



Keep Calm and Cope On: How Families Cope with Childhood Cancer

Christine Czapek and Dr. Lisa Moyer

Eastern Illinois University

School of Family and Consumer Sciences

INTRODUCTION & LITERATURE REVIEW

Over time, medical research and treatment improvements have made it possible for children to survive cancer. However, even though more children survive cancer, the long-term risks to children's health and well-being are compromised due to the potential side effects of treatment, reoccurrence of cancer, and the effect a cancer experience can have on the entire family. Systems theory proposes that families are so intensely connected that every member is affected by one another's emotions, needs, distress, and expectations (Bowen, n.d.; McKenry & Price, 2000). Thus, a diagnosis of childhood cancer has deleterious effects on the child and the other members of the family. The entire system experiences disturbances of daily life, changes in family roles, anxiety, depression, worries about cancer recurrence, and the fear of the loss and death of their loved one (Hagedoorn, Kreicbegs, & Appel, 2011).

In support of the systems theory, a meta-analysis conducted by Silva, Jacob, and Nascimento (2010) regarding the effects of childhood cancer on parental relationships revealed four commonalities among the studies that had been published to date. The four themes that emerged from Silva et al.'s study included: (a) changes in the parent's relationship during the trajectory of the child's illness; (b) difficulty in communication between couples; (c) gender differences in parent stress and coping; and (d) role changes.

Alderfer, Long, Lown, Marsland, Ostrowski, Hock, and Ewing (2010) conducted a meta-analysis on the research that looked at the effects of a cancer diagnosis on the siblings of the patient. The results showed that siblings of children with cancer showed a significant amount of post-traumatic stress symptoms, as well as negative emotional reactions such as shock, fear, worry, sadness, helplessness, anger and guilt. Research also shows that the siblings of a child diagnosed with cancer may experience similar stress to that of the child with the diagnosis. However, families, friends, and even professionals tend to focus all of their time and attention on the child with the illness and may overlook the siblings. Because of this, "siblings have been identified as the most neglected of all family members during serious childhood illness" (Ross-Alaolmolki, Heinzer, Howard, & Marszal, p. 67). Clearly, long term consequences such as, recurrence or second cancers, early death, stunted development, or compromised cognitive functioning affects the entire family system's quality of life.

Very little research has looked exclusively at how the family system adapts and changes after a childhood cancer diagnosis over time. Most of the research in existence looks at coping at the time of diagnosis, six months following diagnosis, and/or one year after diagnosis and even fewer have examined how the family system is affected. Thus, there is a significant gap in the literature regarding family system coping and changes over time following a childhood cancer diagnosis.

STATEMENT OF THE PROBLEM

When a child is diagnosed with cancer, there are consequences for the entire family. Family roles, interactions, emotional responses, and overall well-being is affected. The effects of the diagnosis continue long after the child has gone into remission, or has succumbed to the disease; however, the bulk of the research on family coping has only looked at how the child and family have coped up to a year after the cancer diagnosis. Systems theory indicates that families are profoundly connected and affected by one another. Thus, it is anticipated that the effects of childhood cancer last long after the diagnosis.

This research has implications for families, Child Life Specialists, therapists, teachers, doctors, hospital staff, hospital administrators, and policymakers.

FUTURE DIRECTIONS

While research on this topic has clearly indicated that families are affected by a childhood cancer diagnosis, more research needs to be conducted to look at the long-term effects of cancer on the entire family system. More specifically, the following research questions need to be addressed:

1. How do parental roles and interactions change over time after a child in the family has been diagnosed with cancer?
2. How are the siblings of the child that is diagnosed with cancer affected by the situation over time?
3. Do mothers' and fathers' coping strategies differ from one another over time?

CHILDHOOD CANCER