

Understanding the Needs of Siblings of Children with Cancer:

A Family Systems Perspective

by

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A doctoral project submitted to the faculty of  
the California School of Professional Psychology  
in partial fulfillment of the requirements for the degree of  
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The doctoral project of Cathliyn E. Buranahirun, directed and approved  
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Faculty of the California School of Professional Psychology  
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## DEDICATION

To my brother, Chris, for his unconditional love and support. Without you, I would not be where I am today. I am truly blessed to have you in my life.

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## CHAPTER I

### **Introduction**

Childhood cancer is diagnosed in 1 to 2 out of every 10,000 children each year (Altekruse et al., 2009). In the United States, 10,400 children under the age of 15 were diagnosed with the disease in 2007 (National Cancer Institute, 2008). According to Altekruse and colleagues (2009), the incidence of cancer in children under age 15 has been increasing by approximately 0.6% per year since 1975. The most common cancer in children is leukemia, which constitutes approximately 30% of all pediatric cancers. Cancer of the brain or nervous system is the second most common form of cancer in children, making up approximately 20% of cases diagnosed each year.

Although pediatric cancer is relatively rare, it is among the leading causes of death in children under the age of 15 (Centers for Disease Control and Prevention, 2007). However, the continuing advances in the medical treatment of pediatric cancer have greatly increased survival rates within the past several years. The 5-year survival rate for pediatric cancer diagnosed between 1999 and 2006 is 82.3% for children age 0 to 4, 80.0% for children age 5 to 9, and 81.6% for children age 10 to 14 (Altekruse et al., 2009).

Along with the advances in medical treatment and technology over the years, children who have serious or chronic illnesses have also benefitted from the growth of pediatric psychology. In the past, hospitalized children were allowed very limited contact with their parents and medical staff often concealed serious illnesses or poor prognoses from their patients. The field of pediatric psychology was founded in 1968, and had begun to address issues such as children's rights to be with their parents during

hospitalizations, as well as their rights to be given developmentally appropriate information about their medical conditions and procedures. The initial research in pediatric psychology focused on mother-child relationships and the development of family therapy fostered recognition of the importance of the entire family in the field of pediatric psychology (Seagull, 2000). Coupled with the increase in survival rates, this progress in psychology has resulted in greater research and emphasis on the psychosocial effects of cancer and its treatment on not only the child, but also the family system.

Research indicates that when a child is diagnosed with cancer, the family experiences a significant disruption and adaptation by the entire family system is required (Kazak, 1989). Parents and siblings of the child are typically most distressed in the weeks immediately following diagnosis (Houtzager, et al., 2004; Pai, et al., 2007). However, after the initial stress of receiving the diagnosis, families must also contend with the demands of treatment, side effects, possible medical sequelae, and threats of recurrence. As a result, families must continue to adapt to and cope with the various circumstances with which they are presented over the course of the child's illness and remission.

Houtzager, Grootenhuis, and Last (1999) assert that there has been far less focus on the healthy siblings within these family systems and that this lack of attention given to the healthy sibling may also reflect the sibling's experience in the family during the disease process. In 1979, Cairns et al. conducted one of the first quantitative studies regarding the adjustment of healthy siblings to childhood cancer and found that siblings felt that parents overindulged and overprotected the patient. They also found that siblings experienced significant levels of anxiety and feelings of isolation. Since the 1980s, and increasing number of studies have examined the adjustment of siblings of children with

cancer, including behavior problems, social competence, academic problems, and health (Houtzager, et al., 1999).

### **Justification**

Pediatric oncology care teams have increasingly begun to include mental health professionals and there has been an increase in the literature regarding family-centered treatment. Researchers now recognize that cancer affects all members of the family and that changes in the family resulting from having a child with cancer may lead to distress in the family system. For healthy siblings of children diagnosed with cancer, this may lead to an increased risk of negative psychological effects possibly associated with caregiving responsibilities given to healthy siblings and decreased parental attention to healthy siblings (Sharpe & Rossiter, 2002). Other studies have found that the negative psychological effects may continue even through remission, as a significant number of siblings of childhood cancer survivors reported symptoms of posttraumatic stress disorder, overall low quality of life, and clinically relevant problems 2 years after the diagnosis (Alderfer, 2003; Houtzager, Grootenhuis, Caron, & Last, 2004).

Houtzager et al. (2004) found that most siblings demonstrate significant resilience and that adjustment difficulties often decrease rapidly during the first 6 months after diagnosis. However, approximately one-third of siblings of children diagnosed with cancer demonstrate long-term difficulties with adjustment. This study also examined the effect of family adaptability on siblings and found that while flexibility may be effective temporarily, it may lead to greater adjustment difficulty when a high degree of flexibility exists long-term. In these instances, the high levels of adaptability may result in a

“chaotic” family environment that does not provide sufficient stability to foster positive adjustment.

Despite the research clearly indicating that pediatric cancer affects the entire family system, family therapy is “often absent in pediatric psychology” (Kazak, Simms, & Rourke, 2002, p. 134). Evidence-based interventions with families coping with pediatric cancer continue to be a limited, yet growing area of research, but interventions provided to families often vary between and within organizations (Kazak, et al., 2007). Therefore, it is necessary that mental health professionals are provided information on the effect of pediatric cancer on the family when treating siblings of children diagnosed with cancer. It is important that clinicians understand the impact of this disease on the family, as interventions that incorporate the family may be more effective than individually-focused interventions, which may not be beneficial to the system as a whole (Kazak, 1989). Additionally, coping with the disease often becomes an ongoing issue for many families, as treatment may continue for years and concern regarding the possibility of recurrence lingers through remission.

### **Purpose**

The purpose of this project is to create and deliver a presentation to mental health professionals that provides information regarding the impact of the diagnosis and treatment of pediatric cancer on the siblings of the patient. The presentation will examine changes in family structure and a systems conceptualization of adjustment in healthy siblings of children diagnosed with cancer in families of patients who are recently diagnosed, on treatment, or in remission. This project will consider how mental health professionals may address the needs of the siblings by using systems interventions to

assist families affected by pediatric cancer. The presentation will not include end-of-life issues or bereavement related to pediatric cancer.

### **Goals**

The first goal of this doctoral project is to increase mental health professionals' awareness of the changes that occur in the family system when a child has cancer. The second goal of this project is to increase knowledge of the experiences of siblings in relationship with the patients and parents in families affected by pediatric cancer. A third goal is to research and present how siblings adjust to cancer diagnosis and treatment. The fourth goal is to promote the effectiveness of family therapy by providing professionals with a review of the research and summary of interviews with experts in the field regarding coping and adjustment in siblings of children with cancer. The fifth goal is to provide practical and effective systems interventions that would address family cohesion and communication in order to work with the siblings in families affected by pediatric cancer.

### **Objectives**

The first objective of this project is for participants to identify how the diagnosis and treatment of childhood cancer may lead to potential changes to the family system. The second objective is for participants to be able to identify how those changes in the family system may affect sibling adjustment. The third objective is for participants to utilize effective interventions to improve family structure.

My personal objectives in completing this doctoral project are to create and deliver an effective, professional presentation as well as to improve my public speaking skills. In reviewing the literature and consulting experts in the field, I would also like to

increase my knowledge about the needs of families coping with childhood cancer and effective interventions therapists may use to assist such families.

## CHAPTER II

### Selective Literature Review

#### **Pediatric Cancer and the Family**

Pediatric cancer greatly impacts the lives of the patients as well as their respective families. According to Rolland (1994), the effects of illness can be viewed from a Family Systems-Illness Model, which seeks to integrate the psychosocial demands of illnesses with family functioning. Rolland conceptualizes illnesses according to broad patterns of onset (i.e., acute or gradual), course (i.e., progressive, constant, or relapsing), outcome (i.e., nonfatal, shortened life span, or fatal), and degree of incapacitation (i.e., none, mild, moderate, or severe). Childhood cancer often has an acute onset, which requires rapid changes in family structure and crisis management. Many patients experience recurrence of the cancer and the families of those who do not experience recurrence live with the threat of recurrence. Alternating periods of remission and recurrence require the family to be flexible, essentially moving between two forms of family organization—one during the initial crisis or recurrence and one during remission. Although survival rates of pediatric cancer have increased, childhood cancer continues to be possibly fatal (National Cancer Institute, 2008). A multi-institutional study indicates that 5-year survivors of childhood cancer have 8.4 times higher mortality rates compared to the age-, sex-, and year-matched U.S. general population. Recurrence and progressive disease accounted for the majority of deaths of long-term cancer survivors in the study, but other causes of death also included subsequent neoplasm, diseases of the circulatory system, and diseases of the respiratory system (Mertens et al., 2008). The uncertainty of fatality often leads to overprotection of the patient by the family and possible secondary gains acquired by the



patient (Rolland, 1994). The degree of incapacitation related to cancer and its treatment varies, therefore how the family must adjust in response to the patient's illness also varies.

### **Family Therapy**

Traditionally, clinical psychology has focused on pathology that was thought to be related to the individual's early childhood experiences, difficulty with self-concept, or maladaptive cognitions and treatment was sought to determine the cause of and remedy for pathology. However, family systems theory asserts that adjustment difficulties may lie within the individual, family system, or the interaction between the individual and the family system (Minuchin, 1974). As a result, the individual's behaviors are influenced by the family and the family is influenced by the individual's behaviors. Stressors that affect members of the family system may also affect other members of the system. The family structure is thought to be an "invisible set of functional demands that organizes the ways in which family members interact" (Minuchin, 1974, p. 51). The family operates through "transactional patterns" (Minuchin, 1974, p. 51), which influence the behaviors of family members. As a result of the system and individual being interconnected, it is believed that a change in the family structure will also lead to a change in the behavior of the family members and that these structural changes will reinforce the behavioral changes family members demonstrate.

When examining the impact of pediatric cancer on healthy siblings, it is necessary to consider the family because of the significant influence of the family on each of its members. The Circumplex Model (Olson, 2000) of family systems has been frequently used in the literature regarding families of children with cancer. Within this model, there

are three dimensions of family systems: adaptability/flexibility, cohesion, and communication (Olson, 2000). According to Olson (2000), adaptability is the capacity for change in the leadership, roles of individual family member, and rules in the family. Families with extremely low levels of adaptability are thought to be “rigid,” with one person in charge, roles strictly defined, and rules firmly set. Families with very high levels of adaptability may be “chaotic,” with inconsistent leadership and roles that frequently shift.

Cohesion is “the emotional bonding that family members have towards one another,” (Olson, 2000, p. 145). Families with particularly high levels of cohesion may be “enmeshed.” Family members may be extremely close, rely heavily on one another, and react strongly to one another. Enmeshed family systems may discourage personal independence and associating with others outside of the family. However, it is also necessary to examine cultural norms, as highly cohesive families are typical in certain cultures. Families with extremely low levels of cohesion are thought to be “disengaged.” Within these families, there may be limited interaction among family members and difficulty turning to one another for support (Olson, 2000).

It is believed that very high or very low levels of adaptability and cohesion may be problematic if they occur for a long period of time, whereas moderate levels are more conducive to healthy family functioning (Olson, 2000). Therefore, families must balance change with the need for stability and each member’s independence with the family’s togetherness. Families that are balanced tend to have good communication, while unbalanced family systems with extremely high or low levels of adaptability and cohesion tend to have poor communication (Olson, 2000). In the Circumplex Model,

communication is defined as family members' "listening skills, speaking skills, self-disclosure, clarity, continuity tracking, and respect and regard" (Olson, 2000, pp. 149-150). Communication is considered to be a dimension that facilitates movement within the two other dimensions.

Families that have a child with cancer face ever-changing demands during the course of the illness. Therefore, family adaptability, cohesion, and communication are traits that must be considered when examining how families adjust.

### **Effects of Pediatric Cancer on the Family**

In families that have a child with cancer, adaptability refers to the family's flexibility in restructuring roles and responsibilities when faced with the various demands of diagnosis and treatment of cancer (Rolland, 1994). Horwitz and Kazak (1990) found that adaptability in families of pediatric cancer patients tended to very low or very high more often than controls, indicating an increase likelihood of "rigid" or "chaotic" structure in families affected by childhood cancer. Families that tend to be rigid may have difficulty with change, especially the rapid changes required during initial diagnosis and recurrence of cancer. Some families may also become more rigid, imposing more structure, in an attempt to maintain control during a situation in which they feel is beyond their control. Horwitz and Kazak also stated that other families may become extremely flexible out of necessity, in an effort to deal with the changes and uncertainties of disease, treatment, and side effects. However, families that are exceedingly flexible may become disorganized or chaotic, and have difficulty adhering to treatment regimens (Rolland, 1994).

Research indicates that healthy siblings in highly adaptive families experience fewer adjustment difficulties than siblings in families with lower adaptability (Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1994; Horwitz & Kazak, 1990). However, results of a longitudinal study that assessed the psychosocial adjustment of healthy siblings of children with cancer at 1, 6, 12, and 24 months after diagnosis indicate that families with high levels of adaptability tended to have siblings with adjustment problems (Houtzager et al., 2004). Houtzager and colleagues (2004) asserted that high levels of adaptability may be beneficial short-term, thus explaining the results of cross-sectional studies with lower levels of adjustment problems correlated with high levels of family adaptability, but that these high levels of adaptability long-term may lead to chaotic or disorganized families, which lack stability and security family members need. According to Rolland (1994), families that adjust well have the ability to adapt to their changing circumstances, but also balance that flexibility with their need for traditions and consistent rules for behaviors.

According to Rolland (1994), increased family cohesion is often related to the family's perception of the medical condition being life-threatening. More specifically, the greater the family's perception of the medical condition threatening the life of the child, the greater the increase in family cohesion. Cohen and colleagues (1994) found that high levels of family cohesion are correlated with fewer adjustment problems demonstrated by healthy siblings. Although very high levels of cohesion are thought to be problematic in families, studies suggest that high levels of cohesion may moderate the impact of stress. The high level of familial contact in enmeshed families may make parents more likely to address sibling concerns and provide attention to healthy siblings during the diagnosis

and treatment phases of the illness, when parents may find it most challenging to provide time and attention to healthy siblings (Cohen et al., 1994; Horwitz & Kazak, 1990). This high level of cohesion may be problematic, however, during remission and for long periods of time, as it may interfere with the healthy sibling's development (Houtzager et al., 2004; Sori & Biank, 2006). The literature regarding families of pediatric cancer patients indicates that family structures traditionally considered dysfunctional must be re-evaluated, as levels of adaptability and cohesion that would normally be considered excessively high appear to be in fact helpful when the family must confront the continually changing demands during the course of pediatric cancer (Cohen et al., 1994). Therefore, a family that may be considered "chaotic" and "enmeshed" due to the high levels of adaptability and cohesion may actually be making the necessary adjustments to manage challenges related to caring for the patient (Horwitz & Kazak, 1990).

The diagnosis of cancer is a source of great deal of stress for families. Patiño-Fernandez and colleagues (2008) found that 51% of mothers and 40% of fathers met *DSM-IV-TR* criteria for Acute Stress Disorder immediately following diagnosis of cancer in their children. Houtzager and colleagues (2004) indicated that siblings are also most distressed during the first weeks immediately following the diagnosis of pediatric cancer. During this phase, the family must be flexible in order to restructure and gather resources to make medical treatment decisions, plan how to adjust to the changes to their lives, make sure needed tasks are completed, and meet the needs of family members (Sori & Biank, 2006). Family cohesion is needed during this time in order for family members to provide emotional support for one another.

The demands of cancer treatment often disrupts the healthy sibling's schedule, takes up a great deal of the family's resources, and results in less consistent attention and emotional support from parents (Horwitz & Kazak, 1990). Sloper and While (1996) found that adjustment difficulties in healthy siblings were related to the degree of disruption to family life, resources, and the sibling perception of the negative impact on interpersonal relationships. During this phase, families have achieved a level of stability after the crisis of diagnosis. However, they must continue to be flexible, as treatment may require additional financial resources and parental attention. This may decrease the amount of parental availability for healthy siblings, possibly leading to decreased support and siblings having less access to outside activities and opportunities for socialization with peers. For some siblings, this may also be coupled with an increase in responsibilities at home or with regard to caregiving (of the patient or other siblings) (Sori & Biank, 2006).

During remission, the primary task is for the family to adapt to the end of treatment, when the changes in roles and structure that occurred with diagnosis and treatment are no longer needed (Sori & Biank, 2006). However, the threat of recurrence serves as a chronic stressor for the family (Hoekstra-Weebers, Jaspers, Klip, & Kamps, 2000). High levels of adaptability are no longer appropriate at this time and may lead to greater adjustment difficulty in healthy siblings, if the family continues to be chaotic (Houtzager et al., 2004). Extremely high levels of cohesion are also no longer needed and maintaining such high levels of cohesion may interfere with the patient's and sibling's need to develop independence and autonomy (Sori & Biank, 2006).

If there is recurrence, the family is often distressed, with parents sometimes doubting past treatment decisions they had made. The family must be flexible and begin changes in roles and responsibilities in order to reinstate medical treatment. According to Sori and Biank (2006), families at this point may have less outside support due to the family having previously isolated themselves or friends and community members distancing themselves as well as experience financial difficulty due to the cost of medical care and the possible impact of the patient's illness on parents' employment. The family must pull together and may return to the structure that they had in place during the previous treatment phase, but it often causes great strain, as they have diminished resources when attempting to reorganize. This may increase the likelihood that healthy siblings are given even less time and attention. For older siblings, it may also increase the likelihood that they take on more responsibilities in caring for themselves and other family members.

### **Sibling Relationships**

Sibling relationships are often the longest relationships in an individual's lifetime. This is also often true of half-siblings, stepsiblings, and adoptive siblings (Cicirelli, 1995). In addition to being some of the longest relationships an individual experiences, sibling relationships are also unique in a variety of different ways. They often have daily intimate contact with one another in childhood and adolescence due to sharing a household. Although there are some differences in status or power, siblings typically relate to one another more as equals. This contributes to a long history of shared experiences that are not present in other relationships (Cicirelli, 1995). Siblings influence one another through socialization, helping behaviors, cooperation, companionship, as

well as negative behaviors. Therefore, experiences that affect one sibling also have some effect on the other sibling and other family members.

The sibling relationship is often where children initially learn social skills that are important to maintaining peer relationships. Siblings experiment with skills such as negotiating, competing, and cooperating, and generalize these skills to peer relationships (Minuchin, 1974). It is the conflict and support experienced within sibling interactions that give children opportunities to learn to navigate interactions with others and that are associated with peer relationships and school adjustment (Brody, 1998).

In addition to influencing peer relationships, sibling relationships also influence the individual. In a longitudinal study of protective factors of sibling relationships, Gass, Jenkins, and Dunn (2007) found that positive sibling relationships may help to moderate stressful life events. More specifically, children with positive sibling relationships who had experienced stressful life events were found to be less likely to experience internalizing behaviors.

The literature indicates that parental behavior toward siblings influences the quality of the sibling relationship. According to Dunn (1988), differential treatment of siblings is correlated with increased conflict in the sibling relationship. Brody, Stoneman, and Burke (1987) examined relationships between same-sex siblings and reported a correlation between differential treatment by mothers and decreased social interactions and prosocial behaviors in siblings. In a longitudinal study of the association between paternal behaviors toward siblings and sibling relationships, Brody, Stoneman, and McCoy (1992) found that greater paternal differential behavior is associated with negative sibling behavior. Dunn (1988) indicates that the relationship between



differential treatment by parents and increased conflict is particularly strong in families that experience high levels of stress.

### **Siblings of Pediatric Cancer Patients**

In a study in which siblings of pediatric cancer patients who were off treatment for 2 years or less underwent semi-structured interviews and completed questionnaires regarding the impact of cancer on their lives, Havermans and Eiser (1994) found that most of the children worried about the patient dying and felt distressed by what they saw in the hospital while the patient was on treatment. Siblings in this study also expressed distress related to seeing the changes in the patient's physical appearance.

In another qualitative study, Sloper (2000) presented findings from semi-structured interviews with siblings of pediatric cancer patients 6 months and 18 months after diagnosis. This study indicated that siblings of children with cancer experience multiple losses: parental attention, social activities, sense of security, and companionship. Although these losses were most apparent at the first time period (i.e., 6 months post-diagnosis), some siblings reported that these problems persisted 18 months after the diagnosis. The participants in this study indicated that being provided with information and supportive relationships were helpful in coping with their experience. Sloper (2000) noted that siblings of patients often sought support from family, friends, and teachers, but also found during the parent interview that many of the parents "had been preoccupied with the needs of the ill child and had little time or energy to consider siblings' needs" (p. 305), thus resulting in loss of parental attention and support for siblings during a stressful time.

According to Havermans and Eiser (1994), illness also affects the quality of the sibling relationship by decreasing opportunities for the siblings to interact due to the patient's physical condition or being hospitalized. Siblings may experience loss of companionship related to fewer chances to interact with the patient than before the illness. Additionally, siblings may perceive that parents treat them differently from the patient, perhaps with parents being more permissive of or making more excuses for the ill child (Havermans & Eiser, 1994). Cairns, Clark, Smith, and Lansky (1979) also noted sibling perceptions of parents as overindulgent of the patient and neglecting the sibling in favor of the patient. As previously mentioned, perceived differential treatment often negatively impacts the quality of sibling relationships and is correlated with a higher frequency of conflict within the sibling relationship (Dunn, 1988).

### **Sibling Adjustment**

**Positive effects.** Some research indicates that the experience of being a sibling of a pediatric cancer patient may have positive effects. In a study that included interviews with siblings of pediatric oncology patients, siblings indicated greater levels of empathy and feeling "more mature" (p. 316) as a result of the patient's illness (Havermans & Eiser, 1994). According to a study of preschool children who were siblings of pediatric oncology patients, these siblings demonstrated greater helping behaviors, empathy, and affection than participants in the control group (Horwitz & Kazak, 1990). The authors asserted that these behaviors may have resulted from more frequent opportunities to practice prosocial behaviors, as times of family stress may increase family cohesion and prompt family members to provide support for one another (Horwitz & Kazak, 1990).

**Negative effects.** Literature on the psychosocial effects of pediatric cancer on healthy siblings suggests a greater likelihood of adjustment difficulties. In a meta-analysis of the research on siblings of children with chronic illness, Sharpe and Rossiter (2002) found an overall negative psychological effect for having a sibling with a chronic illness. They also found internalizing behaviors (e.g., depression, anxiety) to be more prominent than externalizing behaviors (e.g., acting out). Research indicates that siblings of children with pediatric cancer demonstrate feelings of isolation and anxiety (Cohen et al., 1994; Hamama, Ronen, & Feigin, 2000; Houtzager, Grootenhuis, Hoekstra-Weebers, & Last, 2005) and negative behavioral changes reported by parents (Breyer, Kunin, Kalish, & Patenaude, 1993; Heffernan & Zaneli, 1997; Sloper & While, 1996). Alderfer, Labay, and Kazak (2003) found that 32% of healthy, adolescent siblings of pediatric cancer patients reported moderate to severe symptoms of posttraumatic stress.

**No effect.** Other researchers report no negative effect on healthy siblings of children with cancer (Horwitz & Kazak, 1990; Madan-Swain, Sexson, Brown, & Ragab, 1993) relative to controls. Additionally, Gallo, Breitmayer, Knafl, and Zoeller (1992) found no differences between healthy siblings of children with chronic illness and a normative sample. In light of the conflicting evidence, researchers have asserted that there is no simple relationship between illness and sibling maladjustment. Instead, chronic illness may be considered a risk factor for adjustment difficulties that is mediated by individual and family characteristics. The influence of family characteristics on the positive adjustment of healthy siblings in a family that has a child diagnosed with cancer supports the importance of working with the family in order to facilitate healthy adaptation during the course of the disease. This indicates that it is necessary to develop

an understanding of the impact of pediatric cancer on the entire family in order to understand and facilitate positive adjustment of healthy siblings in a family that has a child diagnosed with cancer.

### **Risk Factors**

Research indicates various risk factors for adjustment problems in healthy siblings of pediatric cancer patients. Adolescent siblings are more likely to experience negative mood and adolescent female siblings report more difficulty with interpersonal relationships. This may be because parents may give older sisters more responsibilities in the home, allowing less available time for social activities (Houtzager, Grootenhuis, Hoekstra-Weebers, & Last, 2003; Houtzager et al., 2004; Sahler et al., 1994). Sahler and colleagues (1994) found that healthy, male siblings age 11 years and younger of pediatric cancer patients are more likely to demonstrate externalizing behaviors than controls. Sahler and colleagues also found that siblings with pre-existing problems were more likely to have difficulty adjusting when faced with a brother or sister diagnosed with pediatric cancer. In their study, 40 % of siblings with pre-existing problems developed emotional or behavioral problems, while 2% of siblings with no pre-existing problems developed emotional or behavioral problems. For healthy siblings who have pre-existing problems, it is going to be important to work with families systemically in order to facilitate adjustment to the challenges the family faces during the course of the illness and to provide the siblings with support they need.

### **Cultural Considerations**

Much of the current literature in pediatric psychology focuses on European American families and little attention has been given to the needs of ethnic minorities

(Kazak, 2005). However, the way a family copes with pediatric cancer is affected by incidence rates of cancer, mortality rates related to cancer, and expectations regarding participation in healthcare in their culture (Gotay, 2000). Cultural norms also greatly vary regarding the role of the patient, communication about disease and treatment, caregiving, and rituals during different stages of disease (Rolland, 1994). Much of the existing research regarding the family's experience with cancer has focused on Asian populations, with little information regarding other ethnic groups (Thibodeaux & Deatrck, 2007).

Yi (2009) states that families from certain collectivist cultures may experience greater isolation from the community, as societal collectivism may not necessarily support those in need due to the personal needs and beliefs being viewed as secondary to group norms and relationships. Siblings in these families may also experience more stress as their personal needs may be viewed as secondary to the family's needs. Yi (2009) also suggests that although there is no empirical data to support this, there may be a stronger tendency for older female siblings in Asian families to experience stress because they are often expected to play a parental role in the family when emergencies arise. Additionally, in cultures in which the son is preferred, healthy female siblings may feel a stronger sense of guilt and may also be given less time and attention from parents.

Munet-Vilaró (2004) identified beliefs about illness, suffering, and coping strategies that are unique to Latino cultures. Fatalistic views about illness and the belief that they have no control of the disease is common in many Latino families. Another belief in Latino cultures is that the patient was "selected" to suffer from the illness for a special reason. These beliefs may result in passive acceptance, and may be misinterpreted

as a negative view of the situation or hopelessness by mental health professionals who may be unaware of these views of illness that are related to culture (Munet-Vilaró, 2004).

Family communication is greatly influenced by culture and is an important predictor of sibling adaptation in families of children with cancer. However, the more stigmatizing the illness, the less information is communicated to healthy siblings (Lobato, Kao, & Plante, 2005). In cultures in which cancer is greatly stigmatized, there may be less communication to the sibling and therefore fewer opportunities for the well sibling to express their concerns and feelings. A study on healthy Chinese siblings age 7 to 16 years in families coping with pediatric cancer (Wang & Martinson, 1996) found that parents reported that they did not talk to the siblings about the illness because they did not have time, wanted to protect the sibling, believed the child was too young to understand, or did not want to talk about the illness. The parents in this study who did communicate with well siblings about the illness indicated that most discussions were related to the disease progression. In Latino families, open communication within the family regarding the illness may also be difficult, as expression of feelings may be distressing and parents may limit the amount of information provided to siblings (Munet-Vilaró, 2004). When promoting communication within families of diverse backgrounds, it is important to consider cultural norms, as some communication strategies may not be appropriate for all groups (Munet-Vilaró, 2004; Yi, 2009).

## **Treatment**

**Family-centered.** Family-centered treatment is often essential in pediatric oncology, as children must be understood within the context of their family. Each family impacted by pediatric cancer is comprised of a network of relationships between family

members that affect one another. Research indicates that the whole family experiences disruption when a child is diagnosed with cancer (Kazak, 1989). As such, interventions that impact the entire family system may be more effective in facilitating sibling adjustment than individually-focused interventions (Kazak, 1989). In a review of family-based interventions for childhood cancer, Meyler, Guerin, Keirnan, and Breatnach (2010) indicated that the current literature regarding interventions is limited and that there is significant variability between intervention studies to determine which specific interventions are most effective. They suggest that a variety of intervention strategies are required to meet the needs of families affected by pediatric cancer, due to the differences in needs demonstrated by individual families.

**The professional's role.** The Circumplex Model of family systems asserts that “balanced types of couples and families will generally function more adequately than unbalanced types” (Olson, 2000, p. 152). Therefore, the main role of the mental health professional is to assist families in achieving or maintaining a balanced system, despite the multiple transitions during the course of the illness. Families must adapt to each phase of illness, which places different demands on the family system and may result in the clinician having different treatment objectives for each phase.

**Diagnosis.** The diagnosis phase of pediatric cancer is very brief and treatment is often initiated within days of diagnosis. During the diagnosis phase of pediatric cancer, clinicians must help families reorganize and reestablish a sense of stability (Sori & Biank, 2006), given the significant level of distress that is often experienced when such a diagnosis is received. It is also important for clinicians to help parents provide healthy siblings with information regarding the illness that is age-appropriate. This involves

discussion of any magical thinking in younger children as well as encouraging discussion of feelings that healthy siblings may experience (Rolland, 1994).

***Cancer Treatment.*** During the treatment phase, therapists must assess the structural changes that have occurred and how these changes have affected family members. Sherman and Simonton (1999) assert that structural changes are likely to occur at this stage due to the demands of time-consuming treatments, caregiving, and financial strain. The roles of family members may change during this stage in order to maintain daily household functioning. For example, families with two working parents may need one parent to stop working outside the home and care for the patient full-time. Older children may also be required to assume additional caregiving and household responsibilities. During this time when older children may assume some of the responsibilities previously held by parents, it may become increasingly challenging to maintain the hierarchy within the family and clear boundaries between subsystems. Additionally, families may draw on extended family and friends for assistance while attempting to maintain clear boundaries and prevent others from becoming overly involved. Due to the significant demands of cancer treatment, it is important to foster family adaptability while helping families make sure that the needs of healthy siblings are being met during this process (Sori & Biank, 2006). Mental health professionals should also facilitate communication between family members as well as maintain as much “normalcy” as possible, in order to help provide siblings a sense of security during a time that may required significant flexibility and change (McDaniel, Hepworth, & Doherty, 1992).



**Remission.** Cancer remission is another transition for families affected by pediatric cancer. Although families typically consider remission a positive outcome of cancer treatment, mental health professionals should also understand that this transition from treatment to remission also comes with the family's loss of the support system provided by hospital staff. Some families may require assistance dealing with that loss and adjusting to life without the additional support of hospital staff. During this time, families must once again reorganize, as the illness is no longer the focus of the family. Instead, the family now must return to the developmental tasks associated with their particular stage of the family life cycle. During remission, the family may revert back to old patterns of behavior and communication. Sherman and Simonton (1999) indicate that stressors that were present prior to diagnosis are likely to reemerge at this time. However, the family may be required to manage those stressors with fewer sources of support and financial resources. The family may need help meeting individual family members' needs, particularly the patient's and sibling's needs for increased independence (Rolland, 1994). Families may also need help coping with the anxiety related to the threat of cancer recurrence.

### **Interventions.**

The American Psychological Association (APA) defines evidence-based practice in psychology (EBPP) as "the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences" (2005, p. 1). The goal of evidence-based practice in psychology is to "promote effective psychological practice and enhance public health by applying empirically supported principles of psychological assessment, case formulation, therapeutic relationship, and intervention"

(APA Presidential Task Force on Evidence-Based Practice, 2006, p. 273). In a review of family-based interventions, Meyler, Guerin, Kiernan, and Breatnach (2010) indicate that a combination of cognitive behavioral therapy and family therapy into a single intervention has been demonstrated as a promising intervention and that no other interventions thus far have met criteria for validation according to the criteria suggested by the Society for Pediatric Psychology, although most interventions reviewed demonstrated beneficial effects.

***Surviving Cancer Competently Intervention Program (SCCIP).*** The Surviving Cancer Competently Intervention Program (SCCIP) is a 4-session, manualized intervention that was developed at Children's Hospital of Philadelphia (Kazak et al., 1999). It conceptualizes the pediatric cancer as a traumatic event for the family and integrates family systems interventions with cognitive behavioral interventions. The goal of this intervention is to help decrease posttraumatic stress symptoms by facilitating family adaptability and communication (Kazak et al., 1999).

Kazak and colleagues (2004) conducted a randomized controlled trial (RCT) with 150 families of adolescent cancer survivors age 10 to 19 years, in which participants were assigned to either SCCIP or a wait-listed control group. Assessments of posttraumatic stress symptoms and anxiety were conducted at baseline and at 7- to 11-month follow-up. Data were collected from 99 siblings age 10 to 20 years at baseline, but only 19 siblings participated in the intervention due to scheduling difficulties, as the authors advised participating families to prioritize participation based on the availability of parents and the patient. The study indicated a significant decrease in intrusive thoughts among fathers and decreased arousal among patients. However, no significant differences were

demonstrated in siblings, with regard to measures of posttraumatic stress symptoms or anxiety. The authors stated that the small sibling sample did not allow treatment effects to be detected. The small sample size of siblings and prioritization of patients over siblings in the study of an intervention aimed at the family system reinforces the fact that healthy siblings are given less attention than the patient within the family.

***Interventions to promote communication.*** Communication among family members is one factor that facilitates movement along the dimensions of adaptability and cohesion, which help to maintain a balanced family system (Olson, 2000). Sori and Biank (2006) detail a number of family-centered strategies that may be used to enhance communication at various stages of the illness. For instance, having families create a family mural that includes scenes before diagnosis and at different stages of the illness may allow the clinician to observe how family members work together, make decisions, and communicate with one another.

Sori and Biank (2006) also suggest asking family members to draw themselves before the diagnosis, during treatment, and after treatment. Once the drawings have been completed by each family member, they can be encouraged to share their drawings with other family members. This technique may be used to promote discussion regarding changes in the family system and how illness has affected family member and provide insight regarding their specific experiences. For siblings, this technique may provide a opportunity to share their unique experiences and feelings that may have been overlooked due to the family's focus on the patient and the illness.

Another strategy aimed at promoting communication among family members is the "Spin Me a Yarn" activity (Biank & Sori, 2003). Using this technique, each family

member holds a piece of yarn and throws the ball of yarn to another family member. Each time a family member catches the ball of yarn and hold another piece, they answer questions regarding changes in the family, feelings, and family strengths. Questions may be determined by the clinician or other family members. In addition to promoting discussion, this activity may also promote family cohesion, as the family creates a web of yarn that symbolizes their shared experiences and connection to one another.

### **Summary**

It is widely known that pediatric cancer impacts the family. However, healthy siblings within the family are typically given less attention not only in the research, but in the family as well. Healthy siblings experience numerous losses during the course of the illness, including loss of parental attention and availability, sibling companionship, time with friends, as well as time and financial resources for activities (Sori & Biank, 2006). The literature has shown that families that demonstrate high levels of cohesion and adaptability tend to have siblings with fewer adjustment problems, suggesting that such levels of cohesion and adaptability are necessary for the family to adequately cope with the demands placed on them during the illness. Research also suggests, however, that high cohesion and adaptability may be suitable to meet short-term demands, but may not adequately meet the needs of family members if maintained long term, once the cancer is in remission.

Family therapy can help the family to reorganize during each phase of illness, foster adaptability, increase communication, and assist family members in supporting and meeting the needs of one another. According to Sourkes and Proulx (2000), family

therapy “affirms the family unit as a whole, and provides a framework for its healing” (p. 285).

## CHAPTER III

### **Project Methodology**

#### **Target Population**

This doctoral project was designed to be a seminar for mental health professionals who work with children and families. The seminar was presented in a psychoeducational format to a licensed psychologist, two psychology post-doctoral fellows, four psychology interns, and two psychology practicum students in the Behavioral Sciences Section at Children's Hospital Los Angeles. The Behavioral Sciences Section provides psychological and neuropsychological services to assist patients and their families with the challenges of chronic illness. Many of the individuals and families served by this program are referred by the Hematology-Oncology Division of the hospital. As such, the presentation was relevant to the mental health professionals in this program in order to increase their knowledge about the impact of cancer on the family and siblings. The author had received clinical training in the Behavioral Sciences Section, discussed the topic of the presentation with faculty members, and was asked to present as part of the weekly didactic seminars within the program. This presentation took place in December 2010.

#### **Product**

The final product was a structured, 1-hour seminar presented with PowerPoint slides and handouts. The presentation addressed the needs of healthy siblings of children with non-terminal cancer, changes in family structure and its impact on the sibling, as well as the use of systems interventions to assist families affected by pediatric cancer. It was developed through completion of a selective literature review, interviews with

clinical psychologists who have worked with pediatric oncology patients and their families, and feedback from the project supervisor and academic consultant. The seminar was conducted by a doctoral student as part of the requirements for completion of the Doctor of Psychology program at the California School of Professional Psychology at Alliant International University. An evaluation feedback form, which may be found in Appendix B, was provided to participants in order to assess the extent to which the learning objectives were achieved, as well as the clarity and usefulness of the presentation.

### **Design Objectives**

The doctoral project consisted of a presentation designed to increase awareness and knowledge of mental health professional regarding the needs of the healthy sibling in a family with pediatric cancer. More specifically, upon completion of the presentation, participations should 1) be able to identify how changes in the family system during diagnosis and treatment of pediatric cancer may affect sibling adjustment and 2) discuss effective interventions to improve family structure.

The presentation began with background information that included statistics regarding pediatric cancer, common characteristics of families affected by pediatric cancer, and challenges in working with siblings of pediatric cancer patients. The presenter also reviewed literature on sibling relationships, psychosocial effects of pediatric cancer on healthy siblings, and risk factors for adjustment problems in siblings.

Before going on to discuss the effect of pediatric cancer on the family, the presenter reviewed the Circumplex Model (Olson, 2000) of family systems in order to provide participants with a common framework from which to conceptualize families. To

help participants use this model to better understand families, the presenter defined adaptability, cohesion, communication, balanced systems, and unbalanced systems and discussed how these concepts applied to families of pediatric cancer patients and sibling adjustment. Next, the presenter discussed the experiences of and changes in family systems during different phases of illness and how these changes affect sibling adjustment. The goal was to increase participants' awareness of the ever-changing demands on the family during the course of the illness and the effect on the healthy sibling. The presenter then discussed cultural considerations when working with this population in order to help participants gain a greater understanding of how culture may impact the siblings' experiences.

Participants were provided with information regarding the mental health professional's tasks during each phase of illness. With recognition that demands on the family vary with the different phases of illness, the presenter felt it was also important to illustrate how the mental health professional may assist the family with changes at each phase in order to meet the specific needs of the family. This also allowed for discussion regarding transitions from one phase of illness to another (e.g., treatment phase to remission phase). Finally, the presenter provided specific therapeutic interventions and discussed how to use the interventions when working with families affected by pediatric cancer. It was hoped that mental health professionals would be more likely to recognize the needs of the sibling and work effectively with the siblings and families in order to promote communication, family cohesion, and positive sibling adjustment.

The presentation was given by a doctoral student to interested mental health professionals in a group setting. A presentation format was chosen because it is concise,



informative, and time-efficient. The presentation was designed to be conducted in a professional setting where mental health professions who work with families of pediatric cancer patients would be able to attend and participate. The presentation was conducted at Children's Hospital Los Angeles, in the Behavioral Sciences Section of the Children's Center for Cancer and Blood Diseases. The Behavioral Sciences Section provides psychological, neuropsychological, and school transition/re-entry services to assist pediatric cancer patients and their families. This site was chosen because the content of the presentation is relevant to the population served and could be used to help mental health professional provide more comprehensive treatment.

### **Procedures**

The content of this presentation was primarily based on information gathered through a selective review of relevant literature on siblings and families of children with cancer and interviews with field consultants who have clinical experience in the areas of children and families with pediatric cancer. The selective literature review and interviews were provided to the doctoral project supervisor and the academic consultant for feedback and review. This information was then integrated and organized into a PowerPoint presentation designed to last approximately 1 hour. Upon completion of the seminar, participants were asked to complete an evaluation form. The evaluations were compiled, summarized, and results, along with a discussion of the presenter's teaching strategy for the seminar, were incorporated into the final draft of this doctoral project.

### **Evaluation**

An evaluation form was created and distributed to the participants upon completion of the presentation. The evaluation forms were anonymous and assessed the

extent to which the objectives of the presentation were met, overall utility of the presentation, as well as strengths and weaknesses of the presentation. Participants were asked to evaluate whether they felt the presentation 1) helped them to identify how changes in the family system during diagnosis and treatment of pediatric cancer may affect sibling adjustment and 2) discussed effective interventions to improve family structure. Participants were also asked to provide recommendations for improvement. The feedback from these forms were compiled and incorporated into this doctoral project.

### **Resources**

Resources utilized for the development of the presentation included, but were not limited to, the expertise and feedback of the project supervisor, academic consultant, and field consultants, peer-reviewed journal articles, and published books. In addition, essential items, such as a computer with internet access, printer, photocopier, projector, projector screen, telephone, paper, and writing utensils were utilized in the implementation of the presentation.

## CHAPTER IV

### **Professional Feedback**

#### **Interview with Field Consultants**

As part of fulfilling the doctoral project requirements, three field consultants with expertise in working with families affected by pediatric cancer were interviewed to gather current and relevant information regarding healthy siblings of childhood cancer patients in order to fill in “gaps” in the literature and discuss whether the research findings are consistent with observations and practices from the clinical setting. Each field consultant was asked to answer the interview questions found in Appendix B.

Field consultants were chosen based on their knowledge or practice within the field. Mery Macaluso Taylor, Ph.D., Alyssa Oland, Ph.D., and Robyn Westbrook, Ph.D. are clinical psychologists who have worked with patients and families affected by pediatric cancer. Dr. Taylor and Dr. Oland were consulted via email. Dr. Westbrook’s consultation was obtained during a telephone interview that lasted approximately 30 minutes. Below are their responses to the interview questions found in Appendix B.

**Mery Macaluso Taylor, Ph.D.** Dr. Taylor is a clinical psychologist in the Department of Pediatric Psychology at Children’s Hospital of Orange County (CHOC). The Department of Pediatric Psychology provides comprehensive psychological treatment services to patients and families, psychological and neuropsychological assessment services, school re-entry services, and consultation to all inpatient medical services. Psychological treatment includes individual, family, and group psychotherapy. Dr. Taylor developed and coordinates weekly multicultural seminars that focus on helping psychology interns and postdoctoral fellows learn to apply an approach to clinical

work that supports increased cultural competency. Dr. Taylor has worked in the field of psychology for almost 10 years and specifically with oncology patients in pediatric psychology for approximately 5 years. She was contacted upon the recommendation of a pediatric psychology faculty member at Children's Hospital Los Angeles, as Dr. Taylor had previously worked as a postdoctoral fellow in the Hematology-Oncology Division and also coordinated the Teen Impact program at Children's Hospital Los Angeles. The Teen Impact program serves adolescents and young adults with cancer or a blood disease as well as their parents and siblings. The program provides patient, parent, and sibling support groups, retreats, and mentoring.

Dr. Taylor reported that in her clinical experience treating pediatric oncology patients and their families, the main concerns reported by healthy siblings of pediatric cancer patients include the ill child receiving preferential treatment, differing disciplining techniques used for the ill child and the healthy sibling, and sibling anxiety about death or becoming ill themselves. Dr. Taylor noted that symptoms of depression are common in healthy siblings and that this is often a result of decreased attention from parents and worrying about the ill child. She also indicated that behavioral problems such as fighting, bullying, and defiance may also result from decreased attention from parents (M. M. Taylor, personal communication, May 13, 2010). Although the current literature does not specifically indicate fighting, bullying, and defiance as common behaviors of healthy siblings of pediatric cancer patients, Cohen and colleagues (1994) found increased externalizing behaviors. Internalizing indicated by Dr. Taylor are also consistent with those reported in the literature regarding healthy siblings of pediatric cancer patients (Cohen et al., 1994; Hamama, Ronen, Feigin, 2000). The current research does not

clearly establish decreased parental attention as the cause of adjustment difficulty in healthy siblings, but Barrera, Fleming, and Khan's (2004) findings indicate that social support serves as a protective factor in the psychological adjustment of siblings of children with cancer. The authors indicate that social support includes "...being part of a group, reassurance of self-worth, availability of informational, emotional, and material help..." (p. 104). This study found that siblings who perceived high levels of social support, demonstrated fewer symptoms of depression and anxiety, as well as fewer behavior problems than siblings who perceived lower levels of social support. . The decreased social contact with parents and other sources of social support may decrease opportunities to express their feelings and result in emotional and/or behavioral difficulties.

Dr. Taylor reported that family restructuring, psychoeducation, and coping strategies have been helpful in addressing concerns regarding sibling adjustment. Specific to restructuring the family, Dr. Taylor emphasized that parents should make concerted efforts to minimize sibling stress by maintaining as close to normal family routines as prior to diagnosis and treatment. Sherman and Simonton (2001) also emphasize the importance of family routines, adding that these help provide "a sense of predictability" (p. 196) in a situation that is filled with uncertainty. Dr. Taylor stated that it is also important for parents to make special time and provide reassurance for the sibling. Parents should be provided with psychoeducation regarding how cancer treatment may affect the sibling and how to talk to healthy siblings in an age-appropriate manner regarding cancer and hospitalizations (M. M. Taylor, personal communication, May 13, 2010). Sori and Biank (2006) emphasize the importance of communication with healthy

siblings, asserting that children should be provided with information that is developmentally-appropriate and factual, as “children have a tendency to create their own reality, which is often worse than the truth” (p. 228). For healthy siblings who experience anxiety, Dr. Taylor recommended teaching coping strategies that can be practiced alone or with parents, such as “telling their worries to a favorite stuffed animal, making cards for the ill sibling, [or] expressing their emotions through artwork.” For children who demonstrate symptoms of depression, she recommended play therapy or cognitive behavioral therapy to work through negative feelings and to learn how to express themselves in a healthy manner (M. M. Taylor, personal communication, May 13, 2010). Sori and Biank (2006) also recommend play therapy techniques and stated that play often helps to increase awareness and expression of negative feelings.

Dr. Taylor stated that the stages of the disease process during which family therapy is most beneficial in helping to facilitate adjustment in healthy siblings “appear to be at initial diagnosis and treatment, [and] when a treatment has been prolonged and there is a delay in returning to a ‘normal’ family routine” (M. M. Taylor, personal communication, May 13, 2010). This is likely due to the significant disruption to the family routine and changes to previous roles of family members. The literature regarding intervention with families acknowledges the great importance of the phase of illness on the demands families encounter and on therapy, but does not suggest particular phases of the illness during which therapy is particularly indicated, as the way in which families cope with each phase of illness varies depending on factors such as its developmental stage, stressors, resources, and sources of support at that given time (Sherman & Simonton, 2001).

How a family copes with pediatric cancer is often influenced by cultural norms, which influence roles, expectations, communication, and caregiving (Rolland, 1994). Dr. Taylor stated that all cultures appear to give more attention to the ill child, but families with healthy siblings who are older may provide the older siblings with even less attention due to the assumption that they are able to take care of themselves. She asserted that in her experience, “Latino cultures at times can be more dismissive of [the] sibling’s needs regardless of the sibling’s age” (M. M. Taylor, personal communication, May 13, 2010). Dr. Taylor’s observation of Latino cultures being more dismissive of the sibling’s needs may be related to culturally unique beliefs regarding health, suffering, and resignation as well as coping strategies (Munet-Vilaró, 2004). This observation may also be related to the cultural construct of *familismo*, which emphasizes relationships beyond the nuclear family, often including extended family and family friends (Andres-Hyman, Ortiz, Añez, Paris, & Davidson, 2006). It is possible that Latino families may leave healthy siblings with extended family and friends more frequently or for longer periods of time, as these individuals may be given roles similar to co-parents. However, research specifically comparing how siblings’ needs are addressed and changes in caregiving of healthy siblings in Latino and non-Latino cultures was not found in this author’s review of the literature and may suggest an important area of further research. Dr. Taylor has also found that hospital culture can influence the relationship between the patient and the healthy sibling. She indicated that healthy siblings may feel frustration and resentment toward the ill child as a result of the ill child being “lavished with gifts” and sibling “being overlooked by the hospital staff” (M. M. Taylor, personal communication, May 13, 2010). In considering the hospital culture of patient-centered care, it is then important

to note that siblings not only experience less attention from parents, but also from hospital staff, who become part of the family system in most families affected by childhood cancer.

When asked about obstacles to family involvement in therapy with a child with pediatric cancer, Dr. Taylor noted that families with whom she has worked typically have difficulty with time and transportation, especially when the ill child is on treatment. She has found that even when families recognize that the sibling is having difficulty adjusting, they may often defer the sibling problem to a time when the family is experiencing less stress. In order to address these challenges, Dr. Taylor states that mental health professionals must actively assess for them and provide parents with psychoeducation regarding the emotional consequences on the sibling. Even when parents are made aware of the potential effect on siblings, it is likely that parents may not have the time to address these concerns and that health-related issues may be prioritized over the risk of negative psychological impact. She has also found that parents are more likely to come to therapy for the sibling if appointments can be coordinated with other clinic visits or with therapy for the ill child. This is consistent with parents indicating a preference for interventions with flexible timing and citing “time and transportation resources as reasons for their family’s inability to attend” (Ballard, 2004, p. 397).

**Robyn Westbrook, Ph.D.** Dr. Westbrook is a clinical psychologist in private practice, specializing in child and adolescent psychology, as well as end-of-life issues. She has also provided group therapy at weSPARK, a non-profit organization that provides support for individuals and families affected by cancer. At weSPARK, Dr.



Westbrook's work focused on adolescents affected by pediatric cancer and adolescents who have lost a parent or sibling to cancer.

Dr. Westbrook stated that the main issues reported by healthy siblings are often related to parents being gone and not knowing when they will return. She indicated that there is often inconsistency in caregiving because the healthy sibling may be required to stay with extended family or friends while the parent cares for the ill child. Dr. Westbrook asserted that as a result of the parents' absence and less parental attention provided, healthy siblings may also feel anger and resentment toward the patient (R. Westbrook, personal communication, June 9, 2010). Dr. Westbrook reported that she has encountered healthy siblings who wished the ill child dead in order to decrease family stress or wished they were ill because of the attention that they see the sick child receive. She indicated that many younger siblings may also fear that they or their parents will become ill or that cancer is contagious. This is often related to the illness not being explained to the siblings (R. Westbrook, personal communication, June 9, 2010). Havermans and Eiser (1994) state that healthy siblings may have concerns that are not addressed, such as those related to prognosis and possible death. They assert that clinicians should help parents understand that these concerns likely exist and should be addressed even if healthy siblings do not raise specific questions. When healthy siblings are not provided with sufficient information that is age-appropriate, they may pick up misinformation from adult conversations (Sori and Biank, 2006).

To help address the concerns commonly reported by healthy siblings, Dr. Westbrook stated that it is important to normalize all feelings that are expressed and help siblings understand that they are not alone in their feelings and experiences. She

emphasized that clinicians should help family members understand that cancer disrupts the entire family and not just the patient by providing psychoeducation. Ballard (2004) indicated that approximately half of healthy siblings whom parents do not view as being at risk for adjustment difficulties do indeed experience adjustment issues. Ballard goes further to assert that the adjustment difficulties are likely associated with decreased parent willingness to attend interventions targeting siblings and that clinicians should educate parents specifically about the adjustment difficulties potentially experienced by healthy siblings. Dr. Westbrook has found that helping healthy siblings talk about their feelings and normalizing those feelings has been one of the most beneficial interventions. Additionally, she reported that it is important to open up lines of communication and expression of feelings within the family so as to facilitate family members supporting one another (R. Westbrook, personal communication, June 9, 2010). This is consistent with consultation provided by Dr. Taylor, the Circumplex Model of family systems (Olson, 2000), and recommendations from Sori and Biank (2006).

When asked about stages in the disease process during which she has found family therapy most beneficial for healthy siblings, Dr. Westbrook indicated that therapy is typically most needed close to diagnosis and during treatment. She stated that diagnosis is often new, unknown, confusing, and scary for the entire family, so it is important for the clinician to help answer any questions the healthy sibling may have, give them room to express themselves, and process their experiences. Dr. Westbrook reported that during diagnosis and treatment, parents are often so overwhelmed themselves that they find it difficult to help the healthy sibling process their experience (R. Westbrook, personal communication, June 9, 2010). This is consistent with the results of a qualitative study of

parent perceptions about the needs of healthy siblings of pediatric cancer patients, in which parents reported challenges in meeting the needs of each family member (Sidhu, Passmore, & Baker, 2005). In this study, parents also indicated that they were aware that healthy siblings had difficulty with the changes in the family and regretted not having the time to process the changes with the healthy siblings.

With regard to the impact of culture on the experience of the healthy sibling in a family affected by pediatric cancer, Dr. Westbrook stated that healthy siblings within cultures that have more of an extended family system, like Latino cultures, may have an easier time adjusting to less parental attention, because children in those family systems may be more accustomed to multiple caregivers prior to the patient's diagnosis and treatment. She asserts that children from cultures in which extended family play a more prominent role in daily life may have an easier time with the adjustment because there would be a less dramatic shift in caregivers (R. Westbrook, personal communication, June 9, 2010). No research examining potential protective factors related to culture for healthy siblings in families affected by pediatric cancer was found in this author's review of the literature, suggesting that this remains an area for further study.

With regard to obstacles to family involvement in therapy when the family has a child with pediatric cancer, Dr. Westbrook indicates that the biggest obstacle is that health issues typically trump psychological issues in most families, so parents' first priority is to focus on the ill child rather than the physically healthy child. Parents have limited energy, time, and ability, and those resources are typically devoted to caring for the ill child, so it is less common for the parents to seek therapy for the healthy sibling at that time. Secondly, parents may have difficulty expressing their feelings because they

just want to get through the cancer treatment. They need to check out at times, so realizing that their healthy child is being adversely affected compounds the situation. Lastly, the clinician is likely to deal with each member of the family being in a different place in terms of acceptance and having different levels of defenses and coping strategies that may or may not lead to difficulty supporting one another (R. Westbrook, personal communication, June 9, 2010).

In addressing challenges faced when working with families of pediatric cancer patients, Dr. Westbrook indicates that if parents are able to bring the healthy sibling in to sessions in the first place, it is a big accomplishment and very rare. Dr. Westbrook stated that it is important for mental health professionals to provide intervention to the siblings at times and locations that may minimize the amount of resources required by the parent in order to facilitate attendance. This is consistent with the Ballard's (2004) findings and input provided by Dr. Taylor. If families are able to attend sessions, then strategies in addressing the challenges that she has found successful include addressing everyone's feelings, recognizing and normalizing their experience, helping the siblings identify what feelings are and when they have feelings, helping them learn strategies that can help them feel better, identify different forms of support, encouraging everyone to ask questions and ask for clarification (R. Westbrook, personal communication, June 9, 2010).

**Alyssa Oland, Ph.D.** Dr. Oland is a clinical psychologist in the Department of Psychiatry and Behavioral Sciences at The Children's Hospital, Denver, which is a pediatric healthcare facility that serves Colorado. Dr. Oland is the director of the Med/Psych Outpatient Specialty Program which provides services to children with chronic medical conditions who also have psychiatric disorders, with the goal of

integrating medical and psychological services. The program serves patients age 5 to 17 years old and provides evaluation, psychological testing, as well as individual, group, and family therapy. Dr. Oland had previously completed a postdoctoral fellowship in the Pediatric Psychology Program at the University of Southern California University Center for Excellence in Developmental Disabilities Mental Health Center (USC UCEDD) and has co-authored a peer-reviewed journal article on the role of culture in coping themes of mothers of pediatric cancer patients.

Dr. Oland reported that the most common concerns reported by healthy siblings of children with cancer are feelings of guilt and resentment related to the ill child, worry about what will happen to the ill child and the family, missing time with parents, and missing the way things were prior to the ill child's treatment (A. Oland, personal communication, June 2, 2010). A qualitative study by Sloper (2000) found that interviews with healthy siblings yielded themes related to multiple losses; notably, loss of attention from parents, family routines, companionship of the ill child, and feelings of security.

Dr. Oland indicated sibling adjustment can often be addressed by providing group therapy and supportive therapy to the families (A. Oland, personal communication, June 2, 2010). She did not provide specific interventions that have been helpful in her experience, but her assertion regarding group therapy is corroborated in the literature. According to Steinglass (1998), multiple family discussion groups help to increase engagement of family members during the chronic or treatment stage of illness and decrease feelings of isolation and stigmatization. Decreasing feelings of isolation and stigmatization may facilitate expression of feelings among family members and help to

normalize negative feelings experienced by healthy siblings. These groups often focus on family strength and allow the families to establish a sense of community resulting from shared experiences.

Dr. Oland stated that she has found family therapy to be beneficial in facilitating sibling adjustment during “all stages” of the disease process, as sibling adjustment is affected by each unique family’s resources and coping strategies (A. Oland, personal communication, June 2, 2010). This is consistent with literature previously mentioned that indicates that a family’s coping strategies also depend on factors other than the phase of illness (Sherman & Simonton, 2001).

It is documented in the literature that there are significant challenges to obtaining family involvement in therapy with children with pediatric cancer. Dr. Oland indicated that family resources, such as time and social support, are often difficult to obtain. The lack of these resources, in combination with financial difficulty (also noted by Dr. Taylor) the family often experiences makes it extremely difficult for families to make time for therapy (A. Oland, personal communication, June 2, 2010). Dr. Oland also mentioned that there are challenges regarding insurance reimbursement for therapy, especially if the ill child has not been referred for therapy. Although difficulty with obtaining insurance reimbursement was not pointed out by the other field consultants interviewed, it was a common statement made by mental health professionals who were contacted by the author and declined to be interviewed because they worked only with the ill child and did not work with siblings. Instead, siblings are often referred to support groups and camps. Dr. Oland indicates that making sure the family receives sufficient case management by social workers, so as to provide the family with the resources they

need during this time has been the most successful strategy in addressing these challenges (A. Oland, personal communication, June 2, 2010).

## **Discussion**

Much of the information provided by the field consultants supported the existing literature. The field consultants identified issues related to decreased parental attention, preferential treatment, anger, loss, depression, and anxiety experienced by healthy siblings that are also reported in the research. Also consistent with the research was that field consultants identified expression and normalization of feelings, as well as psychoeducation regarding the effect of diagnosis and treatment on the entire family as important interventions in assisting families with healthy sibling adjustment. The field consultants differed regarding during which stage of the illness therapy is most beneficial. However, they agreed that families may benefit from support to help cope with the shock and anxiety experienced at initial diagnosis and that treatment is often most helpful when families experience change from their typical routines. The field consultants agreed that families' limited time and resources are among the most significant challenges in providing treatment. Additionally, medical needs typically take precedence over psychosocial needs, and as such, parents may not notice or seek treatment for siblings who are having difficulty with adjustment. Parents may find it difficult to cope with the sibling's psychological needs in addition to the ill child's substantial medical needs. In response to the challenges related to providing therapy for families affected by pediatric cancer, field consultants emphasized the importance of increasing parental awareness of the possible adjustment difficulty healthy siblings may encounter and facilitating family participation in treatment by providing flexible

scheduling of therapy sessions so that they coincide with the patient's medical treatment in order to decrease time and travel demands on the family. Case management by social workers was noted as important to ensure that the family receives social support and resources necessary and increase the likelihood that families are able to accommodate therapy sessions and find time to address siblings' needs.

The information provided by field consultants also indicated areas in which research is scarce or lacking. Of particular interest is the lack of and difference in responses regarding the impact of culture on the sibling experience. One field consultant stated that culture does indeed impact the experience of the healthy sibling in a family affected by pediatric cancer but did not elaborate on cultural differences. Two field consultants discussed their observations regarding the impact of cancer on healthy siblings in Latino families, but did not discuss other ethnic groups. However, this may reflect the demographics of the families treated at these cancer treatment centers in Southern California. Both consultants have observed that there may be greater involvement of extended family members in caring for the healthy sibling while parents care for the ill child. One consultant speculated that these siblings may experience less difficulty with this aspect of change in the family system because they are accustomed to being cared for by extended family. No research examining potential protective factors related to culture of healthy siblings in families affected by chronic illness was found in this author's review of the literature, suggesting an important area of further study. Research regarding cultural differences in the sibling's experience with cancer is limited and primarily consists of studies regarding Caucasian and Asian families, indicating a need for expanding research across different cultures.



The process of contacting potential field consultants also provided valuable information, as multiple professionals contacted at cancer centers acknowledged the need for early assessment and treatment of sibling adjustment difficulties, but indicated that they did not often provide treatment to siblings due to lack of insurance coverage and family resources. It appeared that although family-centered treatment was emphasized at many cancer centers, mental health professionals often use a behavioral medicine/consultation-liaison approach. McDaniel, Hepworth, and Doherty (1992) assert that in behavioral medicine and consultation-liaison perspectives, family members are seen as background factors that influence the individual patient, whereas medical family therapists concentrate on how medical illness affects the entire family.

In conclusion, all of the information provided by the consultants and the individuals who declined to be interviewed was informative and helpful. They provided valuable insight, clinical observations and recommendations that supplemented the research.

## CHAPTER V

### Results and Discussion

#### Results

The presentation was conducted at Children's Hospital Los Angeles as a seminar in the Behavioral Sciences Section of the Children's Center for Cancer and Blood Diseases. The Behavioral Sciences Section provides comprehensive psychological, neuropsychological, and school transition/re-entry services to assist children and families with the challenges associated with surviving cancer and blood diseases. As such, the presentation was applicable to staff, fellows, interns, and practicum students in order to increase their knowledge about the impact of cancer on the family and siblings. The presentation was attended by two practicum students, four interns, two postdoctoral fellows, and one licensed psychologist. Although two additional psychologists and one social worker were expected to be in attendance, they were unable to attend because this presentation was one of several trainings scheduled that day.

A PowerPoint slide show was used during the presentation and participants were also provided with handouts that consisted of the PowerPoint slides with lines for note-taking. The presentation was developed through completion of a selective literature review regarding sibling relationships, changes in family structure during cancer diagnosis and treatment, and the impact of those changes on siblings. In order to provide relevant information that was not found in the literature, input was solicited from field consultants who are pediatric psychologists and have worked with pediatric cancer patients and their families. Once information from field consultants was integrated into the presentation, the doctoral project supervisor and academic consultant reviewed the

presentation slides and provided feedback that was also incorporated to improve the presentation. The presentation lasted approximately 1 hour, including time for questions and discussion throughout and after the presentation.

Following the presentation, each participant was provided with and asked to complete an evaluation feedback form, which can be found in Appendix C. The evaluation form was developed to help assess the extent to which the learning objectives of the presentation were achieved, the clarity and usefulness of the presentation, as well as audience perception of presenter knowledge and organization. The participants were asked to rate aspects of the presentation, using a 1 to 5 Likert scale, with 1 = strongly disagree, 2 = disagree, 3 = undecided, 4 = agree, and 5 = strongly agree. There were also questions that allowed participants to identify information they felt was most useful to their professional work and to provide comments and suggestions for improvement.

The first question on the evaluation form assessed to what extent the first learning objective of the presentation was achieved. Participants were asked to rate whether the presentation helped them to identify how changes in the family system during diagnosis and treatment of pediatric cancer may affect sibling adjustment. Five participants (56%) rated this question a 5 and four participants (44%) rated this question a 4. The presenter felt that she identified how changes in the family system affect healthy siblings of pediatric cancer patients, but more time could have been devoted to group discussion of the range of feelings and experiences of healthy siblings and use of clinical examples. Although information from the selective literature review was presented fully, further discussion using clinical examples could have helped to increase participants' understanding of how adjustment difficulty noted in the literature may present in a family

or client seeking treatment. This may be particularly helpful to audience members with less clinical experience with families coping with pediatric cancer.

The second question addressed achievement of the second learning objective and asked participants to rate whether the presentation discussed interventions to improve family structure. Eight participants (89%) rated this question a 5 and one participant (11%) rated this question a 4. The presenter believes that the interventions may have been more clearly illustrated with the use of case studies when discussing interventions. This approach may have been particularly helpful to the participants with more limited clinical training, as it would possibly help demonstrate how the interventions discussed may be applied in a clinical setting.

The third question addressed whether the information was presented in a format that was useful and easy to understand. Seven participants (78%) rated this question a 5 and two participants (22%) rated this question a 4. The presenter agrees with the ratings for this question, although the information may have been more clearly illustrated with the use of case examples and other forms of media (e.g., video clips). Given the differences in clinical experience of the participants and the variety of difficulties reported to each therapist by families, case examples or video clips of families may have provided a common basis for discussion and helped participants synthesize the concepts learned.

The fourth question focused on whether the presenter demonstrated knowledge and understanding of the presented material. All participants (100%) rated this question a 5. The presenter agrees with the ratings and recognized the importance of understanding the presented material. The presenter had prepared additional notes that were relevant to

possible questions from the audience and practiced with the PowerPoint slides so as to rely less on the slides and be better able to facilitate input from the participants.

The fifth question assessed whether the presentation was well-organized. Six participants (67%) rated this question a 5 and three participants (33%) rated this question a 4. In preparing for the presentation, the presenter could have been more mindful of the amount of time audience participation and discussion would add in order to be better prepared and organized. The presenter could have also considered ahead of time whether it would have been more beneficial to facilitate audience participation only at the end of the presentation or throughout the entire presentation, given the amount of information to present in the time allotted.

The evaluation form also asked participants to identify information from the presentation they found most useful to their professional work. The responses varied, but there appeared to be trends related to level of clinical training. Both practicum students noted that they found the ideas for family-centered interventions the most helpful. Practicum students may have had less clinical experience than the other participants as well as less exposure to various interventions, so they may have benefited from discussion on practical application of what they had learned. Responses from interns were more closely related to factors to consider when working with families and applying the information to their current clients. Intern responses to this question included: “risk factors,” “considerations regarding collectivist cultures,” and “application towards real cases and opening up the session [for] discussion.” The presenter also noted that during the presentation, the interns appeared especially interested in sharing their clinical experiences and discussing the unique experiences of their clients’ healthy siblings.

Individuals with more extensive clinical training and experience appreciated information regarding current research and literature. One participant noted that the presentation was a “reminder of the importance of sibs.” If this presentation is given again to an audience with varied levels of learning, it may be helpful to point out the specific information that each group may find most pertinent to the work at each level of training and experience. This feedback from participants also provided the presenter with possible aspects of the presentation to expand in the event that future audiences have more similar levels of training (e.g., a presentation provided to psychology interns may focus more on integration of clinical considerations, like specific risk factors, with case material).

Another question requested suggestions for making the presentation more useful. Seven participants (78%) indicated that more time was needed. It appeared that the material presented was adequately covered, as evidenced by participants’ ratings on the learning objectives, but participants also indicated that they “would like to hear more.” Given the limited amount of training in working with siblings and using family systems interventions provided to the participants, the presenter believes that allotting more time for the presentation would have allowed the presenter to address more questions and comments as well as facilitate further discussion on clinical cases. The presenter believes that the participants’ response to this question also illustrates the lack of much-needed training in this area. If this presentation is given again in the future, the presenter will schedule 90 minutes for the presentation in order to allow more time for discussion and participation from the audience.

Two participants also recommended dividing the seminar into two presentations. One of the participants who suggested conducting two presentations indicated during a

discussion after the presentation that she would want to participate in one presentation regarding healthy sibling adjustment, followed by another presentation that focused solely on family-centered interventions. The presenter believes that this may be particularly helpful to participants with relatively limited clinical training. One participant suggested adding a role-playing exercise at the end of the presentation. The presenter believes that adding a role-playing exercise may be quite challenging, given the limited amount of time allotted with the current presentation. However, role-playing may be possible if the presentation were divided into a 2-part series, with the second part focused on interventions. After learning about sibling adjustment and the family system in the first presentation, the participants could volunteer to play different roles in the family and the therapist during the second presentation. After the role-play, the presenter could facilitate discussion regarding the intervention and encourage participants to share their ideas and experiences.

Lastly, the evaluation form included a space for additional comments and feedback. Responses included: “A very useful presentation,” “Very informative,” “Great job including...culture, family communication, systems,” and “I liked your positive attitude and openness towards hearing what others have to say.” One participant stated that the presentation was “really the first learning I have had on siblings of cancer patients. Very helpful.” The presenter’s aims were to provide a relevant and informative presentation to mental health professionals in order to increase awareness about the changes that occur in the family system when a child has cancer, to increase knowledge regarding the experiences of siblings in those family systems, to discuss the effectiveness of family therapy, and provide systems interventions in order to work with siblings and

families. The presenter had also wanted to come across to the participants as approachable and knowledgeable about the topic. From the feedback by participants, it appears those goals were achieved. The presenter was pleased to receive such positive feedback and is encouraged to continue to work to improve the presentation and give it again in the future.

## **Discussion**

Overall, participants reported that they found the presentation to be useful and informative. It appeared that the learning objectives of the presentation had been met, as evidenced by participants' ratings of 4 or 5. The comments and suggestions provided by the participants were supportive and useful in helping to improve the presentation if it is given again. The most consistent feedback from participants was related to suggesting more time for training. As previously mentioned, it appears that the material in the presentation was covered adequately, according to participants' ratings. It is possible that participants' suggestions regarding more time was due to wanting to "hear more," because of the limited training provided in this area. Together with the multiple mental health professions within pediatric psychology who had declined to participate due to their limited experience with sibling, this perhaps points to an area of need in training and clinical practice.

The presenter agrees with many of the suggestions from the participants and plans to use much of the feedback to improve the presentation. More specifically, the presenter will incorporate case examples to better illustrate the effect of diagnosis and treatment of the family system as well as application of the interventions in a clinical setting. Additionally, the presenter will schedule 90 minutes for this presentation in the future in



order to allow more time for discussion and audience participation. The trends in the feedback provided regarding what participants believed to be most useful to them in the presentation can also be used to guide the presenter in adapting the presentation for audiences with more similar levels of training. The presenter will consider providing the information as a two-part series, with the first presentation addressing healthy siblings and family adaptation during different phases of illness and the second presentation focusing on family-centered interventions. This may be particularly helpful to individuals who have had little exposure to and experience with healthy siblings of pediatric cancer patients and family therapy.

### **Limitations**

The first limitation of this topic was the scarcity of research related to the role of culture in the experience of healthy siblings of pediatric cancer patients, as most of the existing literature focuses on European Americans, with some limited research regarding Asian Americans (Yi, 2009) and Latino Americans (Munet-Vilaró, 2004). Information provided by field consultants was used to supplement the literature in this area. However, the field consultants primarily provided information regarding Latino Americans, which may reflect the demographics of the families treated at cancer treatment centers in Southern California, as two of the field consultants were working in Southern California at the time of the interview and one field consultant had recently completed a postdoctoral fellowship in Southern California. Additional research addressing the needs of other cultures and input from field consultants from other regions of the country would have greatly strengthened the project.

A second limitation was that the presenter could have also included interventions that could be implemented during multiple-family group sessions, which are another opportunity for the participants to work with families affected by pediatric cancer. Although the presenter recognizes that group therapy is often utilized in hospitals, interventions for group therapy was not the focus of the presentation and were thus excluded from the information provided to participants. The presentation was focused on family therapy sessions with single families.

A final limitation was the small number of participants in this presentation. In discussing the topic of the presentation with the training faculty of the site at which the presentation was given, it was decided that the presentation would be most appropriate as part of a series of weekly didactic training seminars provided to practicum students, interns, and postdoctoral fellows. However, due to the multiple responsibilities of clinical staff and the current emphasis on training and implementation of evidence-based practices, some of the clinical staff and postdoctoral fellows in the division did not attend. Therefore, this limited the amount of feedback provided regarding the presentation, especially input from mental health professionals with more advanced training in pediatric psychology that would have also helped to enhance the project. It would be helpful for future presentations within the Behavioral Sciences Section to be planned on days that do not coincide with other trainings that involve mental health professionals.

### **Recommendations for Future Research**

The current project addresses the overall experiences and needs of siblings of pediatric cancer patients. However, it would also be beneficial to examine the differences in the experiences of healthy siblings of patients with various types of cancer because the

differences in treatment, level of impairment, and mortality rate are likely to result in differences in the family's stress and coping. In addition, research in the area of cultural differences related to the experience of healthy siblings in families affected by pediatric cancer is significantly lacking. Research specifically comparing changes in caregiving of healthy siblings and how their needs are addressed in different cultures was not found in this author's review of the literature. Finally, research on potential protective factors related to culture and world view for healthy siblings in families affected by pediatric cancer also appears to be lacking and would be an important area of future research.

### **Personal Statement**

The process of completing my doctoral project has been both gratifying and challenging. My first challenge was deciding upon a topic. I had been working with pediatric cancer patients and their families and was struck by the scarcity of family-centered mental health services. Instead, most of the mental health services were provided to the patient, with intermittent family involvement in sessions. I had initially wanted to examine the effect of pediatric cancer on family relationships, but when I examined the existing literature, I realized that the topic was too complex to be covered in a 1-hour presentation. Recognizing that I was not going to be able to provide an in-depth view of family relationships, I decided that perhaps I should provide a presentation that would increase awareness about the fact that pediatric cancer affects the entire family. However, it was apparent that the field of pediatric psychology was aware that cancer affects the entire family. I wanted to contribute to the practice of mental health professionals by disseminating information that would be useful in their clinical practice,

so I finally decided to focus on a group of individuals who are often overlooked in families affected by pediatric cancer—the healthy siblings.

When I began this journey, I had no idea that I would be met with multiple challenges in my personal life that would significantly delay completion of this project. Although I was still able to manage my responsibilities as a student and a psychology intern, I had little motivation to do anything that did not require me to be in a certain place at a certain time. In hindsight, I believe that perhaps I could have returned to managing all of my professional responsibilities (i.e., including my doctoral project) more quickly, had I taken time off to take care of myself during this time in my life. I was eventually able to return to working on the project and had my proposal meeting with my project supervisor and academic consultant in March of 2010. At that time, I had hoped that I would still be able to complete the project by the end of my fourth year.

Once my proposal had been approved, I was not able to immediately contact field consultants, as I was advised by my project committee to obtain information from professionals who did not work at the site at which I was scheduled to present in order to allow for different perspectives to be included in the presentation. Finding new field consultants was a challenge, as many of the mental health professionals I had contacted either did not respond or declined to be interviewed, stating that although they worked with pediatric cancer patients, they did not regularly work with healthy siblings or the entire family. Although these professionals were not able to provide answers to the interview questions I had planned, they were able to demonstrate and discuss the scarcity of mental health services for healthy siblings and other family members. This was a significant part of the project as well as part of my initial interest in this topic. Three

psychologists eventually agreed to serve as field consultants and shared their clinical experiences with me shortly after the Spring semester of my fourth year. Their input added rich, descriptive information that I had not found in the literature and undoubtedly helped to strengthen my presentation.

I gave the presentation in December 2010, soon after my slides had been approved by my project supervisor and academic consultant. I was very nervous about delivering the presentation. Not only do I dread public speaking, but I was also immensely grateful for the support and flexibility that faculty at Children's Hospital Los Angeles had demonstrated throughout this process and did not want to disappoint them. Despite the initial anxiety, I found myself surprisingly calm once I got through the first few slides and gained more confidence as the presentation progressed. If this presentation is given again, I believe it would be helpful for me to practice by giving the presentation to my colleagues and obtain feedback, as well as develop ways to cope with the anxiety that is especially high during the first few slides of the presentation. I felt that the overall presentation was successful and the suggestions from the participants have motivated me to improve upon the product after I complete the doctoral project.

This project has helped me grow professionally and personally. I have a better understanding of the complexities of working with healthy siblings of pediatric cancer patients and would like to continue to work with pediatric cancer patients and their families. Additionally, I would like to gain a better understanding of the experiences of healthy siblings of children with other chronic illnesses and work with families to facilitate positive adjustment. I have also gained a better understanding of my own strengths, where I struggle, and how I cope. I am thankful for the support and

encouragement of my project supervisor, academic consultant, Children's Hospital Los Angeles faculty, family, and friends throughout this process.

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## APPENDIX A

### Interview Consent Form for Field Consultants



### Interview Consent Form for Field Consultants

I have been informed that this doctoral project interview will be conducted by Cathliyn Buranahirun, M.A., a graduate student at the California School of Professional Psychology at Alliant International University, Los Angeles. I understand that this project is designed to study the impact of the diagnosis and treatment of pediatric cancer and changes in the family system on the healthy siblings of the patient, and that I have been contacted by the above student to offer input as a Field Consultant because I have some expertise and/or clinical/professional knowledge about the stated project topic. The purpose of the interview is to not only fill the informational “gaps” that exist in the professional literature about this topic, but to also examine if what is discussed in the research literature is actually being practiced/observed in the community by field professionals.

I am aware that my participation as one of the Field Consultants will involve answering some interview questions (face-to-face, if possible) designed to understand the impact of the diagnosis and treatment of pediatric cancer and changes in the family system on healthy siblings of the patient. I am aware that the interview will be audiotaped -- or conducted via phone or email correspondence, if preferred. The amount of response to these interview questions can be as lengthy or brief as I see appropriate for myself, and I can choose to respond only to those questions that I feel qualified to answer, if needed. The interview process may take approximately 30 minutes of my time to complete, and the interview will be audiotaped (if face-to-face or via phone contact) to ensure its quality and accuracy.

I have been informed that my participation in this study is voluntary and I can withdraw at any time. I understand that this is a professional interview/contact where I will be asked to share my clinical/professional expertise on the stated project topic. Some of the interview contents may be used within the project report as personal communication citations, and my contribution to this study will be appropriately cited within this project. I understand that I may request to review and approve the specific citations and/or contributions of my interview to the Doctoral Project. Such a request should be made at the time of the interview. The Doctoral Project Chair, John Bakaly, PhD has final approval over the content and production of the Doctoral Project.

I am aware that although I may not directly benefit from this study, my participation in this project will further increase knowledge and awareness in the field of psychology -- specifically, pertaining to understanding the impact of diagnosis and treatment of pediatric cancer and changes in the family system on healthy siblings of the patient. I understand that I may contact Cathliyn Buranahirun, M.A. at [cburanahirun@alliant.edu](mailto:cburanahirun@alliant.edu) OR his/her project Chair, John Bakaly, Ph.D. at 1000 S. Fremont Ave. Unit #5, Alhambra, CA, 91803 or (626) 270-3295 if I have any questions regarding this project or my participation in this interview as a Field Consultant. I understand that at the end of this study, I may request a summary of the results or additional information about the study from the above student.

I have read this form and understand what it says. I voluntarily agree to participate in this professional interview as a part of the student’s doctoral project. I understand that I will be signing two copies of this form. I will keep one copy and the student, Cathliyn Buranahirun, M.A. will keep the second copy for his/her records. If I have received this Consent Form and the Interview Questions via email, by returning my answers via reply, I am agreeing to the above-stated conditions.

\_\_\_\_\_  
Participant’s Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Student’s Signature

\_\_\_\_\_  
Date

## APPENDIX B

### Interview Questions for Field Consultants

### **Interview Questions for Field Consultants**

1. From your experience, what are some of the main concerns reported by healthy siblings of children with cancer?
2. What interventions have you found helpful in addressing these concerns within family therapy?
3. During what stages in the disease process have you found family therapy to be most beneficial in facilitating adjustment in healthy siblings?
4. What cultural factors influence the role that the sibling takes within a family affected by pediatric cancer?
5. What are the obstacles to family involvement in therapy with a child with pediatric cancer?
6. What strategies have been successful in addressing these challenges?

## APPENDIX C

### Presentation Evaluation Form

**Presentation Evaluation Form**  
 Understanding the Needs of Siblings of Children with Cancer  
 Cathliyn Buranahirun, M.A.

Thank you for your participation in the presentation. Please take a few minutes to complete this evaluation form.

Please indicate your position (e.g., Licensed Psychologist, Intern, Practicum Student, etc.).

---

Please rate the presentation on a scale of 1 to 5.

1 = Strongly Disagree

2 = Disagree

3 = Undecided

4 = Agree

5 = Strongly Agree

1. The presentation achieved the following learning objectives:

a. Identify how changes in the family system during diagnosis and treatment of pediatric cancer may affect sibling adjustment

1                      2                      3                      4                      5

b. Discuss effective interventions to improve family structure

1                      2                      3                      4                      5

2. The information was presented in a format that was useful and easy to understand.

1                      2                      3                      4                      5

3. The presenter demonstrated knowledge and understanding of the presented material.

1                      2                      3                      4                      5

4. The presenter was well-organized.

1                      2                      3                      4                      5

5. What information did you find the most useful to your professional work?

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6. What suggestions do you have to make this presentation more useful?

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7. Additional comments and feedback.

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Thank you

APPENDIX D  
Presentation Slides



# Understanding the Needs of Siblings of Children with Cancer : A Family Systems Perspective

Cathlyn Buranahirun, M.A.  
California School of Professional Psychology  
Alliant International University



## Purpose

Provide information regarding impact of  
diagnosis and treatment of pediatric  
cancer on the healthy siblings of the  
patient



## Learning Objectives

- Identify how changes in the family system during diagnosis and treatment of pediatric cancer may affect sibling adjustment
- Utilize effective interventions to improve family structure

3

## Statistics

- 1 to 2 out of every 10,000 children are diagnosed with cancer each year (Altekruse et al., 2009)
- 5-year survival rate for pediatric cancer is approximately 61% to 92% (Altekruse et al., 2009)

4

## Characteristics

- Family experiences significant disruption and adaptation by the entire family is required (Kazak, 1989)
- Less focus on healthy siblings within these families in research and clinical practice (Houtzager, Grootenhuis, & Last, 1999).

5

## Challenges

- Recognizing sibling's needs
- Time and transportation
- Family stress
- Insurance reimbursement

6

## Sibling Relationships

- Often the longest relationship within a person's lifetime
- Influence of siblings
- Precursor to peer relationships

7

## Sibling Adjustment

- Greater likelihood of adjustment difficulties and internalizing behaviors more prominent than externalizing behaviors (Sharpe & Rossiter, 2002)
- Feelings of isolation, anxiety, negative behavioral changes, school problems (Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1994; Hamama, Ronen, & Feigin, 2000; Houtzager et al., 2004)

8

## Sibling Adjustment

- Moderate to severe symptoms of posttraumatic stress (Alderfer, Labay, & Kazak, 2003)
- Other studies find no negative effect on healthy siblings of children with cancer (Horwitz & Kazak, 1990; Madan-Swain, Sexson, Brown, & Ragab, 1993)

9

## Sibling Adjustment

- No simple relationship between illness and sibling maladjustment
- Chronic illness as a risk factor
- Supports the need to develop an understanding of the impact of cancer on the family to facilitate positive adjustment of healthy siblings

10

## Risk Factors

- Adolescent female siblings: negative mood, difficulty with interpersonal relationships (Houtzager, Grootenhuis, Hoekstra-Weebers, Caron, & Last, 2003)
- Younger male siblings: externalizing behaviors (Sahler et al., 1994)
- Siblings with pre-existing behavioral/emotional problems (Sahler et al., 1994)

11

## Circumplex Model (Olson, 2000)

- Adaptability
- Cohesion
- Communication
- Balanced systems
- Unbalanced systems

12

## Pediatric Cancer and the Family

- Adaptability
- Cohesion

13

## Pediatric Cancer and the Family

- Phases of illness
  - Diagnosis
  - Treatment
  - Remission
  - Recurrence

14

## Cultural Considerations

- Most current literature focuses on European American families
- Family's coping affected by cultural norms, incidence rates of cancer, mortality rates related to cancer, expectations regarding participation in healthcare

15

## Cultural Considerations

- Collectivist cultures
  - Greater isolation from the community (Yi, 2009)
  - Increased sibling stress (Yi, 2009)
  - Possibly easier adjustment to decreased parental attention (R. Westbrook, personal communication, June 9, 2010)
- Family communication

16



## Cultural Considerations

- Asian Americans
- Latino Americans
- Hospital culture

17



## Professional's Role

### *Diagnosis*

- Reorganize and reestablish stability
- Age-appropriate information for siblings

18



## Professional's Role

### *Treatment*

- Assess structural changes and how they have affected family members
- Foster family adaptability
- Facilitate communication among family members
- Help the family maintain relationships and rituals

19

## Professional's Role

### *Remission*

- Assist with transition, loss of support system provided by hospital staff
- Help family reorganize
- Help family cope with anxiety related to threat of recurrence

20

## Professional's Role

### *Recurrence*

- Support and encouragement to gather resources and reorganize family to begin treatment again
- Help parents cope with guilt, probable change in prognosis, concerns about morbidity

21

## Family-Centered Treatment Interventions

- Draw the family before, during, and after treatment
- Family Mural
- Yarn Game

22

## Summary

- Family experiences significant disruption and siblings receive less focus in the family as well as in clinical practice
- No clear, simple relationship between illness and sibling adjustment

23

## Summary

- Balanced family systems are more conducive to healthy family functioning and sibling adjustment
- Role of the professional changes in each phase of illness
- Family centered interventions can help to promote communication and cohesion

24

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Questions/Discussion

Please complete feedback forms

Thank you!

## APPENDIX E

### Curriculum Vita

## CURRICULUM VITA

## EDUCATION

**Doctoral Candidate for Doctor of Psychology (Psy.D.)**

California School of Professional Psychology  
 Alliant International University, Los Angeles, CA  
 August 2006 – Present

**Master of Arts in Clinical Psychology**

California School of Professional Psychology  
 Alliant International University, Los Angeles, CA  
 August 2006 – August 2008

**Bachelor of Arts in Psychology, concentration in Developmental Disabilities**

University of California Los Angeles, Los Angeles, CA  
 September 1994 – June 1999

## RELATED EXPERIENCES

**Consultant (Center for Behavior Research and Education)****Rancho Cucamonga, California****June 2009 – present**

- Conduct functional behavior assessments for children and adolescents with developmental disabilities
- Provide didactic training seminars on Applied Behavior Analysis (ABA), child development, and data collection

**Regional Director (California Institute of Behavior Analysis, Inc.)****Orange, California****September 2004 – August 2008**

- Conducted functional behavior assessments of children with developmental disabilities and generated reports, including treatment recommendations
- Generated IEP goals and participated in IEP meetings
- Provided didactic seminars on ABA and child development
- Assisted in development of staff training curriculum

**Behavior Consultant / Program Supervisor (Lovaas Institute)****Los Angeles, California****September 1998 – September 2004**

- Conducted functional behavior assessments and generated reports, including treatment plans
- Supervised behavioral treatment of children with autism and related disorders
- Provided parent consultation to address behavior management and generalization of acquired skills
- Generated IEP goals and participated in IEP meetings

**Staff Research Associate (UCLA Neuropsychiatric Institute)****Los Angeles, California****November 1999 – December 2001**

- Administered neuropsychological and language assessments
- Coordinated and collected data for an NINDS-funded longitudinal study on the effect of seizure disorders on communication skills and thought disorder

**Teaching Assistant (UCLA Psychology Department)****Los Angeles, California****September 1998 – September 2001**

- Instructed, led discussion sections; generated, proctored, and graded exams in a series of upper division psychology courses

**Research Assistant (Lanterman Developmental Center)****Pomona, California****January 1999 – September 1999**

- Conducted research on brainstem-evoked responses using EEG data
- Provided one-to-one assistance to adult males with mental retardation and mental illness
- Developed and implemented behavior interventions and learning programs

**PROFESSIONAL TRAINING****Clinical Psychology Intern (Los Angeles Child Guidance Center)****Los Angeles, California****September 2009 – June 2010****Neuropsychology Extern (Children's Hospital Los Angeles)****Los Angeles, California****July 2008 – August 2009****Psychology Trainee (The Help Group)****Van Nuys, California****August 2007 – June 2008****PUBLICATIONS**

O'Neil, S. H., Azoff, J., Buranahirun, C., ...Finlay, J. (2010). Neurocognitive outcomes in pediatric and adolescent patients with central nervous system germinoma treated with a strategy of chemotherapy followed by reduced-dose and volume irradiation. *Neuro-Oncology*, 12(4), iv58-iv61.

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