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The Role of Child Life Specialists in Meeting the Needs of Children with Chronically Ill Siblings

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THE ROLE OF CHILD LIFE SPECIALISTS IN MEETING THE NEEDS OF
CHILDREN WITH CHRONICALLY ILL SIBLINGS

by

JENNA L. MATHIS

A thesis submitted in partial fulfillment of the requirements
for the Honors in the Major Program in Early Childhood Development
in the College of Education and Human Performance
and in The Burnett Honors College
at the University of Central Florida
Orlando, Florida

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Thesis Chair: Dr. Anne McDonald Culp

ABSTRACT

The purposes of this study were to explore the needs and concerns of the siblings of children hospitalized with a chronic illness and to explore the role that Child Life Specialists play in the lives of siblings. Face-to-face and telephone interviews with Child Life Specialists from three central Florida pediatric hospitals were conducted and analyzed. Through these interviews, I gained the perspective of the Child Life Specialist's role concerning the needs and concerns of siblings as well as their role in meeting those needs. The interviews were tape-recorded and later transcribed and analyzed with a qualitative approach.

I predicted that the results would show many similarities among Child Life Specialists' perceptions related to their experiences with siblings and would solidify the role that they play in meeting the needs of siblings. This study validated the worth of the Child Life Specialist in the hospital setting in aiding in the psychosocial development of hospitalized children and their families.

I concluded from the data that all of the Child Life Specialists agreed that they were needed in the hospitals to help siblings deal with the psychosocial needs separate from the needs of the hospitalized child. All the Child Life Specialists helped siblings in the hospital; however there was a fair amount of inconsistency regarding how the needs of siblings were met. All the Specialists believed they were relieving anxiety; with differences in the methods to relieve anxiety. They all believed they made a positive impact in the siblings' hospital experiences with a fair amount of variance in their perceived level of impact.

There are very few research studies in the fields of child development and child life regarding psychosocial development of siblings of chronically ill children. Therefore, I felt it

pertinent to conduct an exploratory study that would provide relevant and factual information to both fields that could, in turn, inspire future research in both fields. Through this study, I have discovered that Child Life Specialists employ a variety of methods in meeting the needs of siblings of children diagnosed with a chronic illness. I have also discovered that Child Life Specialists perceive themselves as being able to make a positive impact on the coping and psychosocial needs of the siblings of children hospitalized with chronic illness

Further research in this area is needed. First and foremost, a study is needed in which the siblings are interviewed so that their needs are correctly identified, and Child Life Specialists can intervene appropriately. Second, this particular study focused on central Florida, and future studies should expand the geographic regions to other areas of the United States. Third, this particular study focused on chronic disease diagnosis of the child in the hospital, and additional studies are needed so that all siblings of all children in the hospital for any reason are studied. Therefore, I predicted that siblings would have different needs of attention from one another, depending on diagnosis of chronically ill sibling and family situation, and that Child Life Specialists would employ a variety of methods in differentiating for and meeting those needs.

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I wish to also thank the 10 Child Life Specialists who participated in this thesis project. You not only contributed to the academic progress of an aspiring Child Life Specialist, but also to the field of Child Life.

For my parents, Nancy and Richard Mathis, thank you for your endless support, love, and for always encouraging me to reach for the stars.

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CHAPTER 1: INTRODUCTION

This thesis describes the needs and concerns of siblings of children with a chronic disease as perceived by a set of Child Life Specialists. In addition, the descriptive study will discuss the role that Child Life Specialists perform in helping siblings cope with a chronic illness of their brother or sister. I was drawn to the population of siblings of chronically ill siblings as they are often considered a forgotten population. As chronically ill patients receive so much attention both from hospital staff and presumably from parents and family, it is understood that well siblings of these patients may begin to have feelings of jealousy or resentment towards their ill sibling (Vermaes et al., 2012). Additionally, in lieu of the lack of attention or familial stimulation that the well siblings may receive, the well sibling has the potential to suffer developmentally and emotionally. This can, in turn, cause behavioral problems, emotional strain, anxiety and fear, and a number of other issues in the sibling (Williams, 1997). This is why Child Life Specialists' interventions are so crucial when working with siblings of chronically ill patients.

There is little data in the field of child development regarding psychosocial development of siblings of chronically ill children. Specifically, very little data is available regarding the needs and concerns of the children who have siblings diagnosed with chronic disease, specifically with cancer. Additionally, there are very few recent research studies in the field of Child Life. This lack of research means that very little information and data has been recorded regarding Child Life Specialists interventions, especially data regarding interventions with children who have siblings with cancer. The lack of knowledge concerning the effects of childhood cancer on children whose siblings carry the diagnosis, and the interventions child life

specialists implement to negate these effects, are definite inadequacies in both the medical field and the childhood development field. Research is needed to further understand the needs of children who have siblings who are chronically ill. Therefore, I felt it pertinent to carry out a study that would provide relevant and factual information to both fields that could in turn inspire further research.

CHAPTER 2: LITERATURE REVIEW

An initial literature review for the effects of childhood chronic illness and hospitalization on siblings and related child life interventions was conducted in the databases ERIC and PsycINFO, using the key search terms “childhood chronic illness” or “childhood cancer” and “siblings” and “Child Life Specialists”, yielding results from the following academic journals: *Clinical Child Psychology and Psychiatry, Children's Health Care, American Journal of Family Therapy, Cancer Nursing Practice, Exceptional Parent, Children's Health Care, Journal of Pediatric Psychology, International Journal of Nursing Studies, Journal of Behavioral Medicine, Health and Social Work, Families, Systems, and Health, Child: Care, Health, and Development, The Journal of Pain, Australian Journal of Early Childhood*. After further review, 16 relevant studies and meta-analyses met inclusion criteria which are defined below.

The literature review is organized under four topics: 1) Siblings of Chronically Ill Children, 2) The Impact of Chronic Illness of the Family, 3) Recent Studies on Siblings of Cancer Patients, and 4) The Role of the Child Life Specialist in Hospitals.

Siblings of Chronically Ill Children

In a literature review by Williams (1997), he cites more than 40 studies that were published between 1970 and 1995 and identified the extent and nature of risks to siblings of chronically ill children. Williams' method of gathering the studies was through computer-based searches in various nursing, pediatric, and social science journals. Williams broke down the studies that were gathered and reviewed into three groupings of outcomes to siblings: increased risk, no risk, and positive and negative outcomes. Among the reviewed studies, the participants were individuals ranging from ages 3 years to 21 years.

Williams (1997) indicated in the literature review that "the majority of the reviewed studies reported an increased risk in siblings which were manifested in various ways" (p. 317-318). The manifestations that occurred included higher internalizing and externalizing behavior problems. Internalizing behaviors such as low self-esteem, withdrawal or shyness, feelings of loneliness and isolation, anxiety, depression, vulnerability, anger, worry about ill child were reported (Williams, 1997). Examples of externalizing behaviors are somatic complaints, multiple behavior problems, poor peer relations or delinquency, and schools problems related to a decrease in school grades (Williams, 1997).

In the few longitudinal studies that were reviewed, it was concluded that the siblings of chronically ill children were worse off than they were five years prior due to higher levels of aggression, depressive affect, and social isolation (Williams, 1997). It was also found in these studies that mothers of chronically ill children showed greater symptoms of depression.

Adversely, several studies report if not beneficial, minimal negative effects on siblings of chronically ill children. Five of the reviewed studies reported growth-enhancing effects of

pediatric chronic illness on siblings as well as increased family cohesion and evidences of personal growth (Williams, 1997). Williams (1997) concluded that one explanation for these positive findings is that “the subjects were siblings of chronically ill children under the care of the researchers, and that the at-risk siblings gained resilience through appropriate management” (p. 318). Additionally, the absence of parental depression, good marital adjustment, high levels of neighborhood and community support and family resources, and effective parent-sibling communication about illness were found to be predictors of positive sibling adjustment in a study of children diagnosed with cancer (Williams, 1997).

Another meta-analysis of previous literature by Vermaes, Susante, and Bakel (2012) relates how chronic health conditions affect siblings. This meta-analysis built upon previous meta-analyses by adding 13 new research reports with further data on moderating variables (Vermaes et al., 2012). The authors of this study examined two main questions, “how is the psychological functioning of siblings of children with chronic health conditions compared to siblings of healthy children” and “can variations in siblings’ psychological functioning be explained by methodological and demographic factors” (Vermaes et al., 2012, p. 165). Vermaes et al. (2012) hypothesized that chronic health conditions would cause daily hassles and therefore act as stressors for a chronically ill child and their family. A second hypothesis was for “siblings to be more inclined to internalize, rather than externalize their feelings” because of the lack of attention they receive in relation to the ill child (Vermaes et al., 2012, p. 167). A third hypothesis was that “stressors may also generate resilient responses and reinforce personal assets” (Vermaes et al., 2012). A hypothesis regarded demographics was that “younger children would be less negatively affected by CHCs than older children” (Vermaes et al., 2012, p. 167).

For this study, a meta-analysis of 52 studies was conducted. Two types of effects were investigated throughout these studies: “the effects of chronic health conditions on siblings’ internalizing problems, externalizing problems, and positive self-attributes” and “demographic moderation effects (gender, age, and birth-order position), type of CHC, intrusiveness of treatment, and life-threatening potential” (Vermaes et al., 2012, p. 168). To conduct this meta-analysis, a computer search in PsychInfo, Medline, and PubMed using a variety of terms yielded studies from which 52 were selected based on the fact that the studies had been peer-reviewed, the sample was greater than or equal to ten, and reported statistics on internalizing and externalizing problems among siblings. Of these studies, the samples sizes ranged from 10 children to 254 children. Thirty-six studies included parents and twenty-five studies included siblings as informants. The majority of the studies were conducted in North-America and Europe, but some took place in Asia and Australia. The proportion of female participants ranged from 31% to 100%. The siblings’ mean ages ranged from 5 to 16 years and the proportion of siblings younger than the chronically ill child ranged from 0% to 80% (Vermaes et al., 2012).

The meta-analysis yielded results concluding that there is a small negative effect of having a chronically ill sibling. The overarching consensus was that siblings are especially vulnerable to internalizing problems, younger siblings’ positive self-attributes are less negatively affected than older siblings’ self-attributes, and siblings of children with life-threatening chronic health conditions appear more at risk of psychological problems (Vermaes et al., 2012). In lieu of this, Vermaes et al. (2012) suggest that “services can be made more effective for siblings by focusing on the identification of those siblings who are especially at risk for mental health

problems and by developing evidence-based sibling coping programs, especially targeted these high-risk siblings” (p. 173).

The purpose of an additional meta-analysis, by Sharpe and Rossiter (2002) was to review the literature specifically relating to siblings of chronically ill children. A methodological hypothesis was that “studies published more recently would show fewer negative and more positive outcomes than earlier studies” (Sharpe and Rossiter, 2002, p. 700). A second methodological hypothesis was that “more negative effects would be found for parental reports than sibling self-reports” (Sharpe and Rossiter, 2002, p. 700). To conduct this meta-analysis, fifty studies published within the last thirty years representing a sample of over twenty-five hundred siblings of chronically ill children were investigated.

The results derived from this meta-analysis were divided into three sections: tests of effect sizes, the role of methodological moderator variables, and substantive moderator variables. Regarding the first section, there was no positive correlation between the number of sibling participants and the absolute value of the effect sizes at the outcome level (Sharpe and Rossiter, 2002). In regard to the second section of results, there are non-significant correlations between publication year and study-level effect sizes, as well as a negative correlation between year of publication and sample size at the study level, concluding that sample sizes have decreased over the years and effect sizes are becoming more positive (Sharpe and Rossiter, 2002). Finally, in the third section of results, “psychological functioning, peer activities, and cognitive development effect size clusters produced negative mean effect sizes significantly different from zero” (Sharpe and Rossiter, 2002, p. 703). Overall, this study resulted in the finding of a negative overall effect on children who have a sibling with a chronic illness. The findings of

Madan-Swain et al. (1993) are consistent with quantitative reviews of the literature and traditional literature reviews pertaining to siblings of children with chronic illnesses.

In the literature review by Barlow and Ellard (2006), an overview of the current literature regarding the psychosocial well-being of children with chronic disease and their families was provided. The method of collecting the literature contained inclusion criteria of systematic reviews, meta-analyses, and overviews as well as reviewing abstracts and later obtaining full copies of the selected literature. The selected literature was found through the following databases using an electronic search: AMED, CINAHL, Cochrane Database, DARE, HTA, MEDLINE, NHS EED, PsycLIT, PsycINFO and PubMed. A total of three hundred and ninety-one papers were identified and after the review process took place, ten papers met inclusion criteria and were evaluated.

Among the literature was a meta-analysis review of studies of depressive symptoms among children and adolescents with chronic medical problems, a traditional review of literature on adjustment within siblings of children with cancer, a meta-analysis review studies of correlates of children's adjustment to physical disorders, a meta-analysis review of the behavioral adjustment of children and adolescents with asthma, and a traditional review of literature concerning psychosocial adjustment associated with rheumatic diseases in children. The advantage of gathering the aforementioned literature is that the evidence was gathered across multiple conditions and is able to highlight patterns within the field of chronic illness (Barlow & Ellard, 2006). A consistency within the literature is that children with chronic disease show higher risks of psychological distress. Conversely, an inconsistency within the literature is the notion of self-concept and where it lies with impact from chronic illness. From all the

literature review, the effect of chronic illness on siblings is still unclear. Mixed findings have been found across the board with inconsistencies ranging from negative effects to positive effects. This literature review provides further demonstration that there is a greater need for evidence of the psychosocial well-being of children with chronic illness and the impact of illness on siblings and family.

In the narrative literature review by Malone and Price (2012) a search was conducted specifically on research about the needs of siblings. Malone and Price (2012) searched the databases Cumulative Index to Nursing and Allied Health Literature, PsycINFO and MEDLINE for articles in English using terms such as ‘siblings’, ‘childhood cancer’, ‘impact’, ‘coping’, ‘family’ and ‘adjustment’. Inclusion criteria were established and results yielded articles between 1981 and 2011 that were primarily research studies. Sibling adjustment and adaption, emotional impact on siblings, coping strategies, and unmet needs were evaluated amongst the selected literature.

In conclusion from the literature review completed by Malone and Price (2012), “it is clear from the literature reviewed in this article that a family-centered approach in childhood cancer care is not simply a parent-centered approach, but should include siblings” (Malone and Price, 2012, p. 30). With that being said, it was also found that nurses or health care professionals directly servicing families should be aware of the detrimental impact that childhood cancer has on siblings and in turn should offer support, education, and counseling (Malone and Price, 2012). Malone and Price (2012) also state that “targeted support is essential to ensure siblings’ social and emotional needs are met” and that “the play specialist can reduce

anxiety and encourage the expression of feelings through the use of constructive age-appropriate play” (p. 30).

A structural equation model (SEM) was used to examine interrelationships among psychosocial variables that are known to affect the development of well siblings and parents of a child with a chronic illness in a study conducted by Williams et al. (2002). This study used eight variables to assess these simultaneous relationships. These variables are as follows: sibling knowledge about illness, sibling mood, sibling attitude towards illness, sibling self-esteem, sibling social support, child behavior problem, parent mood, and family cohesion (Williams et al., 2002). Additionally, several covariates were included in the SEM and are as follows: the ages of siblings which were believed to affect several study variables and the knowledge scores of the siblings were controlled for age, treatment group placement, and for three of the four diagnoses (Williams et al., 2002).

In the Williams et al. study, a sample of 252 pairs of parents and siblings of a child with a chronic illness of either cancer, cystic fibrosis, diabetes, or spina bifida, was investigated with the mean age of the siblings being 11 years, two thirds being older than the ill child, 50% being male, and approximately 86% being Caucasian (Williams et al., 2002). The majority of these children lived in two-parent families with a mean annual income in the range of \$40,000-\$49,000 (Williams et al., 2002). Using dyads of this sample, socioeconomic status and family cohesion were compared with the parent-reported behavior of the well sibling (Williams et al., 2002).

The results of the Williams et al. (2002) study yielded that all measures of fit of the SEM suggest a good fit except the chi-square measure to the high number of observations or study subjects (Williams et al., 2002). It was found that socioeconomic status strongly and directly

affects both the behavior of the sibling and the mood of the parent while the behavior of the sibling is also affected by cohesion in the family and knowledge about the illness (Williams et al., 2002). It was also found that the knowledge about the illness had a significant effect on the attitude of the sibling toward the illness and its impact on the self and the family, sibling mood directly affects sibling self-esteem which in turn affects the attitude of the sibling toward the illness, and support felt by the sibling had a direct effect on sibling self-esteem (Williams et al., 2002). In regards to parent-sibling interaction, it was found that the mood of the parent affects cohesion within the family, however, this had no effects on the behavior of the sibling, or the feeling of social support of the sibling. Adversely, family cohesion has direct effects on the behavior of the sibling, the attitude of the sibling toward the illness, and on the sibling's view of social support (Williams et al., 2002). Williams et al. (2002) concluded that "these variables and relationships among them appear to be amenable to treatment through well-designed focused interventions" (p. 422). Williams et al. (2002) further suggested that interventions might be explored in family settings, giving attention to the psychosocial variables mentioned previously and furthermore to enhance family cohesion.

The purpose of the study by Gardner (1998) was to use grounded theory to explore how well siblings of children with chronic illnesses think and feel in an effort to cope. According to Eli Gardner (1998), the primary investigator for this study and author of this article, the grounded theory approach was the qualitative methodology chosen for this study because "it offers the best opportunity to create theory in areas that are hard to access with traditional quantitative methods while also allowing data to be collected in single interviews and systematically analyzed" (p. 215). A goal when using this approach is to gather a small sample

size, from which answers can derive amongst diverse areas and hypothesis can be generated, further offering a foundation upon later research to build upon (Gardner, 1998).

The Gardner (1998) study involved a sample consisting of five boys (two 11-year-olds, two 12-year-olds, and one 15-year-old) and five girls (three 11-year-olds-, one 12-year-old, and one 15-year-old). Of this sample, six well children were older than their ill sibling and four well children were younger (Gardner, 1998). No further information was provided about the participants. Data was collected through semi-structured interviews involving neutral, open ended, and clear questions in order to elicit maximum unbiased answers (Gardner, 1998). These interviews were conducted with each child, lasting 75 minutes each.

The findings from this study included a variety of stressors and coping strategies among the participants, appraisals relating to oneself and relating to others, as well as effects related to parental responses. From an analysis of the siblings' responses, hypotheses were generated about which factors related to the coping process. Gardner narrowed her observations into two categories. The first being factors that decrease the impact of a stressor, which included perception of the event as being within their ability to manage, a parental response that is perceived to meet the child's needs, successful coping strategies, perception of some control over events, and achievement of a balance between thinking of oneself and thinking of others. The second being factors that exacerbate the impact of a stressor, which included perception of situation as beyond their ability to manage, a parental response that is perceived not to meet the child's needs, catastrophic or omnipotent thinking, attributing negative events to be permanent, perception of no control, and repeated, ineffective strategies. From these analyses, Gardner (1998) reported three major findings about the coping capabilities of siblings of chronically ill

children. She found that a confusion among the children about what was wrong with their sibling existed, that children felt responsible for causing the illness or otherwise felt a responsibility for keeping their sibling alive as well as feeling unsupported by their parents, and finally that the role of parental responses is vital to enabling those children to “mobilize their own internal resources” (Gardner, 1998, p. 226).

The Impact of Chronic Illness on the Family

In the literature review by Cohen (1999), selected research about families coping with childhood chronic illness was reviewed and prevalence data regarding the effects and risks among chronically ill children, their parents, and their siblings is summarized. This literature review sought to emphasize finding about “the negative impact that illness demands can have on the family and the positive impact that family system resources can have on illness management” (Cohen, 1999, p. 149). The found research was placed into two categories; prevalence and nature of mental health risks, and illness demands and family resources. Among these two categories a variety of subcategories were also classified.

In the category of research titled “prevalence and nature of mental health risks”, the chronically ill child, the parents, and the siblings were all identified as presenting long-term risks. It was found that the chronically ill child are at greater risk of mental health problems such as emotional disorders, abnormal behavioral symptoms, and school-related adjustment problems (Cohen, 1999). It was found that chronic illness in a child also presents mental health risks to parents such as caregiving burdens, increase in parental stresses, and vulnerability to depression and marital problems (Cohen, 1999). Regarding siblings, it was reported that healthy siblings are negatively impacted by their ill sibling’s chronic illness. Cohen (1999) stated that “Parents

may have less time to spend in social and recreational activities that nurture well siblings and their development” as well as “Well siblings may also experience differential treatment in relation to the ill child” (p. 151). Research has also found that the majority of well siblings present psychological and behavioral symptoms. In regard to signs of resilience among families coping with childhood chronic illness, Cohen found that “illness stressors are associated with increased risks to mental health” and that “families coping with childhood chronic illness carry an increased burden of psychiatric symptoms and stressors” (p. 152).

In the category of research titled illness demands and family resources, Cohen found that there are four key findings regarding the interactions between illness demands and family resources. These four key findings are as follows: the demands of childhood chronic illness impose severe stresses on families; resources of the total family system impact the course of illness and patient outcomes; the most powerful factors affecting patient and family adaptation to illness are concentrated in the family system as a whole; family biopsychosocial processes may also have negative effects.

In summation, Cohen (1999) concluded through this review of research that:

Resources families need to nurture resilience are right within reach because: Family system variables are more powerful predictors of adaptation and adjustment than disease factors or illness severity. The synergy of the total family system is more important to resilience than specific, isolated family factors. The family system and the illness share a reciprocal, interactive relationship that allows the family to "put the illness in its place." Clinicians can support family adaptation through a wide range of interventions: reducing

illness demands, increasing family resources, creating affirmative meanings, and supporting the *total* family system. (p. 12).

The purpose of the study by Madan-Swain, Sexson, Brown, and Ragab (1993) was to examine coping, adaptation, and family functioning in siblings of cancer patients, the cancer patients themselves, and a control group of nonclinical children who have healthy siblings (Madan-Swain et al., 1993). Madan-Swain et al. (1993) made two hypothesis, that the sibling group would “differ from nonclinical controls in adaptation and coping” and that “family constellation variables and individual differences would be related to sibling adaptation and coping” (p. 62). This study investigated a sample of 32 siblings, 15 male and 17 female, with ages ranging from 5 to 16 years. “Of the 32 siblings, 19 had a brother or sister diagnosed with acute lymphocytic leukemia, 7 had a brother or sister with a brain tumor, and 6 had a brother or sister with a solid tumor” (Madan-Swain et al., 1993, p. 62). The nonclinical comparison group was comprised of ten children, two males and eight females whose ages ranged from 7 years to 17 years. The assessment consisted of children’s self-report measures of coping and family adaptation. The following coping strategies were reported: distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem solving, emotional regulation, wishful thinking, seeking social support and resignation (Madan-Swain et al., 1993).

The Madan-Swain et al. (1993) study concluded that there were no significant differences among the three groups on measures of coping, adaptation, and family functioning (Madan-Swain et al., 1993). Conversely, siblings of children with brain or solid tumors showed more frequent engagement in wishful thinking (Madan-Swain et al., 1993). The findings also indicated that “as siblings’ chronological ages increased so did their endorsement of the efficacy

and frequency of these coping strategies” (Madan-Swain et al., 1993, p. 66). Furthermore, older siblings reported that blaming others and problem solving were more efficacious than any of the other coping strategies (Madan-Swain et al., 1993). Additionally, “the more siblings in the family, the better adjustment reported by the siblings as evidence by better adaptation with more positive attributions for good events” (Madan-Swain et al., 1993, p. 67). Madan-Swain et al. (1993) concludes from these findings that “older siblings may have been given greater responsibility for caring for younger siblings and taking care of domestic activities at home while their brother or sister was ill. Thus, having an ill brother or sister results in increased responsibility of older siblings, decreased participation in family activities, resulting in less positive feelings regarding their family and the cancer experience” (p. 67). Finally, Madan-Swain et al. concludes that there may not be a universally negative impact on siblings or families of chronically ill children, and that further studies are needed to examine sibling adaptation, adjustment and family functioning with a focus on the process by which siblings adjust and factors that may predict poor adjustments.

In a study by Menke (1987), 72 school aged children and their parents participated in a study regarding how chronic illness of a sibling impacts school-aged children. The age of the participants was School-aged, between 6 and 12 years old, with a mean age of 9.6 years. Fifty-two children were older and twenty were younger than the chronically ill sibling. Thirty-nine of the subjects were girls and thirty-three were boys. Ethnicity was not mentioned. The annual family income levels ranged from less than \$10,000 to more than \$30,000. Education level of children is assumed to be from kindergarten to sixth grade based on the ages provided. The research questions of this study were as follows: What are the needs and concerns of the

siblings? What is their perception of changes experienced by the family related to having a child with a chronic illness?

The data were gathered through structured interviews. Interviews were conducted by appointment and were completed by an investigator. The majority of the interviews took place in the subjects' homes and the remaining took place at the hospitals where the chronically ill child was receiving treatment. Each interview was transcribed verbatim and was later analyzed by a minimum of two individuals.

The measures pertaining to the siblings were as follows: the child's knowledge of the sibling's illness and concerns about this sibling; the child's concerns, fears, and worries about self and the family; changes in the family; how health providers may help. The measures pertaining to the parents were as follows: history of the child's personality; the child's knowledge and understanding of the sibling's illness; any changes in the family system; background information. Each variable was measured through structured interview schedules, ensuring that the same questions were asked of each subject. Menke (1987) reported that "content validity of the interview schedules was established by having them critiqued by three experts in the care of families with chronically ill children and/or child development" (p. 134).

The results of the Menke (1987) study were instrumental in understanding the impact of a chronic illness of a school-aged sibling. All of the children in the study had some knowledge about their sibling's illness that was provided to them by their parents. Sixty-eight percent of the children in the study expressed worries and concerns about their chronically ill sibling. Some siblings also expressed worries about themselves and their parents. Forty-nine percent of the siblings expressed protective concerns for their ill brother or sister. Sixty percent of the siblings

identified something that was difficult about having a chronically ill sibling. An additional concern realized was the attention the parents gave the ill child compared to the attention received by the well sibling. Sixty-four percent of the siblings perceived their parents as having changed since the onset of their sibling's illness. Thirty-six percent of the siblings thought that they themselves had changed. Twenty-five percent of the siblings noted that their relatives, teachers, or friends changed in the way they treated them. Parents stated that the changes they observed in their children during this time were positive. A final conclusion that 97 % of the well siblings had no "negative behavioral or emotional responses that were related to having a sibling with a serious illness" (Menke, 1987, p .137). This data suggests that the well siblings were coping with the situation at hand. The coping behaviors of the parents and how they respond to their chronically ill child might be an influencing factor on the siblings' coping behaviors.

Recent Study of Siblings of Cancer Patients

In a study by Hamama, Ronen, and Rahav (2008), 100 healthy siblings of a child with cancer participated in a study examining a variety of stressors of siblings of children with cancer. The participants ranged in age from 8 to 19 years. Fifty-three participants were boys and forty-seven were girls. All children were of Israeli Jewish decent. Eighty-two fathers and forty-nine mothers of the participants were employed, and eighteen fathers and fifty-one mothers were unemployed while twenty-four fathers had less than 12 years of education and thirty-eight had 12 years or more. Suitable families for the study were sought out and agreement to participate was obtained. Data were then gathered from the ill child's medical files and the health children

completed the questionnaires. Initially, parents completed a scale on demographic data that was specifically designed for this study.

The research hypotheses of the Mamama, Ronen and Rahav (2008) study were as follows: healthy siblings with higher role overload will also present a higher level of anxiety and a higher number of psychosomatic symptoms; healthy siblings with a higher level of self-control (SC) skills and a higher level of illness-related self-efficacy (SE) will present a lower level of role overload; healthy siblings with a higher level of SC and a higher level of illness-related SE will present lower levels of role overload and duress responses (anxiety and psychosomatic symptoms); healthy siblings who report higher levels of SC and illness-related SE will present a lower correlation between role overload and duress responses (anxiety and psychosomatic symptoms) than will HSCC reporting lower levels of coping resources (Hamama, Ronen, & Rahav, 2008). In regard to the variables and measures of this study, Role Overload was measured by Hamama, Ronen, and Rahav adaptation of the Zarit and Zarit's Burden Interview, State Anxiety was measured by the State-Trait Anxiety for Children Scale developed by Spielberger, Edwards, Montouri, and Lushene Psychosomatic Symptoms was measured by the frequent symptoms scale developed by Lapouse and Monk, Self-control was measured by the Children's Self-Control Scale, a 17-item self-report scale developed for children by Rosenbaum and Ronen, and Self-efficacy was measured by a single item tapping the healthy siblings' specific belief in their ability to cope with the tasks evoked by the abnormal situation they confronted in having an ill sibling (Hamama, Ronen, & Rahav, 2008).

The results of this study were instructive in understanding the direct effect of cancer on siblings. Hamama, Ronen and Rahav (2008) reported that "greater overload was associated with

more intense duress responses. The outcomes regarding the association between high role overload and high levels of anxiety and psychosomatic symptoms support previous findings that showed a link between a change in the healthy siblings' roles at home and a high level of symptoms” (p. 128). Hamama, Ronen and Rahav (2008) also stated that “regression analyses highlighted the contribution of sociodemographic variables—gender and family size—to the explained variance in siblings' anxiety. The gender outcome resembles previous studies emphasizing that girls tend to report anxiety more than boys” (p. 127-128). In summation, the results of Hamama, Ronen and Rahav’s (2008) study lead to the belief that when self-control and self-efficacy responses were greater, anxiety responses and psychosomatic symptoms were milder in contrast.

The Role of Child Life Specialists in Hospitals

I did not identify any research studies on Child Life Specialists’ role with siblings of children in hospitals. However, the general role of the Child Life Specialist is important to understand. In an article by Bandstra et al (2008), 607 Child Life Specialists were surveyed regarding the use of various non-pharmacological strategies in pediatric pain management. Of these 607, the ages of the participants ranged from 22 to 70 years. Ninety-seven were female and three percent were male. Ninety-one percent were Caucasian, two percent were Latina/Latino, one percent was Asian American/Canadian, one percent was African American/Canadian, and the remaining percent classified as other. The income levels of the participants were not listed though thirty-eight percent attended graduate or professional school.

The purpose of the Bandstra et al. (2008) survey was to determine Child Life Specialists’ use of various non-pharmacological strategies, to describe the efficacy of these strategies, and to

determine how much training Child Life Specialists had in the various strategies as well as assess the level of interest in receiving future training. An online survey was developed by a team of three pediatric pain experts, five Child Life Specialists, and two graduate students with experience in pediatric pain. Once the online survey was complete, four Child Life Specialists within the research team completed the survey to assess its relevance, usability, and total time for completion. Survey items were rated on a 5-point Likert-type scale. Recruitment for the study was accomplished by way of emailing hospitals provided by the Child Life Council's directory of Child Life Programs and asking for email addresses of staff members.

The results of this study were conclusive. The majority of the Child Life Specialists' reported to providing pain management to more than half of their patients. Bandstra et al. (2008) found that "across categories, participants reported most commonly using the following strategies to manage the pain of the pediatric patient in their care: providing information/preparation, behavioral distraction, and therapeutic play" (p. 325). Providing information/preparation was perceived as being the most effective strategy for reducing and managing pain. Bandstra et al. (2008) also found that "across categories, participants reported having received the most formal training in providing information/preparation, medical play, and therapeutic play" (p. 326). Overall, more than two-thirds of the Child Life Specialists' reported having received education relating to non-pharmacological pediatric pain management during their training (Bandstra et al., 2008).

In an article, by Cole, Diener, and Wright (2001), 228 health care professionals at a 232 tertiary care children's hospital with a well-established child life program participated in a study regarding health care professionals' perceptions of Child Life Specialists. The demographics of

the participants were not listed. The research questions of this study were as follows: What is the extent of contact with child life professionals? What are the perceptions of child life responsibilities? What is the perceived importance in patients' psychosocial well-being? To assess these, questionnaires were distributed through participants' hospital mailboxes.

Respondents rated how often they had contact with Child Life Specialists on an 8-point scale ranging from one to eight. An open-ended question asked participants to list their perceptions of what Child Life Specialists do with their time. Categories were developed from the responses, they are as follows: Amuse and Entertain; Preparation and Orientation; Growth and Development; Patient Advocacy; Member of Health Care Team; Patient Support; Family Support; Therapeutic or Health Care Play; Facilitate Coping; Play; Decrease Distress; Make Pleasant and Normalize; Educate Staff. Participants were also asked about the importance of Child Life Specialists to patients' psychosocial well-being on a ten-point scale ranging from one to ten.

The results of the Cole, Diener and Wright (2001) study showed that the majority of health care professionals perceived Child Life Specialists to be of high importance and reported having daily contact with them. They reported that "Preparation and Orientation was the most commonly reported responsibility for Child Life Specialists. Each group of health care professionals perceived this to be an important responsibility, with close to 50% of the total sample mentioning this as a responsibility" (p. 7). Family support was also seen as a responsibility of Child Life Specialists rather than a responsibility of other health care professional (Cole et al. 2001). Overall, Child Life Specialists were amongst the positions in

health care that were given the highest mean rating for importance in patients' psychosocial well-being (Cole et al. 2001).

In the article by Gaynard, Hausslein, and DeMarsh (1989), five Child Life Specialists affiliated with four different pediatric hospitals in various urban settings participated in a study with the purpose of observing Child Life Specialists as members of the pediatric health care team and to report on the time they spent interacting with patients, families, and hospital staff. Initially, 25 child life directors were contacted and asked to participate, as well as ten pediatric facilities, eight large general hospitals, and seven small community settings. Approximately one hundred hours of observation data were collected for this study across the four aforementioned sites. A form was designed and implemented to chart the observed Child Life Specialists' daily activities and interactions (Gaynard et al., 1989).

Observation times for each Child Life Specialist and each site were selected and agreed upon between both the observer and the participant. The average length of observation time was 5 hours and 31 minutes per day while the range of observation time per period was 2 hours to 11 hours and 5 minutes. Each subject was observed for an average of 17 hours. Observation time was measured by the minute with the use of a stopwatch.

Data were organized into the following activity categories: direct service/patient support, direct service/parent and family support, direct service/growth and development, administrative duties, interactions of Child Life Specialists. Content analysis of the data took place and resulted in a variety of interesting findings. Gaynard et al. (1989) reported, "a similar pattern of activities and interactions for all Child Life Specialists was observed across settings", they also noted that, "Child Life Specialists spent the majority of their time in direct patient service

activities including patient support, developmental maintenance, patient and family support, amusement and entertainment, and therapeutic play” (p. 6). It was also reported that Child Life Specialists devoted a lot of time to contact with other individuals such as staff and visitors, also that Child Life Specialists spend little contact with other health care professionals, and that Child Life Specialists perform a small variety of administrative duties for small amounts of time (Gaynard et al. 1989).

Conclusion of Literature and Research Question

Though the information gathered from this literature review was deemed relevant and substantial, very little data are available regarding children diagnosed specifically with cancer and the effects that this diagnosis, treatment, and thereafter had on the siblings involved. With that being said, very little information and data have been recorded regarding Child Life Specialists interventions, especially specialized data regarding interventions with cancer patients. The lack of knowledge concerning the effects of childhood cancer on siblings and the interventions Child Life Specialists implement to negate these effects is a definite inadequacy in the medical field and childhood development field alike. Research is needed to further understand the needs of siblings of children who are chronically ill. Therefore, the research question for this study is “What are the needs of the siblings of children who have been diagnosed with a chronic illness?”

CHAPTER 3: METHODOLOGY

The purposes of this study were to explore the needs and concerns of the siblings of children hospitalized with a chronic illness and to explore the role that Child Life Specialists play in the lives of siblings who have specific needs and concerns. Face to face interviews or telephone interviews were conducted with 10 Child Life Specialists from Nemours Children's Hospital, Arnold Palmer Children's Hospital, and Florida Hospital for Children. No further background information on each participant's socioeconomic status or demographics was obtained, only the participant's place of work was identified. The interviews were tape-recorded and later transcribed and analyzed through a qualitative approach.

Three applications were submitted to the University of Central Florida Institutional Review Board (IRB) for the three separate pediatric hospitals involved in the study. All three IRB applications were approved. See Appendices A, B, and C.

Interview

The interview was a set of 9 questions given to the first three Child Life Specialists. Because the interview was brief and felt inconclusive, I added three questions so that the remaining seven interviews would reveal additional information. The interviews with the Child Life Specialists took no longer than 30 minutes. See Appendix D.

Analysis of Data

The information from the interviews was synthesized utilizing qualitative analysis. All answers to each question were summarized. The results were then written as single case studies. The questions across the cases that had similar responses were pooled and then categorized and coded by identifying importance sentences and words among the responses. The questions

across cases that yielded dissimilar responses were analyzed separately in the same manner. See Appendix E.

CHAPTER 4: RESULTS

Questions 1 and 2: Demographics of Siblings

The first two questions of the interview described the demographics of sibling populations that the interviewed Child Life Specialists served. The number of siblings who visited the hospital ranged from one to three siblings per family. The ages of siblings ranged from three years old to 21 years old, with the majority of siblings under the age of 10 years old.

Question 3: Sibling Visitation

In regard to how often the siblings visited the hospital, the responses varied from every other week, daily, two to three times per week, once a week, once during the entire hospital stay, and every other day, respectively.

Question 4: Meeting Needs of Siblings: Talking

There was little to no variance in Child Life Specialist perceptions of their ability and availability of interaction with siblings. They all agreed that yes, they should be available to the siblings of any hospitalized child.

In regard to meeting needs of siblings, Child Life Specialists responded in a wide array of answers. The answers ranged from talking with the sibling, providing education, building rapport, providing social support, preparing the sibling, and providing normalcy (see Fig. 1).

Three Child Life Specialists interviewed responded that they met the needs of siblings by just talking to the siblings about why their sibling was hospitalized and about how they were coping with their sibling's hospitalization. Three Child Life Specialists interviewed responded that they met the needs of siblings by providing education. For example, when a child is hospitalized or is about to undergo a procedure, these Child Life Specialists would provide education to the

siblings of the hospitalized child regarding diagnoses or procedures to ensure they understand the situations at hand. One Child Life Specialist interviewed responded that they met the needs of siblings by building rapport with the sibling. This was done by playing and talking to siblings, discovering their interests, and providing a fun environment for siblings. One Child Life Specialist interviewed responded that they met the needs of siblings by providing social support to the sibling, which would result from providing safe discussion and providing a listening ear. One Child Life Specialist interviewed responded that they met the needs of siblings by preparing the sibling for a variety of hospital experiences, such as an upcoming surgery, blood transfusion, chemotherapy, or the like. Two Child Life Specialists interviewed responded that they met the needs of siblings by providing normalcy in the hospital setting for the sibling. For example, they would play games or provide opportunities for siblings that they would normally receive outside of the hospital.



Figure 1: Methods of meeting needs of siblings by talking

Questions 5 and 6: Meeting Needs of Siblings: Activities

Child Life Specialists also responded to meeting needs of children by providing activities for siblings such as diversional activities, arts and crafts, activities both at bedside and in play space, to activities for sibling and patient to interact together (see Fig. 2). Two Child Life Specialists interviewed responded that they met the needs of siblings by providing diversional activities siblings, such as providing appropriate games and toys for siblings. Five Child Life Specialists interviewed responded that they met the needs of siblings by providing arts and crafts activities for siblings, such as group or individual activities that could provide some level of therapeutic expression for siblings. Two Child Life Specialists interviewed responded that they met the needs of siblings by providing both bedside and play space activities for siblings. Three Child Life Specialists interviewed responded that they met the needs of siblings by providing activities for both the sibling and patient to complete together.

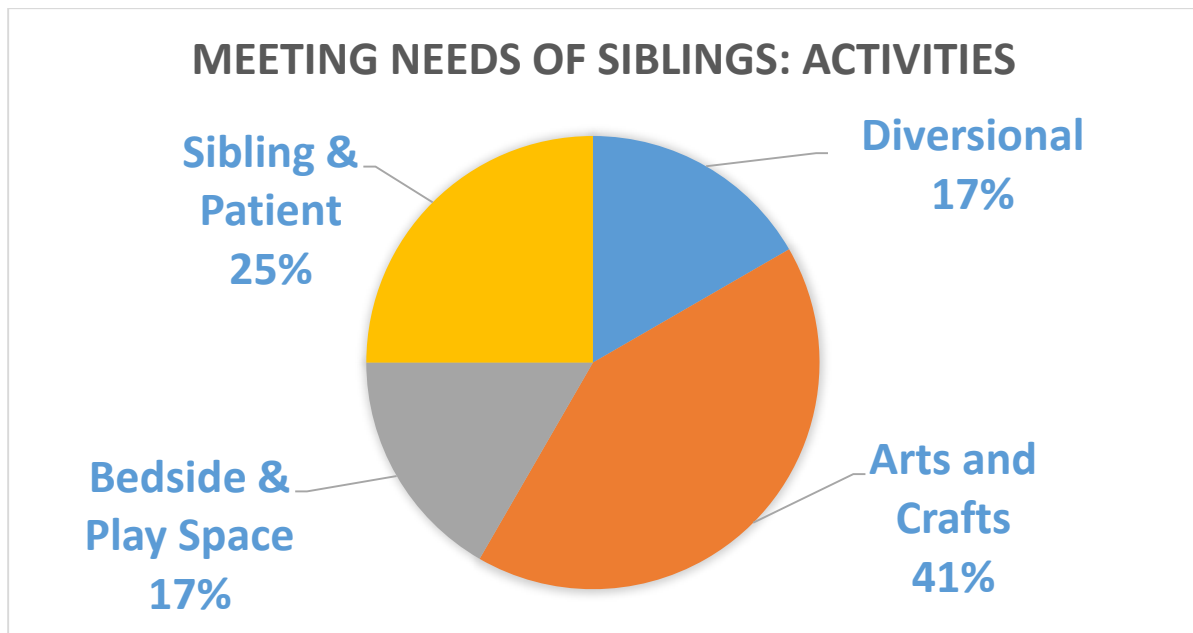


Figure 2: Methods of meeting needs of siblings by providing activities

Questions 7, 8 and 9: Sibling Anxiety

In regard to whether siblings showed any emotion of fear or anxiety, six Child Life Specialists responded “yes” to this question while one Child Life Specialist responded “not really”, two Child Life Specialists responded “no”, and one Child Life Specialist responded “not at the hospital but in the home”. The reasoning determined by the Child Life Specialists behind the anxiety and fear differed and ranged from fear of sibling dying, fear of equipment, fear of procedures that sibling had to undergo, anxiety due to being away from home and family, anxiety about why the patient was in the hospital, and anxiety due to shyness.

There was a consistent response from Child Life Specialists related to ability to relieve fear and anxiety in siblings and variance in methods ranging from providing parents tips, usage of play and therapeutic activity, education, to validation of feelings (see Fig. 3). One Child Life Specialist interviewed responded that they were able to relieve anxiety within siblings by providing tips for parents to aid in the relief of anxiety at home. Three Child Life Specialists interviewed responded that they were able to relieve anxiety within siblings by providing play and therapeutic activity opportunities for siblings. Four Child Life Specialists interviewed responded that they were able to relieve anxiety within siblings by providing education about hospital interventions, procedures, and experiences to the siblings. One Child Life Specialist interviewed responded that they were able to relieve anxiety within siblings by providing validation to the sibling about worries and concerns. One Child Life Specialist interviewed responded that they were able to relieve anxiety within siblings by creating a plan with both the sibling and the parent for the duration of the hospital stay.

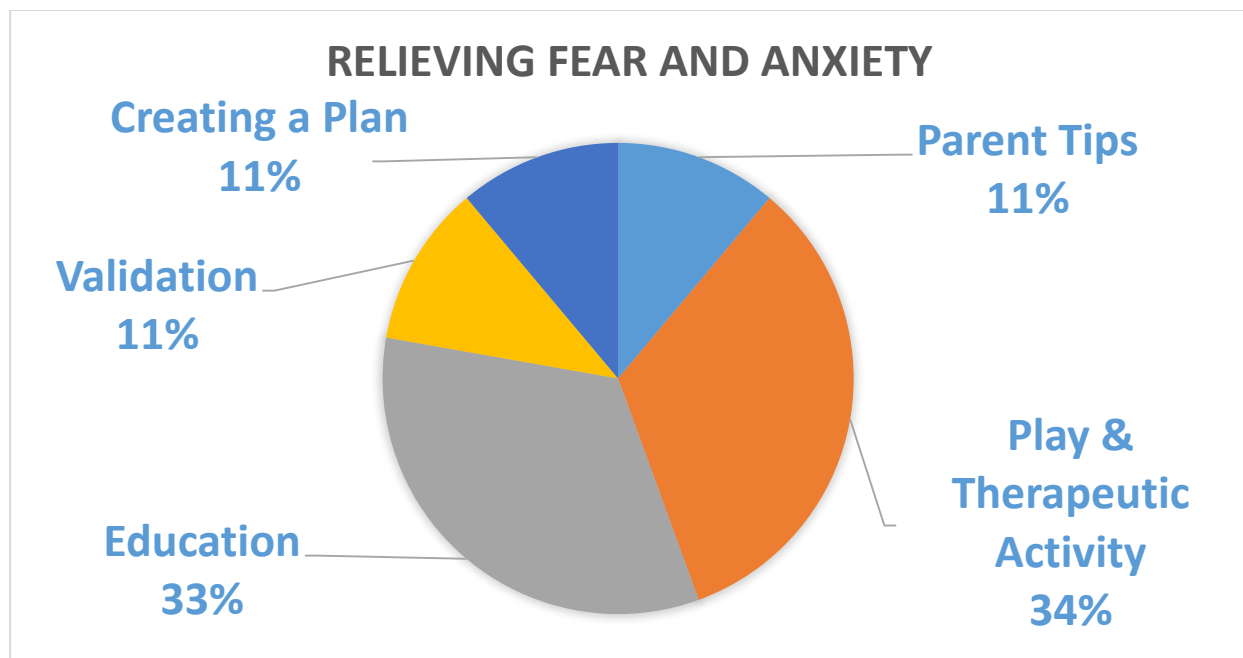


Figure 3: Methods of relieving fear and anxiety

Questions 10 and 11: Level of Impact

There was a consistent response from Child Life Specialists related to having an impact on siblings in regard to ability to help siblings cope with experience, and variance in level of impact ranging from advocating for siblings, supporting siblings emotionally, providing safe environment, to providing fun environment (see Fig. 4). One Child Life Specialist interviewed responded that they felt they were able to impact the sibling's hospital experience by advocating for the sibling. Three Child Life Specialists interviewed responded that they felt they were able to impact the sibling's hospital experience by providing emotional support to the sibling. This could be through safe discussion and therapeutic conversation. Three Child Life Specialists interviewed responded that they felt they were able to impact the sibling's hospital experience by providing a safe environment for the siblings to express themselves. Two Child Life Specialists

interviewed responded that they felt they were able to impact the sibling's hospital experience by providing a fun environment for the sibling.

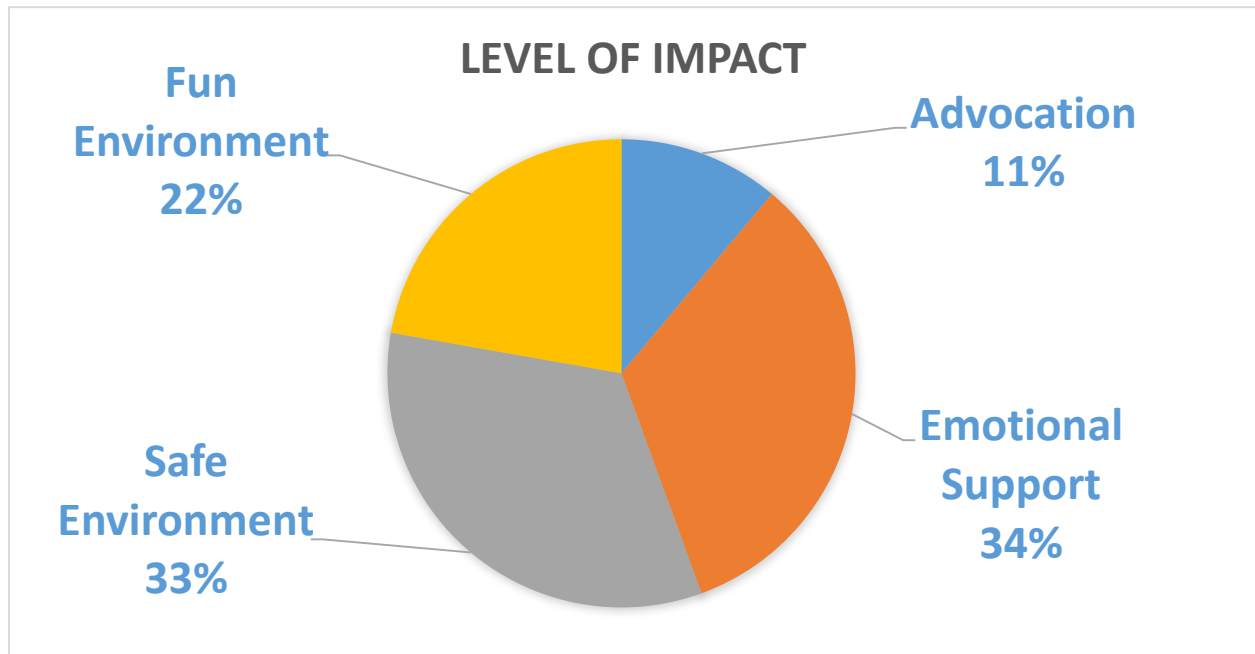


Figure 4: Level and method of perceived impact on siblings

Question 12: Recommendations

The final question of the interview regarded what recommendations the participants had for other Child Life Specialists so that they feel they can also help siblings. The responses for this question were the most varied among all of the interview questions. All of the Child Life Specialists had different responses and different recommendations, all with one underlying goal though; to include siblings whenever possible and to provide families with utmost support and family centered care opportunities. The responses provided were as follows: talk with parents and check in about school and behavior problems, gather background information, talk about

ways to redirect behavior; do not punish for bad behavior, praise for good behavior, talk throughout the hospital experience and take note of special holidays and birthdays so the siblings do not feel forgotten; meet siblings where they are at and allow it to be okay if they are not ready for certain interventions; provide education and support whenever possible and don't leave siblings out of experience; involve the music therapist as much as possible; be available for questions and always answer honestly; be supportive to the whole family, not just the patient; provide resources to bring home for those siblings that cannot make it to the hospital to visit; be honest with children and provide them with a relationship built on trust and reliance; and continue sibling sessions throughout the entire hospital experience not only at the beginning.

CHAPTER 5: DISCUSSION AND IMPLICATIONS

This study sought to explore the needs of children with chronically ill siblings and what the role of Child Life Specialists in pediatric hospitals is in meeting those needs. Through this study I was able to gain the perspective of Child Life Specialists from the three pediatric hospitals in the greater Orlando area in regard to what their role is in serving children with chronically ill siblings. I was also able to gather the perspective of Child Life Specialists regarding their impact on siblings and the effectiveness of their interventions. Finally, I was able to document the Child Life Specialists' recommendations for working with siblings in this distinct population.

Child Life Specialists employ a variety of methods in meeting the needs of children with chronically ill siblings. For example, Child Life Specialists aim to meet the needs of siblings with chronically ill siblings by both talking to siblings and providing activities for siblings. In talking to siblings, Child Life Specialists can meet sibling needs by just talking, providing education, building rapport, providing social support, providing preparation, and providing normalcy. In providing activities for siblings, Child Life Specialists can use diversional activities, arts and crafts, activities both at bedside and in play space, to activities for sibling and patient to interact together. In using these methods to meet sibling needs, Child Life Specialists are able to normalize the hospital environment for siblings while ensuring that they are comfortable and coping adequately with their sibling's chronic illness and hospitalization.

Child Life Specialists perceive themselves as being able to make an impact in the life of children with chronically ill siblings in regard to their psychosocial development and coping. For example, Child Life Specialists can have an impact on siblings by helping them cope with

the hospital experience, advocating for siblings, supporting siblings emotionally, providing a safe environment, and providing a fun environment.

Child Life Specialists also have a number of perceptions related to recommendation that they would provide to other Child Life Specialists so that they may also help siblings of chronically ill patients. All of the Child Life Specialists had different responses and different recommendations, all with one underlying goal; to include siblings whenever possible and to provide families with utmost support and family centered care opportunities.

Considering there is still so little research in the field of Child Life and especially regarding Child Life interventions as reflected by the literature review, future research is still greatly needed. This study was limited to Child Life Specialists in the greater central Florida area and focused only on chronic population patients and the results reflected this. Future research in this area could expand potential participants to other areas as well focus on a variety of other hospitalized populations. This would further the understanding of the impact of Child Life Specialists. Research could also be conducted with the siblings themselves to further the understanding of the impact of Child Life Specialists from the sibling's direct perspective. In regard to methodology and data collection, it would be beneficial in future research to collect demographics and socioeconomic status of participants in order to solidify the population at hand. I plan to further this research in one or all of the aforementioned capacities when I attend Graduate School to pursue further education in the fields of Child Development and Child Life.

APPENDIX A: HOSPITAL 1 IRB APPROVAL LETTER



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: **UCF Institutional Review Board #1
FWA00000351, IRB00001138**

To: **Anne McDonald Culp and Co-PI: Jenna Mathis**

Date: **June 23, 2014**

Dear Researcher:

On 6/23/2014, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review:	Exempt Determination
Project Title:	The Role of Child Life Specialists in Meeting the Needs of Children with Chronically Ill Siblings
Investigator:	Anne McDonald Culp
IRB Number:	SBE-14-10389
Funding Agency:	
Grant Title:	
Research ID:	N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 06/23/2014 01:43:14 PM EDT

A handwritten signature in cursive script that reads 'Joanne Muratori'.

IRB Coordinator

APPENDIX B: HOSPITAL 2 IRB APPROVAL LETTER



University of Central Florida Institutional Review Board
Office of Research & Commercialization
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Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: **UCF Institutional Review Board #1
FWA00000351, IRB00001138**

To: **Anne McDonald Culp and Co-PI: Jenna Mathis**

Date: **July 16, 2014**

Dear Researcher:

On 7/16/2014, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review:	Exempt Determination
Project Title:	The Role of Child Life Specialists at Arnold Palmer Hospital in Meeting the Needs of Children with Chronically Ill Siblings
Investigator:	Anne McDonald Culp
IRB Number:	SBE-14-10429
Funding Agency:	
Grant Title:	
Research ID:	N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 07/16/2014 09:06:30 AM EDT

A handwritten signature in black ink that reads 'Joanne Muratori'.

IRB Coordinator

APPENDIX C: HOSPITAL 3 IRB APPROVAL LETTER



University of Central Florida Institutional Review Board
Office of Research & Commercialization
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Orlando, Florida 32826-3246
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www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To: **Anne McDonald Culp and Co-PI: Jenna Mathis**

Date: **September 17, 2014**

Dear Researcher:

On 9/17/2014, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination
Project Title: The Role of Child Life Specialists at Nemours Children's Hospital in Meeting the Needs of Children with Chronically Ill Siblings
Investigator: Anne McDonald Culp
IRB Number: SBE-14-10582
Funding Agency:
Grant Title:
Research ID: N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 09/17/2014 05:06:54 AM EDT

A handwritten signature in black ink that reads "Joanne Muratori".

IRB Coordinator

APPENDIX D: CHILD LIFE SPECIALIST INTERVIEW SCHEDULE

Think about the last patient you had with a chronic illness.

1. Did they have a sibling that visited the hospital? Yes/no
2. How old was the sibling?
3. How often would you say the sibling visited?

Daily? How often? _____

Weekly? How often? _____

4. When the sibling was here, did you get a chance to talk with him/her?
5. When the sibling was here, were you able to provide any activities for them?
6. If so, what activities did you provide?
7. Was the sibling showing any emotion of fear or anxiety?
8. If so, were you able to relieve the anxiety?
9. If so, how did you do that?
10. Do you feel you had the time to be with the sibling?
11. How do you feel your efforts impacted the sibling's hospital experience?
12. What recommendations do you have for other Child Life Specialists so that they feel they can help siblings?

APPENDIX E: INTERVIEW ANALYSIS AND DATA CODING

ID	Hospital	Q1: Sib Visit	Q2: Age of Sib	Q3: Amount Visited	Q4: Talk w/ Meet Needs	Q6: Activities	Q7: Anxious	Q9: Relieve Anxiety	Q10: Time With	Q11: Impact	Q12: Recommendations
101	1	Yes	7, 9, 14	1	2	N/A	Yes	1	Yes	N/A	1
102	1	Yes	5	3	2, 3	N/A	Yes	2, 3	Yes	N/A	2
103	1	Yes	4, 6	2	1	N/A	Yes	2, 3	Yes	N/A	3
104	2	Yes	6	1	1	1	Yes	4	Yes	1	4
105	2	Yes	10	2	1	1	Yes	2	Yes	2, 3	5
106	2	Yes	10, 14, 21	3	2, 4, 5	2, 4	No	N/A	Yes	4	6
107	3	Yes	6	3	6	2, 3, 4		3	Yes	3	7
108	3	Yes	3, 9	3	6	2, 3	No	N/A	No	2	8
109	3	Yes	4	3	2	2	Yes	3	Yes	3, 4	9
110	3	Yes	5	2	1	2, 4	Yes	5	Yes	2	10

Q3 Legend	Q4 Legend	Q6 Legend	Q9 Legend	Q11 Legend
1=Low amount	1=Just talking	1=Diversional	1=Tips for parents	1=Advocation
2=Moderate amount	2=Providing education	2=Arts Crafts	2=Play & Therapeutic Activity	2=Emotional support
3=High amount	3=Building rapport	3=Playroom & Bedside	3=Education	3=Safe environment
	4=Providing social support	4=Sibling & Patient	4=Validation	4=Fun environment
	5=Preparing sibling		5=Creating a plan	
	6=Providing normalcy			

Q12 Legend
1= Communicate throughout entire hospital experience with parents about school and behavior problems, ways to redirect behavior, do not punish for bad behavior, praise for good behavior, and take note of special holidays and birthdays
2= Meet sibs at emotional level, allow time before certain interventions
3= Provide education and support whenever possible and don't leave siblings out of experience
4= Gather background info. And make assessments, include sibling
5= Play with sibs, encourage questions
6= Involve music therapist
7= Engage sibs in activities and including them in experience and interventions, be available for questions and always answer honestly
8= Be supportive to the whole family, not just the patient, provide resources to bring home for those siblings that cannot make it to the hospital to visit
9= Be honest with children and provide them with a relationship built on trust and reliance
10= Continue sibling sessions throughout the entire hospital experience not only at the beginning

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