper & While, 1996). In addition, it is important for nurses to remind these parents not to place disproportionate responsibilities on their healthy children and that they need to provide consistent discipline for all their children (Murray, 2002). The household tasks that their children perform should also be age-appropriate and as fairly distributed as possible (Kiburz).

Furthermore, it would be advantageous for nurses to encourage parents to allow healthy siblings to join a support group whose members include other siblings of chronically ill children so that they have the opportunity to talk to peers about how they feel (Derouin & Jesse, 1996; Houtzager et al., 2001 & Spinetta et al., 1999). Research has also indicated that attending school and other social activities help healthy siblings cope as they provide a way of escape from the “sick” household (Jackson, 1999). When given the opportunity, it is also important for nurses to take the time to listen to and empathize with how healthy siblings and their parents are feeling. This is because nursing interventions that lack an emotional component are usually not recognized as helpful (Murray, 2000). If the healthy siblings are having a hard time vocally expressing how they feel about their sibling’s illness, they should be encouraged to use drawing as a way of expressing how they feel (Moyer, 1997). Nurses can also reassure healthy siblings that it is normal to experience negative emotions such as resentment and jealousy towards their ill sibling to some extent (Murray, 1998 & Noll et al., 1995). Additionally,
nurses should focus on teaching the parents how to facilitate their children’s coping skills as well as how to control or change the modifiable risk factors that put these healthy siblings at a greater risk for poor adjustment (Moyer, 1997).

In addition to all of the above, it is recommended that nurses educate the parents on the importance of maintaining sibling involvement as well as about the need to maintain consistent routines (Wong et al., 1999). If the ill child is living at home, parents should be encouraged to plan activities for the children to do together so that their interactions and involvement in each others’ lives is maintained. Nurses can impact family adjustment in a positive way by making the siblings an integral part of caring for the chronically ill child (Williams et al, 1997). Another nurse researcher identified with many of the above nursing interventions but describes those actions as “family empowerment”. She suggests several other ways to increase family empowerment by first building trust and establishing rapport with the family. She also recommends that nurses assist the family in assessing their own strengths and weaknesses as well as in setting their own goals (Hulme, 1999). In addition, she advises addressing the family’s perceived needs before addressing the needs that the nurse feels that they have. Furthermore, she proposes that nurses should help family members develop negotiating skills so that they can communicate effectively with health care professionals. Finally, she suggests that nurses acknowledge family members when they provide good care (Hulme).
Summary

Based on the existing research, health care providers can reassure parents that although healthy siblings may be at a higher risk for developing psychosocial problems, such difficulties do not always arise. Moreover, nurses can help parents focus on the positive outcomes that a pediatric chronic illness can have on ones family system such as enhanced family closeness and an increased sympathy for others (Derouin & Jesses, 1996). In addition, parents can be reassured that information is available in regards to recommended measures they can implement that are likely to help their healthy children successfully adapt.

It is estimated that between 15 and 18 percent of U.S. children will experience a chronic illness or disability at some point during their childhood (Chernoff, et al., 2002). Research has demonstrated that the presence of a pediatric chronic illness in the home, in combination with multiple other variables, does influence the psychosocial outcome of healthy siblings. This impact can be explained by Family Systems Theory as its main hypothesis is what happens to one family member will in turn impact every other family member. Nurses are in a position where they may interact with chronically ill children and their family members on a regular basis. Only when appropriately informed can they provide as well as recommend interventions that have been proven effective when it comes to improving healthy sibling outcomes. This is why nurses need to be knowledgeable research consumers and why research pertinent to this topic needs to continue.
REFERENCES


