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UNIVERSITY OF LA VERNE
LA VERNE, CALIFORNIA

The Effects of Childhood Cancer on Siblings

A Paper Prepared for EDUC 596
In Partial Fulfillment of
The Requirements for the Degree
Master of Child Life

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December 2010
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Section I: The Problem

Purpose of the Project

A family’s world is turned upside down when a child is diagnosed with a serious illness, like cancer. Siblings are often forgotten and unsupported during the time of diagnosis and throughout the cancer trajectory. They experience a range of conflicting emotions during this critical time as a response to the changes within the family. When caregivers, health care professionals, and educators do not meet the needs of the sibling, we fail to provide care that is family-centered. From a Child Life perspective, there are limited resources that provide readily available information and interventions that support the needs of the sibling.

The purpose of this creative project is to provide an awareness and understanding of the siblings’ experience. This creative project is a concise, yet comprehensive resource handbook for Child Life Specialists, parents or adult caregivers, health care professionals, and educators. It serves as an educational tool that provides the psychosocial, cultural, and developmental effects of cancer on healthy siblings within the areas of the home, hospital, and school. Therapeutic interventions are also provided to assist in promoting positive coping in healthy siblings.
Section II: Literature Review

Abstract

Childhood cancer is a life-changing experience that disrupts families throughout the world. Medical advancements to treat cancer have significantly improved the prognosis for pediatric cancer patients. Although the outcomes of these treatments are still uncertain, the course of treatment can be strenuous for the family to adjust to a child who has increased medical and emotional needs. Research studies have examined the impact of pediatric cancer on the patient and parents, however studies have transitioned to document the psychosocial effects in healthy siblings of childhood cancer patients. It is beneficial for health care professionals, parents, teachers, and Child Life Specialists to understand the effects on siblings to effectively provide supportive care.
The Effects of Childhood Cancer on Siblings

In the United States, an estimated 12,400 children and adolescents will be diagnosed with cancer each year, and it is the leading cause of death by disease (Ries et al., 1999). As the incidence for childhood cancer increase, it simultaneously affects about 18,000 siblings, who are often referred to as the “forgotten ones” or “shadow survivors” (as cited in Rollins, 1990, p. 21; SuperSibs!, 2008). The cancer experience is an emotionally challenging journey, as families cope with the changes that result from living with a child who has cancer. Families encounter an array of challenges, such as invasive medical treatments, frequent hospitalizations, financial difficulties, and changes in family life.

For siblings, they experience psychosocial changes dealing with the uncertainty of the future, family and school disruption, decreased parental involvement, and increased parental expectations. Studies often describe siblings to be emotionally in need and distraught than any family member (Kramer, 1984). It is important for parents, health care professionals, teachers, and Child Life Specialists to recognize the effects of cancer on the siblings’ adjustment to provide support that will be a “positive influence,” not an “emotional scar” (SuperSibs!, 2008). The purpose of this literature review is to provide an overview of the psychosocial effects of childhood cancer on the siblings that can be experienced within the areas of the home, hospital, and school.

Psychosocial Outcomes of Siblings

Emotional Responses

Childhood cancer is an ongoing stressor, when combined with variables such as age, coping strategies, previous experience to an illness, decreased parental attention, separation from family members, and changes in family roles and responsibilities can influence a siblings’
adjustment (American Cancer Society [ACS], 2009; Rollins, 2005). Regardless of these factors, the impact on the healthy sibling of a child with cancer will be unique to their experience. Several research studies have reported siblings to exhibit feelings of fear, anxiety, worry, anger, jealousy, resentment, loneliness, guilt, sadness, neglect, confusion, embarrassment, and grief (American Society of Clinical Oncology [ASCO], 2010, Fleitas, 2000; Hamama et al., 2000; Havermans & Elser, 1994; Houtzager et al., 2004; Kramer, 1984; Martinson et al., 1990; Menke, 1987; Sloper, 2000; SuperSibs, 2008; Woodgate, 2006).

To support these findings, a case study by Kramer (1984), interviewed 11 siblings of leukemic children about their experiences with pediatric cancer. This study documented the negative and emotional responses to two main stressors, in addition, the study found positive responses by siblings. The stressors generated by the siblings responses included difficulties with “emotional realignment” and separation of the family. Siblings specifically reported decreased involvement with their parents and the sibling with cancer, which decreased parental support and increased expectations. These siblings reacted to these stressors with increased sibling rivalry, anger and frustration, rejection, sadness, confusion, anxiety, loneliness/isolation, and guilt.

A study by Woodgate supports findings from Kramer’s study (Woodgate, 2006). She conducted a longitudinal study of 30 siblings of a brother or sister with cancer in Western Canada from July 1998 to December 2000. She administered in-person interviews and observations to ask siblings to share their experiences and understanding of childhood cancer. This study found that siblings felt jealous when their basic necessities were not met due to the parent’s care for the ill child. Significantly, the study by Kramer (1984) found that parents expected siblings to tolerate their parent’s preoccupation with the sibling who is sick and take on
more responsibility, even if they did not agree. In Woodgates’ study, all of the siblings interviewed expressed sadness, in regards to the changes in their family life. This study found that parents and the sibling with cancer knew the healthy siblings were sad, but reported feelings of fear, guilt, jealousy, and loneliness instead. Furthermore, siblings shielded their emotions and needs from their parents, as they believed their experience was not comparable to the experience of their sibling who is sick.

Slopers’ longitudinal study of 94 siblings from five pediatric oncology centers supports Woodgate’s and Kramer’s findings that siblings hid their negative feelings from everyone (Sloper, 2000). Sloper interviewed siblings 6 and 18 months after the diagnosis to explore the siblings’ reaction to the diagnosis. She found siblings to feel resentment, sadness, and anger in regards to the disruption in their normal family routines at 6 months after diagnosis. Siblings in response to the diagnosis reported shock, fear and disbelief. The study also found that at 18 months after the diagnosis, siblings’ worries and fears decreased.

A study by Hamama, Ronen, & Feigin (2000) used a descriptive study of 62 siblings aged 9 to 18 in central Israel. Self-report questionnaires were used to gather information about anxiety and loneliness in siblings. Anxiety was found to be apparent during earlier periods of diagnosis. As children begin to cope with their brother or sister’s illness, anxiety levels began to decrease. The study found older siblings to be less anxious than younger siblings due to their understanding of the illness. However, siblings who were younger and were female expressed feelings of loneliness. In order to help siblings adjust to the diagnosis of cancer, parents who spend quality time with their healthy child had seen a decrease in feelings of loneliness (Woodgate, 2006).
Despite the negative responses by siblings, these studies also found positive responses from siblings. Kramer (1984) found feelings of empathy, love, and a sense of protection from siblings towards the ill child and parents. Sloper (2000) found compassion, increased confidence as siblings matured in relation to their increased responsibilities at home and had a greater understanding about the illness.

**Behavioral and Somatic Response**

Carpenter and Levant (1994) found behavior changes of siblings at home and at school. They found a decrease in academic achievement and negative behaviors at school and isolation from peers and family (Carpenter & Levant, 1994). Siblings can show behaviors of “aggression, temper or withdrawal from family or friends, rudeness, bullying and demanding attention” (Cook, 1999). Siblings tend to regress to previous developmental behaviors such as “thumb-sucking, bed-wetting, clinging, eating problems or school refusal” (ASCO, 2009; Cook, 1999). A sense of security that is not provided can lead to separation anxiety and an increase need for parental presence (ASCO, 2009).

Siblings can have somatic symptoms such as headaches, tiredness, nausea, vomiting, diarrhea, constipation, aching limbs stomachaches, bed-wetting, trouble sleeping and change in eating habits (Carpenter & Levant, 1994; Cook, 1999). Siblings may also exhibit sympathy pains that resemble their ill sibling’s condition (Cook, 1999). Zeltzers’ study demonstrated an increase in “somatic” responses and “risk-taking” behaviors (as cited in Terzo, 1999, p. 309). These responses in children depend on the sibling’s adjustment to the illness and family lifestyle during the experience. Heffernan and Zanellis’ study also report changes in behavior and somatic responses. However, they noted positive behavior such as “increased sensitivity to the needs of others and being more thoughtful” (as cited in Terzo, 1999, p. 309).
Family Dynamics

Hospitalization takes a toll on family relationships and affects the sibling’s adjustment to the experience. Woodgate’s study found siblings to be neglected, as the family members did not interact with one another (Woodgate, 2006). Their needs were not met, and feelings of insecurity were present during their experience. Healthy siblings would help the family by taking on extra responsibilities. Siblings felt a need to consider their parents and ill siblings’ response by not adding their own stressors onto the family. Siblings consider the experience with cancer to be an experience reserved for their ill sibling and parents, in which the well sibling is not part of the experience.

Siblings need an opportunity to feel included in the family role of helping the sick sibling. Breyer, Kunin, Kalish, and Patenaude (1993) conducted a Descriptive Study of 73 siblings and 51 parents in the Dana-Farber Cancer Institute in Boston. They administered a questionnaire for parents and siblings that asked about the “impact of having a child with cancer in the family” (Breyer et al., 1993 p. 203). They found that siblings were worried about their sibling with illness. The study found continued sibling relationships between the sick and healthy child are important to maintain, even when the dynamics have changed. Incorporating the healthy child in the experience can help the well sibling cope with the illness and develop an understanding about illness.

Sibling Relationships

Labay and Walco (2004) conducted a descriptive study of 29 culturally diverse groups of siblings and 14 children diagnosed with 3 types of cancer. They used self and parent report questionnaires. They found that the relationship between an older sibling and the patient had less conflict and a better relationship was seen. However, when the sibling who is ill is younger than
the healthy sibling there is an increase in “behavioral, social, and academic problems” (Labay & Walco, 2004, p. 312). Older siblings tend to have more responsibilities placed on them during this time. Houtzager et al’s (2004), results support Labay and Walcos’ findings. Houtzager et al., (2004) conducted a Longitudinal Study of 83 siblings from Emma Children’s Hospital in the Academic Medical Center in Amsterdam and from the University Hospital in Groningen, Netherlands. The siblings were studied in four intervals: 1 month after diagnosis, 6 months, 12 months, and 24 months. The participants were assessed in their homes, interviews were conducted and questionnaires were used. The study found that anxiety levels were high one month after diagnosis and then decreased at 6 months. This is due to the resilience in children and their coping abilities.

Conclusion

Siblings are a group of individuals that are often forgotten during a family experience of a sibling with cancer. The focus is generally on the parents and the child with cancer. However, research has shown the need to focus on the healthy siblings in order to provide assistance in coping within a family centered care. Siblings are affected emotionally and behaviorally. The family dynamics during the experience is important in that it effects the healthy siblings adjustment to the situation. Overall, the effects of cancer on siblings have been documented in recent studies.
Section III: Procedure

I remember watching, “A Lion in the House” in class and I was inspired by one of the sibling’s cancer experience. The film helped me to see the need in supporting the siblings through the cancer journey. From my internships and practicum, I realized that siblings were not provided any support. The interventions were all geared toward the ill child and family. With this in mind, I wanted to create a handbook that would provide information about the effects of cancer and provide interventions for child life specialists. In talking with my Child Life advisor, I decided to create a handbook for child life specialists and provide information on how siblings are affected by the cancer within the areas of the home, school, and hospital. As I began gathering research, I decided I would create the handbook for child life specialists, educators and caregivers. After completing this project, I will implement it in my future career as a Child Life Specialist. It is a quick and easy tool to provide to others to use for supporting siblings.
Section IV: Evaluation

My creative project was evaluated by Dr. Leslie Anne Young, Program Chair of the Masters Child Life Program at the University of La Verne, and Gina Day Padre Vaughan, MS, CCLS, CIMI, a Certified Child Life Specialist at Citrus Valley Medical Center, Queen of the Valley Campus. Both evaluators expressed the project’s importance in assisting Child Life Specialists, parents, educators, and the medical team to understand the effects of cancer on siblings within the home, school, and hospital.

I met with Dr. Young to discuss my evaluation in person, she thought my project was a “practical guide” that provided information and tools to the targeted audience. She thought the statistics in the preface was “powerful” and prepared the reader on the topics of my project. Dr. Young appreciated the use of colorful pictures that were culturally sensitive and encourage the use of generational pictures as well. She expressed the use of Piaget and Erikson, as good developmental information that will help the readers to look past the sibling’s behavior and understand what is happening in a developmental aspect.

Dr. Young made a few constructive criticisms to improve my project. First, she recommended including development, communication, and culture in the preface. She would like to see information on how “culture, gender, generational, and diversity of thought” influences the family adjusting to life with cancer. She advised that “caregivers” be changed to “parents/adult caregiver/grandparents,” to signify an adult in the sibling’s lives. She suggested providing a brief introduction for each chapter that tells the reader what the chapter will be about. Dr. Young thought a conclusion chapter would be valuable to summarize, provide encouragement, and specify to the readers to look at families individually. She also informed me to cite my sources when providing facts. Dr. Young pointed out that the title “gives the reader a
clear vision of what will be addressed,” but questioned if siblings are “siblings of childhood cancer” or “siblings of brothers and sisters with cancer.” She wanted the title to focus on the sibling, not on the diagnosis and recommended to change the title.

Gina also praised my project to be a beneficial resource to help children, siblings, and families coping with a child diagnosed with cancer. She enjoyed the pictures and quotes of siblings and families to be “inspirational.” Gina appreciated the use of lists and charts that were easy to find information, concise, and comprehensive to understand.

A few suggestions Gina made were to include page numbers on the table of contents, using “laymen’s terms,” being aware of word connotation (for example: “wrong” or “strange”), and changing “ill-sibling” to “a sibling who is sick or diagnosed with cancer.” Gina mentioned citing resources and incorporating an information paragraph before the chapters that coincided with Dr. Young’s suggestions. She also suggested using chart forms to be consistent in the layout and to provide examples to illustrate within the charts. She advised adding two tips for parents (for example, “take care of yourself” and “parent support groups”) and for educators to add in “contact hospital teacher/child life specialist,” for school re-integration. She would like to see the empowerment strategies on a new page with examples. Gina also suggested creating an interactive workbook for the siblings, which I decided not to include, as I was gearing this book more for the adults.
References


http://www.onconurse.com/factsheets/siblings_cc.html


