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# Comprehensive Assessment: Interventions and Coping Strategies Professionals use to Increase Adaptation of a Sibling with an Ill Brother or Sister

Carrie L. Christensen  
*St. Catherine University*

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Running head: INTERVENTIONS & COPING STRATEGIES USED FOR INCREASED  
ADAPTATION

Comprehensive Assessment: Interventions and Coping Strategies Professionals use to Increase

Adaptation of a Sibling with an Ill Brother or Sister

Carrie L. Christensen

University of St. Thomas/ St. Catherine University

## Introduction

Cancer is the #1 cause of death among children between infancy and age 15 in the U.S (National Cancer Institute). The American Cancer Society estimates 12,060 children ages birth to 15 years will receive a cancer diagnosis in 2012. The effects of a cancer diagnosis are not limited to only the patient and parents, but siblings as well. Previous research has focused on the emotional and psychological effects of cancer on the pediatric cancer patient; however, there is a lack of clinical research on the effects of a cancer diagnosis on the well sibling (Labay and Walco, 2004; Houtzager, Grootenhuis, Hoekstra-Weebers, Last, 2005; Madan-Swain, Sexson, Brown, and Ragab, 1993).

The limited research conducted has shown significant distress with psychological, emotional adjustment in well siblings; and furthermore, a decrease in activities, social relationships, school performance, and behavioral adjustment (Labay and Walco, 2004; Houtzager et al., 2005; Madan-Swain, Sexson, Brown, and Ragab, 1993). Furthermore, several risk factors have been identified as affecting well sibling's adjustment to an ill brother or sister. Family size, role overload, and demographic characteristics have been attributed to a decrease in well siblings overall adaptation and adjustment to ill sibling (Labay and Walco, 2004; Hamama, Ronen, and Rahav, 2008; Houtzager, Grootenhuis, Hoekstra-Weebers, and Caron, 2005; Houtzager, Oort, Hoekstra-Weebers, and Caron, 2004).

For purposes of this study pediatric cancer is defined as any childhood cancer that is diagnosed between infancy and age 18. The common childhood cancers that are referenced in current literature include: Leukemia (acute lymphoblastic leukemia and acute myelocytic leukemia), Hodgkin and non-Hodgkin's Lymphoma, and brain tumors. Mental health professionals that work closely with pediatric cancer patients and their families are social

workers, child life professionals, and psychologist. These professionals will be surveyed in order to identify current interventions and strategies used to increase sibling's adaptation.

The professionals will be contacted via email through professional contact lists. These professionals will be asked to participate in both a qualitative and quantitative survey. The survey will be both open ended and descriptive questions that are used to create a list of methodologies, professional lens, interventions, and strategies by age that these professionals identify as using in their practice.

Coping strategies have been identified as a key component to well sibling's adjustment. Well siblings that use effective coping strategies tend to adjust better to their siblings illness than those that do not use coping strategies or use ineffective techniques (Houtzager et al., 2004; Madan-Swain, 1993; Murray, 2001; Packman et al., 2005; Sloper, 2000). However, the types of coping strategies and interventions that well-siblings use, and that have been identified in current research are minimal. This research is designed to expand the current knowledge of coping strategies and interventions that mental health professionals can use when working with well-siblings of pediatric cancer patients.

The purpose of this study is first to investigate the interventions mental health professionals (social workers, psychologists, and child life specialists) use, and identify as useful in increasing well-siblings coping and adaptation. Moreover, the methodologies, and professional lens (paradigms) these professionals have utilized in their practice with well-siblings. Second, the study investigates whether techniques of mental health professionals change if the well-siblings family struggles with adaptability and changes in family cohesion.

### **Literature Review**

With no preventive measures for childhood cancer, children will continue to receive cancer diagnoses and well-siblings will continue to need to learn to cope and utilize resource in order to adjust to the family changes caused by the illness. Therefore, adjustment of well-siblings will be an on-going problem. Clinical research on adjustment and coping of well-siblings emerged in the 1970s. Most of the research conducted in the 1970s was by doctors, nurses and other medical professionals; very little research was conducted by social workers or in conjunction with social workers. The research primarily conducted by other medical professionals focused on the adaptation of families during treatment, communication during illness, and emotional impact on ill siblings and families (Cairns, Clark, Smith, & Lansky, 1979; Peck, 1979; Share, 1972). The effect of cancer on the well sibling was brought to attention by significantly noticeable changes in sibling's behavior and emotional state that was recognized by teachers, parents, and other family members. Siblings are often asked to increase their family responsibilities (especially older siblings); however, with less attention and support from parents (Powell & Ogel, 1985). Therefore, it is logical that behavioral problems and adjustment difficulties for well siblings would follow after the cancer diagnosis. Past and current research has resulted in siblings experiencing difficulty in adjustment and loss in current social, emotional, and academic performance.

### **Adjustment Difficulties**

In 2004, Labay and Walco investigated empathy and psychological adjustment in siblings of children with cancer. With a sample of 29 siblings of cancer patients diagnosed with ALL, AML, and non-Hodgkin's lymphoma, researchers used self and parent report questionnaires by combining questions from: *Index Empathy for Children*, *Concept of Illness*, *Child Behavior Checklist*, and *Sibling Relationship Questionnaire*. The researcher found that siblings scored

significantly below the mean for activity involvement ( $M = 44.5$ ,  $SD = 8.01$ ;  $t = -3.71$ ,  $p = .001$ ), social relationships ( $M = 44.1$ ,  $SD = 9.71$ ;  $t = -3.19$ ,  $p = .004$ ), and school performance ( $M = 45.5$ ,  $SD = 9.48$ ;  $t = -2.59$ ,  $p = .015$ ; Labay and Walco, 2004). These results are congruent with previous research by Sloper and While (1996) which showed findings that indicated at six months post-diagnosis, one quarter of siblings of children with cancer (sample set of 99 siblings) had experienced behavioral adjustment difficulties and displayed negative behavior changes.

Well-siblings have reported other difficulties with having an ill sibling. Well-siblings report a number of losses during treatment of their ill sibling, including: loss of attention and status within the family, a loss in social life and activities, and loss of psychological security which came with the vulnerability to events such as cancer (Sloper and While, 2000). Furthermore, these siblings have reported less perception of their own family involvement, feelings of anger, sadness, worry, gloom, jealousy, and fear (Labay and Walco, 2004; Madan-Swain et al., 1993; Houtzager et al., 2005). Siblings can even experience such extreme difficulties in adjustment and coping to their ill siblings that they can have PTSD like symptoms (Alderfer, Labay, & Kazak, 2003). Although several studies conducted were congruent with findings that siblings of a patient of childhood cancer experience adjustment difficulties, other research results indicate that healthy siblings do not struggle with adjustment or coping when a sibling has cancer.

A study conducted in 1993 by Madan-Swain and colleagues found that when siblings of cancer patients were compared to the control group (children who do not have siblings with cancer), there was not a significant overall difference among the groups in measures of coping, adaptation, and family functioning. This indicates that patients with cancer and siblings of childhood cancer patients generally have good coping strategies and minimal adjustment

difficulties (Madan-Swain et al., 1996). If the well sibling is psychologically and emotionally healthy prior to the childhood cancer diagnosis of their brother or sister, research indicates that the well-sibling will quickly readjust to the new demands and obligations (Labay & Walco, 2004). Moreover, if the ill sibling has poor prognosis (normal identified as either a brain or solid tumor diagnoses) well siblings have poor adjustment (Houtzager et al., 2004; Sloper & While, 1996). However, types of cancer seemed to be a risk factor that affected coping regardless of well-siblings psychological or emotional health prior to their ill sibling. Siblings with brain tumors or solid tumor diagnosis were found to have a higher risk of coping difficulties (Madan-Swain et al., 1996). Besides types of cancer diagnoses there are other external and internal risk factors that can increase the length of adjustment for siblings.

### **Risk Factors**

There are several risk factors affecting the adjustment of well siblings. The risk factors include age and gender, role overload, communication, family size and birth order, self-control, diagnosis and treatment plan, and family cohesion and adaptability. Risk factors not only affect the adjustment of unhealthy siblings but healthy siblings as well.

Researchers have used age and gender as a variable for years in an attempt to distinguish their affect on siblings of cancer patients (Labay & Walco, 2004; Houtzager et al., 2003; Houtzager et al., 2005; Madan-Swain et al., 1993). Investigators report that older siblings and girls seemed to be most at risk for adjustment problems (Hamama, Ronen, and Rahav, 2008; Labay & Walco, 2004; Madan-Swain et al., 1993). Older siblings report higher levels of anxiety, lower quality of life, more insecurity, and loneliness than younger siblings (Houtzager et al., 2004), and moreover, sisters are at higher risk for emotional and behavioral problems than brothers (Houtzager et al., 2005). This can possibly be attributed to the change in family role and

increase in responsibility that is normally placed on older, female siblings (Labay and Walco, 2004; Houtzager et al., 2005; Houtzager, Oort, Hoekstra-Weebers, and Caron, 2004). Besides older siblings and girls being at higher risk for adjustment difficulties, research has identified siblings between the ages of seven and eleven years old to be at higher risk for adjustment difficulties.

Houtzager et al, 2004 conducted one of the few longitudinal studies on adaptation of well-siblings. The results demonstrated that children between the ages of seven and eleven reported impaired emotional, social, and physical quality of life than did any other age group two years after diagnosis (Houtzager et al., 2004). This demonstrates that when ill siblings are finished with treatment (normally cancer treatments last two years) the siblings between the age of seven and eleven experience some adjustment difficulties (Houtzager et al., 2004). Furthermore, these results were similar to an earlier study conducted by Houtzager et al. (2003) in which quality of life was examined one month after diagnosis. It appears that this age group needs more interventions and strategies for coping with their ill brother and sister.

Age is also correlated with a well sibling's ability to cope. Congruent with the other two articles, Madan-Swain et al. (1993) found that as sibling's chronological age increased so did their frequency of these coping strategies. The results of the analyses indicated that age was positively related to the majority of coping strategies, including frequency of social withdrawal, blaming others, problem solving, and emotional restructuring (Madan-Swain et al., 1993).

Another risk factor is role overload. Role overload is referred to as an imbalance between the role demands placed on the individual and the resources at the person's disposal to meet those demands (as cited in French & Caplan, 1973). Hamama, et al. 2008 reported that

siblings' role overload correlated significantly with anxiety, indicating that greater role overload was linked with higher levels of state anxiety and more psychosomatic symptoms.

Breyer, Kunin, Kalish, and Patenaude (1993) findings indicated that when there was at least some communication regarding sibling's illness between parents and well siblings, there were positive behavior changes. When there was a lack of communication between parent and well-sibling, negative behavior was noticed. Open communication from the parents about ill siblings current medical state is important for well siblings since it can provide a sense of belonging, family cohesion, and perceived family involvement of the sibling. Moreover, increase of knowledge has shown to increase well sibling's adjustment and adaptation to an ill brother or sister (Evans, Stevens, Cushway, & Houghton, 1996; Madan-Swain et al., 1993 Sloper, 2000;). As is communication, self-control and self-efficacy are important factors that can either increase or decrease a sibling's ability to adjust.

Self- control is the ability for one to direct his or hers own life and foster feelings of power, confidence, comfort, and independence (Hamama et al., 2008). Self-efficacy is a sense of personal competence (Hutchison, 2008). Well-siblings who have greater self-control and self-efficacy correlated with lower anxiety and psychosomatic symptoms (Hamama et al., 2008). It is critical for risk factors (role responsibility, communication, self-control, and self-efficacy) to be identified by a working professional or family member in order to assist in well-siblings ability to adjust and cope with their ill sibling.

Researchers have shown psychological adjustment is correlated with family size and birth order (Labay & Walco, 2004; Houtzager, Grootenhuis, Hoekstra-Weebers, and Caron, 2005; Houtzager, Oort, Hoekstra-Weebers, and Caron, 2004; Madan-Swain et al., 1993). When the child with cancer was later in the birth order, siblings exhibited more behavioral, social, and

academic problems (Labay & Walco, 2004), and furthermore, larger families had more sibling dysfunction and adjustment problems (Labay & Walco, 2004). However, in contradictory to existing research, Madan-Swain and colleagues' (1993) found that the more siblings in a family, the better adjustment reported by the siblings. This possibly can be attributed to greater potential availability of older siblings to provide support to one another (Madan-Swain et al., 1993).

There are several reasons noted for birth order and family size being a predictor of psychological adjustment difficulties. First, family responsibilities change once the sibling becomes ill, and older well siblings take on parental roles and extra tasks. Second, there is possibly an increase of attention on the child with cancer and the other siblings are fighting for time with parents. Third, the added responsibility distracts the well siblings from other daily tasks, such as school and friendships (Labay & Walco, 2004; Houtzager et al., 2004; Houtzager et al., 2005). However, Houtzager et al. (2004) furthered the discussion noting that family size and birth order can be predictors, but family adaptability and family cohesion are greater indicators of siblings adjustment.

Cohen, Friedrich, Jaworski, Copeland, and Pendergrass (1994) examined family adaptability and cohesion. The study included 129 parents who completed questionnaires. The findings indicated that siblings obtained the most desirable adjustment scores from chaotic families who had pathologically high levels of adaptability and enmeshment (cohesion) (Cohen et al., 1994). The cause for this may be that families who already have a chaotic life style and have experience with change and stressors may adjust easier to childhood cancer. Therefore, families who have little exposure to stress or change may struggle with the adjustment and coping of the childhood illness.

Houtzager et al. (2004) found incongruent results in their later study. Results indicated that families who had a balance between stability and change appeared to have fewer struggles with adjustment problems of the siblings. Moreover, families with overall low levels of adaptability or cohesion throughout the disease process showed significantly more adjustment problems in several areas including: anxiety, overall quality of life, behavioral-emotional problems, insecurity, and loneliness (Houtzager et al., 2004). Age and gender have also been demographic variables that have affected the research regarding sibling's ability to adjust with their brother or sisters illness.

### **Siblings' Coping Strategies**

Research has identified siblings with effective coping techniques and or interventions to have less difficulty adjusting to the changes caused by an ill sibling. Coping strategies that have been identified in current research include an increase in siblings' perception of sibling illness (siblings knowledge), an increase in emotionally supportive relationships, and increasing optimism and hope (Houtzager et al., 2004; Madan-Swain, 1993; Murray, 2001; Packman et al., 2005; Sloper, 2000). These coping techniques and intervention have been the focus of research for the last decade; however, no other coping techniques have been discussed or studied. Without a family that is high functioning, supportive, have access to several resources, and adaptable, these three resources would not be useful for siblings adjusting to their brother or sister's cancer diagnosis.

Supportive relationships have not only been identified as an effective resource for the siblings, but for the parents as well. Supportive relationships have been identified as effective when family members or other family supports, such as friends, are emotionally available, allow siblings to talk about their situation, and provide support to their own feelings

outside of the illness (Sloper, 2000). Supportive relationships can come in the form of relatives, teachers, counselors, or parents.

Sloper (2000) conducted a study on the experiences and support needs of siblings of children with cancer. In the study, researchers conducted two interviews with 64 siblings. The interviews were semi-structured, and the siblings responded to questions about whether changes had occurred in different areas of their lives since their brother or sister had been diagnosed with cancer. The results of the investigation identified that relationships which allowed them to talk about their situation, and provided comfort and support for their feelings were noted to be at a scale 8 out of 10 for importance (Sloper, 2000). Furthermore, when supportive relationships are not a resource for families, siblings appeared to be at increased risk (Sloper, 2000). Sloper's (2000) results indicated what a positive support system would include:

Information to make sense of the situation and understand the reason for family disruption; reassurance to avoid fear and guilt and to understand the feelings of resentment or anger can be normal and acceptable; attention to values and maintain self-esteem; support to maintain their own interests and activities; and opportunities and understanding to express their feelings (Sloper, 2000).

This is similar to Sloper and While's (1996) study that identified the importance of support from friends and family for the parents in caring for the other siblings and helping in the day-to-day running of the home, as well as in providing emotional support. The communication is what defines the relationship as effective and supportive during time of illness. It has been documented that communication regarding the illness of the childhood cancer patient is just as effective in adjustment and coping.

Some have suggested that well-siblings knowledge about their sibling's illness is positively correlated to better adjustment and coping (Evans, Stevens, Cushway, and Houghton, 1996; Madan-Swain et al., 1993; Sloper, 2000). Evans et al. (1992) studied sibling's knowledge about the child's illness and found it is positively correlated to sibling social competence and negatively correlated to the incidence of behavior problems. The results indicated that if parents perceived the level of sibling knowledge to be high and the sibling demonstrated a high level of knowledge to the researcher, and then they also possessed high levels of social competence (Evans et al., 1996). However, Evans et al. (1996) results revealed that sibling knowledge was less related to behavior problems than anticipated. This suggests that sibling knowledge is helpful in coping and adjusting to brother or sisters illness; however, it needs to be mediated with other resources, such as supportive relationships, camps, and optimism.

Siblings who were able to remain optimistic regarding the course of ill siblings disease, felt less anxious, less insecure, and less lonely (Houtzager et al., 2004). However, nights of hospitalizations and unfavorable course of disease had an effect on sibling's hope and optimism (Houtzager et al., 2004; Sloper & While, 1993). Optimism and hope for recovery of the ill child was a better indicator of adjustment than sibling's knowledge and cancer camps. This suggests that ill siblings that have a favorable disease have fewer struggles with adjustment to illness, and that support needs to be provided to siblings with a brother or sister who have an unfavorable illness or course of treatment. Further research should provide a better understanding of siblings coping strategies when their siblings have unfavorable disease course or outcome.

### **Interventions**

Supportive relationships and enhancing optimism are essential for increasing adaptability for well siblings. However, there are two interventions that have been instrumental in increasing

coping adaptation in well siblings. Current literature focuses on risk factors affect on different interventions; however, camps and support groups have been identified as the effective interventions when working with siblings who have an ill brother or sister (Murry, 2001; Packman et al., 2005; Sloper, 2000; and Sloper & While, 1993).

Packman et al. (2005) conducted the first study using both quantitative and qualitative methodologies. The sample size was 77 siblings of cancer patients who attended a summer camp. The quantitative findings suggested that all siblings reported marked improvement in emotional and social domains (Packman et al., 2005). The emotional health scale accounted for the greatest change pre to post test. Before the camp the mean score for emotional health was 72.04 (SD = 13.62); and at post camp the mean score was 76.67 (SD = 14.27) (Packman et al., 2005). The qualitative finding reported the same results.

The results reported that the camp had a positive impact on their social and emotional health. The majority of the siblings emphasized the effect of the group cohesion, universality, socializing, and catharsis (Packman et al., 2005). These results show apparent increase in emotional and social adjustment of siblings of a patient of childhood cancer. This could possibly be attributed to an increase in normalization of home environment. Camps create an environment where siblings feel important and normal. It helps to create normalcy in the well siblings daily lives, and a sense of belonging (Murry, 2000). Camps are important and medical facilities have begun implementing resources regarding camps and support groups.

Murray (2000) found similar results, which demonstrated that healthy siblings who attended summer camp for siblings of children with cancer scored higher on the PAIC (Personal Attribute Inventory for Children) than healthy siblings who did not attend camp. The results support the theory that suggests that social support in the form of summer camps play an

important role in siblings coping with their brother or sisters cancer diagnosis (Murray, 2000). Camps have shown to be effective in supporting sibling's adjustment to childhood cancer patients, but the common denominator is that camps provide social support and less isolation.

Support groups also provide needed social support and less isolation. Support groups offer children the opportunity to explore why things happen, forum for expression of feelings that can feel foreign, and an environment with people who are similar (Mitchell, Wesner, Garand, Gale, Havill, and Brownson, 2007; Metel & Barnes, 2011). Support groups help establish normalcy that can be carried over into home environment; and furthermore, allows the children to create friendships with people outside their current network.

The purpose of the present study is to provide a better understanding of the effective coping strategies and interventions that working professionals use in assisting well siblings in adjustment to a sibling with cancer. This study will provide a list of interventions and coping strategies to help increase effectiveness of working professionals practice with siblings of pediatric cancer patients.

### **Conceptual Framework: Attachment Theory and Family Systems Theory**

There are two theories that have shaped this study, and previous research. The first theory is family systems. Family systems theory is premised on the belief that families need to be viewed as complete organizations which are subject to multiple and competing internal and external influences and how these may interact over time (Jackson, 1965). The second theory that played an important role in the study was attachment theory. John Bowlby, and Mary Ainsworth developed attachment theory. Its function in this paper is to add another lens into how breakage of relationships between humans can cause behavior and/or difficulty in adjustment for well siblings.

### **Family Systems Theory**

To define family is difficult since there are several types of families: blended, single parent, and extended, which is defined differently from family to family. However, family systems includes all types of families and assumes that family is a complex integrated model, wherein individual family members are necessarily interdependent, exerting a continuous and reciprocal influence on one another (as cited in Cox, 2010). Families are designed to remain cohesive during times of emotional conflict, and never lose ties between one another (as cited in Cox, 2010). However, when the homeostasis of the family is interrupted, it is inevitable that members of the family struggle with the dependence that is exerted upon them.

Family system has two key terms that help frame the perspective, family adaptability and family cohesion. Family adaptability is defined as the tendency of a family system to change its power structure, role relations, and relationship rules in relation to distress (as cited in Houtzager et al., 2004). The second term is family cohesion. Family cohesion is defined as the amount of closeness and mutual involvement experienced in the family system (as cited in Houtzager et al., 2005). These two key terms help provide understanding regarding siblings adaptability and cohesion during a brother or sister's illness.

Family systems theory assumes that families who are balanced, which means that they are stable, yet capable of change have less difficulties with adaptability than families who either have high levels of adaptability or do not handle stress well (Houtzager et al., 2005). All parts of the family system function as a whole, and have a lack of meaning when defined singularly. This means that once a child becomes ill and functions of each family member change, then the family has to adapt and create new meaning for one another.

This is critical for families who have a sibling that is ill. Boundaries and responsibilities change and new alliances are formed. Older siblings inherit more responsibility, boundaries blur between parent and child and between siblings, and a new alliance forms between the parents and ill child. Older siblings become more withdrawn and perceive themselves as less involved in the family and older siblings boundaries that they had with their now ill sibling changes to a more parent-child relationship (Madan-Swain et al., 1993). Furthermore, the new alliance between the ill child and parent is perceived as distancing and isolating from the well siblings (Madan-Swain et al., 1993). The new roles, responsibilities, blurred boundaries, and new alliances within the family circle change the homeostasis of the family.

### **Attachment Theory**

Attachment Theory has the premise that the attachment figure (mother) should maintain an affectionate bond with her off spring in order to maintain normal human development.

Attachment theory postulates that with a secure attachment and secure base infants are able to explore the physical and social environment (Forte, 2007). Secure base refers to the physical and psychological experience provided by the responsive caretakers that frees the infant to explore the physical and social environment and return knowing for sure that he/she will be welcomed and attended to (Forte, 2007). There are four types of attachment: secure, insecure avoidant, insecure ambivalent, and insecure disorganized. Each of these types of attachment plays a role in attachment later in life and can lead to difficulties in adjustment.

Characteristics of a secure attachment in adulthood is that the adult trust others, reaches out for care and assistance easily, forms satisfying relationships, and bounces back from emotional distress; characteristics of a insecure avoidant attachment in adulthood is that the adult is more likely to inhibit their feelings, deny need for support, and defensively

proclaim their self-sufficiency; characteristics of an insecure ambivalent attachment in adulthood is that they are overly dependent, reluctant to try new activities, and begin new relationships; and characteristics of a insecure disorganized attachment in adulthood is that feelings of attachment affection is not in awareness, and it is difficult for the adult to discuss their attachment histories (Forte, 2007).

The main function that attachment theory has in understanding sibling's adjustment to a brother or sisters childhood cancer diagnosis is whether the well-sibling experiences separation from their attachment figure—the mother (Murray, 2000). Parents spend a lot of their time in the hospital and at the medical faculty with the ill child, providing insufficient time with the other siblings. Thus, this is congruent with studies that noticed adjustment difficulties with siblings whose brother or sister were more likely to have more nights in the hospital (Houtzager et al., 2004; Sloper & While, 1996). Moreover, research shows that type of diagnosis does not play a significant role in adjustment, but rather unfavorable course and number of days in hospital (Houtzager et al., 2004; Sloper & While, 1996).

The separation of attachment figure for well siblings can be contributed to the adaptation and adjustment difficulties. Furthermore, the adaptation and adjustment difficulties of the well sibling can be better understood as unavailability or deactivation of attachment figure for length of sibling's illness (Murray, 2000). As cited in Murray (2000) John Bowlby identified the expressed symptoms (anger, anxiety, and depression) of well siblings to be an expression of mourning from the attachment figure. Attachment Theory is critical in analyzing the adjustment difficulties of sibling with an ill brother or sister.

### **Methods**

The purpose of the present study was to gain a better understanding of the interventions that working professionals use in assisting well siblings in adjustment to their ill

brother or sister. This study generated a list of interventions and coping techniques to help increase effectiveness of working professionals practice with siblings of pediatric cancer patients.

### **Subjects**

The sample for this study was made up of mental health professionals, which included: social workers and child life specialists who work with families of children with cancer between the ages of 6 and 18 years of age. The inclusion criteria was not based on the mental health professionals demographics, but rather that they work with pediatric cancer patients well sibling whom range in age from 6 to 18 years old when siblings were diagnosed. Both the well sibling and their ill brother or sister should range in age from 6 to 18 years of age in order for the professional to be included in the sample.

The mental health professionals were contacted via snowball sampling from a current professional contact list. Snowball sampling is defined as a type of non-probability sampling characterized by a few cases of the type that we wish to study, which lead to more cases, which in turn, lead to still more cases, until a sufficient sample is achieved (Monette, Sullivan, & DeJong, 2010). Not every professional that works with pediatric cancer children's siblings had equal opportunity to participate in this study, since the researcher did not have access to all pediatric oncology professionals contact information and due to utilizing snowball sampling. Instead, potential participants were contacted using the researchers' professional and personal contacts. Once the survey email were sent, each professional on the contact list were contacted three weeks later to remind him or her to complete the survey and to forward the email on to the other mental health professionals.

Non-probability sampling and more precisely snowball sampling was used for this study. Non-probability was more appropriate for this research since the design had an inclusion

criterion for participation, which limited available participants. Also, there was no accessible list of social workers and child life specialist, which work with this exact population; which made snowball sampling more appropriate since researcher had access to a minimal professional contact list.

Furthermore, since the design is exploratory, which mean the research is inquiring about specific information (strategies and interventions) non-probability sampling improves the opportunity for the information to be discovered (Monette et al., 2010).

### **Research Design**

This study utilized an exploratory design. The exploratory study's goal was to determine why or how something occurs (Monette et al., 2010). Furthermore, the survey including both open and close-ended questions used a mix-mode method. Both exploratory design and mix-mode method was suitable for this research since the end product of the proposal was is to have a list of effective interventions and coping strategies that mental health professionals use and find effective. Moreover, mental health professionals were asked to complete questions regarding their career with this population and answer more specific questions about their unique interventions and strategies they use in their practice.

The instrument that was used to collect the data was a survey. The survey was better suited for this design since it was capable of reaching professionals from several different locations, while being less time consuming. Furthermore, it is more appropriate when analyzing descriptive statistics.

Data was collected at one point in time. Qualtrics, the online survey engine, collected the data. The survey was available for completion for one month, starting the date of when the emails were sent to the mental health professionals.

## **Human Subjects**

The research proposal was reviewed by the St. Thomas University IRB to ensure no harm upon the participants. The IRB protects participants by reviewing the proposals and determining whether the researcher can proceed with the actual survey or interviews. If the survey or interview questions have the potential to do harm towards the participant, then the IRB will not let the researcher continue. IRB will process applications and approve or require changes in order for proposals to be approved and surveys/interviews to be distributed/completed.

Prior to completion of survey, each participant was provided with an informed consent (Appendix A) through email. The email required the mental health professionals to read through the email prior to clicking on the survey link. The informed consent made it clear that the professionals are not required to answer every question and that all information provided will be confidential and anonymous. The survey did not elicit for any identifiable information, or allow space for names or mental health professional's employment. One month after the first email for participation was sent, the researcher collected the data.

## **Data Analysis**

Quantitative questions were used to delineate the characteristics of the mental health professionals. Each of the questions variables will be analyzed using descriptive statistics. Qualitative questions (the open-ended questions) were used to elicit specific professionals techniques used when working with pediatric cancer patient's siblings. These questions were coded for themes between the surveys. Coding is referred to as the process by which the researcher transforms raw data into a machine-readable format suitable for data analysis (Monette et al., 2010). Similarities between the open-ended questions were coded and used to generate a list of interventions. Furthermore, the number of times each intervention is mentioned in the survey was documented and used for descriptive statistics.

Once data was collected, raw data from the coding system and descriptive questions (close-ended questions) were entered in to SPSS. SPSS is a data entry program that computes the statistics (Monette et al., 2010). Once data was entered it was distributed. Data will be distributed by a frequency distribution, which provided a visual display of the frequency of a certain answer for each question.

Reliability and validity was ensured during the study. To increase reliability two raters were used to score the survey. Both researcher and a colleague coded the open-ended questions and rated the close-ended questions. Multiple questions regarding interventions for siblings with an ill brother or sister was used to increase content validity of the survey and ensure that the survey is measuring the research question accurately. Content validity is a complex approach to establishing the validity of measures that involves relating the measure to a complete theoretical framework (Monette et al., 2010).

### **Limitations of Research**

There are several limitations of the research design. First, the sampling design (non-probability and snowball sampling) limits the ability for results to be generalized amongst the population. Furthermore, the inclusion criterion limits the opportunity for all working professionals who work with pediatric cancer patients to participate, and moreover the limited professional contact list enhances the potential for a small sample size and the inability to generalize. Another limitation is how the data is collected and entered. Since the data was transferred from Qualtrics to SPSS, there is a chance that data could have been entered improperly. Lastly, participants were asked to self-report regarding their practice; therefore, information obtained from the survey can only be taken at face value.

## **Results**

Professional interventions and coping strategies used to increase adaptation of siblings with an ill brother or sister were measured with a survey that consisted of open and close-ended questions. The survey measured mental health professional's self-reflection of their work with pediatric oncology patient's siblings. Ten mental health professionals with varying demographics participated in the survey. Demographics measured were licensures across social work and child life specialist professions, years of experience ranging from one year to more than 10 years, sibling's age group from 3 years old to 18 years of age, and pediatric patients diagnosis which included ALL/AML, brain tumors, Hodgkin's/non-Hodgkin's, and other body tumors. The other concepts measured were theory/professional lens, interventions and techniques, and risk factors.

### **Professional Lens for Practice**

As assessed by a multiple-choice question in the survey, mental health professionals reported utilizing strength perspective and family systems theory as the overarching paradigm when working with pediatric patient's siblings. Strengths perspective refers to a way in understanding families that focuses on identifying how the family has coped creatively with adversity in the past and on helping family members use these strengths to build toward needed change (Hutchinson, 2008). Family Systems theory refers to the ability for a family to adjust to adversity based on family cohesion and family flexibility (Cite). However, two participants reported using a collective approach when working with pediatric cancer patient's siblings, which refers to integrating more than one theory at a time. In conjunction with family systems and strengths perspective, CBT was reported as the preferred theory when providing treatment

techniques. Three participants did not answer this question, and one participant reported incorporating humanistic theory with their work with siblings of an ill brother or sister.

### **Interventions**

Open-ended questions and ranking of six different interventions that were mentioned in current research were used to identify techniques and coping interventions that mental health professionals utilize in their practice and identify as useful. Participants were asked to report effectiveness of interventions twice throughout the survey. The first rankings of interventions asked participants to rank interventions regardless of risk factors. The rankings reported increased siblings knowledge, normalizing environment, and sibling camps as the most effective when assisting well-siblings adjustment to their ill brother or sister, and bridging strong support system and family support groups were reported as the least effective (Table II).

Several different interventions were identified by the open-ended question. Journaling was reported twice and in-hospital sibling events were reported three times. Other identified interventions were: scrapbooking, art, short-term therapy, medical play, and educational activities that would increase siblings knowledge. The participants reported these interventions (the ranked interventions and the additional interventions) to be effective in well sibling's adjustment to an ill brother or sister. However, 100% of the participants reported that family flexibility and adaptation of stressors affect the adjustment of well siblings. This changed the ranking order of interventions for eight of the ten participants.

Statistic	Enhancing optimism and hope	Helping bridge strong support groups	Increasing well-siblings knowledge (well-siblings perception) of their ill sibling	Normalizing home environment	Family Support groups	Sibling Camps
Min Value	1	1	1	2	1	2
Max Value	6	5	6	5	4	6
Mean	3.50	2.86	4.78	4.11	2.20	4.50
Variance	3.43	1.81	3.94	1.36	1.29	1.61
Standard Deviation	1.85	1.35	1.99	1.17	1.14	1.27
Total Responses	8	7	9	9	10	10

Eight of the ten participants increased their importance of family support groups and bridging of support systems. However, increase in sibling's knowledge of their ill brother and sister, normalizing environment, and sibling camps were still ranked as most important and effective.

Statistic	Enhancing optimism and hope	Helping bridge strong support systems	Increasing well-siblings knowledge (well-siblings perception) of their ill brother or sister	Normalizing home environment	Family support groups	Sibling camps
Min Value	1	1	2	1	1	2
Max Value	6	5	6	6	5	6
Mean	3.57	3.33	4.00	3.29	3.00	3.86
Variance	4.95	1.87	4.80	3.57	3.20	2.14
Standard Deviation	2.23	1.37	2.19	1.89	1.79	1.46
Total Responses	7	6	6	7	6	7

## **Risk Factors**

Several risks factors were identified in the research to be variables that affect the adjustment and/or coping of well siblings. As in conjunction with current literature, switching of family roles and responsibilities and separation from attachment figure were reported by the mental health professionals to be most influential in decreasing well siblings adjustment. This links with family systems theory that was reported to be the lens and professional perspective that mental health professionals utilize when work with families of an ill child. Family systems theory focuses on the impact of family cohesion and flexibility in adaption of family members during times of adversity. Family systems theory states that families with high cohesion and high flexibility will adapt quicker with less struggles, while families with high cohesion and low flexibility will have difficulties in adjusting to stress (Houtzager et al., 2005). The professionals reported to change their focus and emphasis on interventions due to family flexibility and cohesion.

Identifying risk factors and family cohesion and flexibility are important in order to identify effective coping strategies. However, results indicate that though risk factors and family systems theory is useful when working with pediatric cancer patients siblings, sibling camps, normalizing home environment, and increased knowledge of well siblings are the three most effective interventions. Sibling camps, increased knowledge of well siblings, and normalizing home environment are effective regardless of risk factor or family structure.

## **Discussion**

Cancer affects thousands of families worldwide, psychologically and emotionally. The emotional and psychological effects of cancer are not only limited to the ill brother or sister, but also parents and other siblings in the family. Therefore, it is not surprising that current research

is beginning to focus on the impact of an ill brother or sister on well siblings. There are several interventions and coping strategies that social workers and child life specialists are already implementing to improve adaptation and decrease behavioral adjustment difficulties. These interventions and coping strategies that social workers and child life specialists utilize when working with well siblings were measured to identify the interventions Social Workers and Child Life Specialists find effective as well as generate a collective list of coping strategies. Sibling camps, normalizing environment, and siblings knowledge of their ill brother or sister was reported to be the most effective in increasing well sibling's adaptation in this study.

The results of this study reinforce current research on the effectiveness of sibling camps and increased well sibling's knowledge (Evans et al., 1992; Houghton, 1996; Houtzager et al., 2004; Madan-Swain et al., 1993; Murray, 2001; Packman et al., 2005; and Sloper, 2000). Current literature reports sibling camps and increased knowledge of well siblings, to have substantial improvement emotionally and socially for well siblings as well as demonstrate high levels of social competence and decreased behavioral issues (Evans et al., 1996 and Packer et al., 2005). These positive outcomes from sibling's camps and increased well siblings knowledge are congruent with what Social Workers and Child Life Specialist perceive to be effective. However, one of the interventions that was reported to be effective by Social Workers and Child Life Specialists, and not in current literature, was normalizing well sibling's home environment. This is a new finding, and future research should focus on the effectiveness of normalizing home environment for well siblings. Future studies on the effectiveness of normalizing home environment would be useful in increasing the likelihood of well sibling adjusting to an ill brother or sister. Furthermore, research on how professionals address normalizing well siblings' environment and what aspects of the well siblings life the professional's emphasize. Studies

conducted on effective adjustment of well siblings have been focused on cancer camps, support networks, optimism, and increased knowledge of well sibling.

Current literature references Family Systems Theory and Attachment Theory, which were discussed in detail earlier. The survey used several questions to identify the theory and/or paradigm that social workers and child life specialists utilize. Results of this survey indicated that Family Systems Theory was the most frequently used model when working with families who have a child with cancer. All ten of the participants reported family support groups and bridging of support systems to be the least effective in adaptation of well siblings; however, when asked about the effectiveness of interventions when families are cohesive and inflexible, 8 of the 10 participants increased the importance of family support groups, and bridging support systems. This is similar to current literature. Literature focuses on two aspects, family cohesion and family flexibility, which notes families that are cohesive and flexible seem to adjust to stressful situations better than families who are less flexible and cohesive (Houtzager et al., 2005). The conclusion is that social workers and child life specialists need to adapt their approach depending on family structure (family cohesion and family flexibility).

The list of interventions and coping strategies that were generated from the survey appeared to split into two categories, a social work category and a child life specialist category. These categories were determined when Social Work participants reported the same interventions as other Social Work participants, and when Child Life Specialists reported the same interventions as other Child Life Specialists participants. Social workers reported interventions and coping strategies such as bereavement groups, therapy, writing, and art; while child life specialist reported interventions such as medical play, and sibling support groups. This is not surprising since each profession has different theoretical orientations. However, what

is surprising about the results between the two professions are that both identified sibling camps, normalizing home environment, and increased knowledge of well siblings to be the three most effective interventions. This increases the significance of utilizing sibling camps, increasing knowledge of well siblings, and normalizing home environment. The results demonstrate that regardless of risk factors, family structure (which was mentioned earlier), and now professional orientation, that sibling camps, increasing knowledge of well siblings, and normalizing home environment should be utilized over other interventions. Generating a list of effective interventions in which both social workers and child life specialist can both utilize would increase the chance for adjustment of well siblings; furthermore, it expands the interventions and coping strategies that both working professionals can utilize.

### **Limitations**

The study has several limitations. An important implication of the study, which has been mentioned, is the small sample size. The results of this study are limited and cannot be generalized. The results add to already supporting literature, but are not capable of standing alone. In addition, the study required professionals to self-disclose about their current practice, which can be affected by the professional's personal perceptions of their work and bias. The study was conducted to generate a professional list of interventions and coping strategies that working professionals can utilize, which established this study as preliminary and exploratory. Interventions and coping strategies should be used cautiously within appropriate settings and family systems. Finally, professionals that work with pediatric cancer families were not represented. This is due to the inclusion criteria, and the researchers inability to make contact with other professionals.

Prior to this study, there had been no studies conducted on professionals perceived understanding of the effectiveness of interventions. This study provides a preliminary list of interventions and perceived effectiveness of interventions that professionals identified. Recommended future studies should focus on continuing to generate a list of interventions and coping strategies that professionals are utilizing. The research design (survey) was effective in reaching people, even participants with limited-time, which broadened the target population. Lastly, the research is congruent with current literature and encourages professionals to utilize sibling camps and increase knowledge of well sibling's. Furthermore, this research reported a new finding that encourages future researchers to focus on normalizing home environment as an intervention.

### **Implications**

The implication of these findings for professionals working with well siblings of a brother or sister with cancer is that sibling camps, increasing knowledge of well siblings, and normalizing well sibling's home environment are the interventions that professional reported to be effective. The other interventions listed, such as, support groups, bridging support systems, and increasing optimism, were not identified as effective in well sibling's adaptation. This is important to take note of for oncology social work education. Social work education does not provide an emphasis for differing career paths. Masters level social work education provides a general overview of social work topics, with everyone receiving the same education regardless of desired emphasis. It would be beneficial for social workers to have an extended educational period (semester) as part of their MSW education in classes that pertain to their career choice. This would allow new social workers to already have an educational understanding of their clientele, instead of learning everything while on the job. Social workers with a passion for

oncology could spend their last semester of graduate school learning different interventions and theories that are orientated towards oncology work. Educations regarding specific topics should be maintained through CEU's for increased and up to date information. This would increase best practice and decrease laps of knowledge at the beginning of a social workers career.

Social workers and child life specialists, regardless of their professional orientation should utilize these three interventions, while assessing the family structure from a Family System Theory in order to determine other interventions or coping strategies. Further research on the implications of using Family System Theory should focus on the interventions that are more effective with different family structures. It is important for professionals to be aware of the effective interventions in order for the well sibling to adjusting quickly and more effectively.

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