

The Acceptability, Feasibility, and Preliminary Effects
of a Coping Intervention Program for

Mothers of Children Newly Diagnosed with Cancer

by

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ABSTRACT

There are approximately 12, 000 children diagnosed with cancer every year in the United States. The diagnosis of childhood cancer impacts the entire family. Mothers of children newly diagnosed with cancer often exhibit symptoms of stress, depression, and anxiety. Also, children diagnosed with cancer often exhibit behavioral changes during and after the treatment for childhood cancer. A synthesis of the current literature from a comprehensive search demonstrates an urgent need for larger theory-based randomized controlled trials (RCTs) with attention control groups for parents of newly diagnosed children with cancer in order to improve both their own and their children's coping/mental health outcomes. The purpose of this pilot study was to determine the impact of a theory-based manualized intervention to improve the mental health/coping outcomes of mothers of children newly diagnosed with cancer and their children. The primary aim of this pilot study was to assess the feasibility (timing, format, and length), acceptability (content and general acceptability) and preliminary effects of a three-phase manualized educational/skills building intervention with mothers of children newly diagnosed with cancer (i.e., COPE-PCC). Outcome measures included maternal depression and anxiety, and internalizing and externalizing behaviors in the child with cancer. Maternal beliefs about their ability to parent a child with cancer was a proposed mediator for this study. The total sample for this pilot study included 15 mothers of children aged 2 to 8 years old diagnosed with cancer. Mothers reported significant decreases in depression and anxiety and an increase in their beliefs about their ability to parent their child with cancer after completion of the intervention. In addition, mothers reported a decrease in negative behavioral symptoms in their children (i.e., externalizing

and internalizing behaviors) after completion of the intervention. These findings support a need to provide mothers psychosocial support soon after their children's cancer diagnosis as well as refine the intervention and test both its short- and long-term effects in a full-scale RCT with mothers of children newly diagnosed with cancer.

DEDICATION

This dissertation is dedicated to my mother who has supported me in every endeavor.

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CHAPTER 1. INTRODUCTION

There are approximately 13,500 children diagnosed with cancer every year in the United States (Centers for Disease Control and Prevention, 2014). Although survival rates for childhood cancer have increased substantially since the 1970s, approximately 2,200 children die from cancer each year, making the threat of death very real for children and their families (American Cancer Society, 2012). The diagnosis and treatment of childhood cancer present numerous challenges and sources of stress for children and their parents (Dunn et al., 2012; Fedele, Mullins, Wolfe-Christensen & Carpentier, 2011; Felicity et al., 2012). Not only are these families faced with the fear and stress of a life-threatening illness, but the treatment itself can be extremely stressful. Treatment of childhood cancer involves painful medical procedures, unpredictable hospital stays, frequent medical visits, difficult side effects of medication, financial burden, and significant changes to daily living; i.e., parent missing work, child missing school, distribution of daily activities (Jurbergs, Long, Ticona, & Phipps, 2009; Kurtz & Abrams, 2011). In addition, parents also report feeling that they need to be a primary source of emotional support for their child and often report feeling unsure in their role of parenting a child with cancer (Dunn et al., 2012; Kurtz & Abrams, 2011).

The diagnosis of cancer is a traumatic experience for both the family and the child. The psychological sequelae of childhood cancer in parents and children has been well documented and includes posttraumatic stress symptoms, depressive symptoms, and anxiety (Dunn et al., 2012; Fedele et al., 2011; Felicity et al., 2012). Childhood cancer involves the whole family: the diagnosed child, the parents, and the siblings.

The diagnosis of cancer causes a great deal of disruption in the family that can be manifested as parental role confusion as well as parental distress about the child's future. In addition, parents of children newly diagnosed with cancer must cope with their own reaction to their child's diagnosis as well as their child's reaction (Norberg & Boman, 2013). Parents may have feelings of anger, guilt, fear, and grief. The parents' ability to cope with these emotions impacts their mental health outcomes which can result in depression, anxiety, and posttraumatic stress (Bayat, Erdem, & Kuzucu, 2008; Dunn et al., 2012; Jurbergs et al., 2009; Long & Marsland, 2011; Norberg & Boman, 2013).

Historically, the majority of research in childhood cancers has been focused on improving physical health outcomes. However, as adulthood is now attainable for most children treated with childhood cancers there is an emerging need for improving mental and emotional health outcomes in the child and family (Marsland et al., 2013; Mullins et al., 2012). Several studies have shown that although the child survives, there is considerable morbidity, distress, and disruption in the family life that persists indefinitely after the child's completion of the cancer treatment (Felicity et al., 2012; Norberg & Boman, 2013). Unfortunately, there are currently no standards of care to facilitate coping outcomes in the parent and the child during and after the cancer diagnosis and its associated treatment.

Previous research with a variety of populations has shown that parents' own emotional distress can result in changes in their parenting behavior (Melnyk et al., 2004). Other studies have demonstrated that parents' symptoms of anxiety and depression are often correlated with more negative parenting styles by both mothers and fathers (Geest et al., 2014; Kazak et al., 2012; Warner et al., 2011).

Findings from research have indicated that parental stress negatively impacts the child's social, emotional, and behavioral adjustment to the diagnosis and treatment of cancer as well as the parent's participation and compliance with their child's complex healthcare needs (Bayat et al., 2008; Geest et al., 2014; Kazak et al., 2012; Melnyk et al., 2004; Warner et al., 2011). Therefore, using psychological interventions to decrease parental stress, depressive symptoms, and anxiety is important to enhance coping outcomes in children newly diagnosed with cancer and their parents.

A large body of research has indicated the presence of parental (particularly maternal) distress around the time a child is diagnosed with cancer, including increased depression, anxiety, and stress (Klassen et al., 2011; Long & Marsland, 2011; Rodriguez et al., 2012; Stehl et al., 2009). Several studies indicate that depression, anxiety, and stress are at their highest at the time of the cancer diagnosis and during the first few months of treatment and can subsequently diminish over the first year after the cancer diagnosis (Dunn et al., 2012; Geest et al., 2014; Rodriguez et al., 2012). Additional studies indicate that many parents and children experience persistent and/or escalated emotional distress and report higher levels of distress during and after completion of treatment which can last for 1 to 2 years based on the child's cancer (Dunn et al., 2012; Fedele et al., 2011; Jurbergs et al., 2009; Kazak et al., 2012; Long & Marsland, 2011).

In addition, behavioral and emotional problems have been reported among children diagnosed with cancer (Engelen et al., 2011; Lund, Schmiegelow, Rechnitzer, & Johansen, 2011; Wechsler & Sánchez-Iglesias, 2013). Several studies found that long-term survivors of childhood cancer experience a greater number of problems with social competence and more symptoms of depression compared to healthy children and siblings

(Wolfe-Christensen, Mullins, Stinnett, Carpentier, & Fedele, 2009; Engelen et al., 2011; Fedele et al., 2011; Wolfe-Christensen et al., 2010). In addition, Small and Melynk (2006) found young children (age 1 to 7 years) as being at risk for post-hospital behavioral sequelae, especially when confronted with an acute illness and an unplanned or unanticipated hospitalization.

Although the emotional distress for the parent and child after the child's cancer diagnosis has been well documented, unfortunately to date there have been very few interventions directed at improving coping in the parent and child after the cancer diagnosis (Pai, Drotar, Zebracki, Moore, & Youngstom, 2006; Peek & Melynk, 2010; Stehl et al., 2009). There is an imperative need for theory-based research to address the unique coping needs of the parent and child.

The purpose of this pilot study, which used a one group pre- and post-test pre-experimental design, was to test the feasibility, acceptability, and preliminary effects of a theory-based manualized intervention to improve the mental health/coping outcomes of mothers of children diagnosed with cancer and their children. The intervention was an adapted version from the Creating Opportunities for Parent Empowerment (COPE) program, a manualized evidence-based intervention program for parents of hospitalized and critically ill children, which is based on self-regulation theory and control theory. Through a series of randomized controlled trials (RCTs), COPE has been shown to reduce short- and long-term stress, anxiety, depression, and posttraumatic stress disorder symptoms in parents of as well as decrease internalizing and externalizing behavior problems in the children.

Background and Significance

Impact of the cancer diagnosis on the mother. The diagnosis of cancer has a strong impact on the coping skills of parents, particularly the mother (Fedele et al., 2011; Hoekstra-Weebers, Wijnberg-Williams, Jaspers, Kamps, & Wiel, 2012; Siham, 2013). Parents of children newly diagnosed with cancer first hear the diagnosis of cancer and then must cope with the impact of the diagnosis including the ongoing demands of treatment such as frequent hospitalizations, side effects of treatment, and the child's emotional and physical response. Parents of children newly diagnosed with cancer are often afraid of what the diagnosis means while being suddenly confronted with making complex medical decisions based on their child's diagnosis which can increase parental stress and anxiety (Bayat et al., 2008; Long & Marsland, 2011; Norberg & Boman, 2013). They report much higher levels of depression, anxiety, and stress, and decreased personal well-being than parents of healthy children (Dunn et al., 2012; Kazak et al., 2005). Parents of children with cancer also must suddenly adjust to the fear about their child's diagnosis, the caregiving demands, and uncertainty about their role in their child's care and their child's future (Flury, Calfisch, Ullmann-Bremi, & Spichiger, 2011). Often, the parent is the first to hear the diagnosis and then is asked to tell the child about the diagnosis and answer the child's questions about the diagnosis and the treatment (Long & Marsland, 2011). Parents are unexpectedly parenting an acutely ill child in a situation for which they have no or very little knowledge as well as facing their own fears (Dunn et al, 2012; Hildenbrand, Clawson, Alderfer, & Marsac, 2011). In addition, Mack and colleagues (2011) reported that parents of children with cancer often have to miss work to care for their child which decreases their financial resources and leads to feelings of

increased stress and a sense of life disruption. These adverse feelings that present during diagnosis may continue during the child's treatment and may persist for years after completion of the child's treatment (Kazak, 2005; McCarthy, Ashley, Lee, & Anderson, 2012; Stoppelbein, Greening, & Wells, 2013).

There is much evidence to suggest that having a child diagnosed with cancer places a parent at an increased risk to develop depressive symptomatology and other negative emotional states (Dunn et al., 2012; McCarthy et al., 2012; Wolfe-Christensen et al., 2010). Several factors associated with poorer psychological adjustment and appropriate interventions to better support the parents and families of children diagnosed with cancer have been explored. Parents' trait anxiety has been found to be the strongest predictor of posttraumatic stress symptoms (Davis, Para, & Phipps, 2010; Elkin et al., 2007; McCarthy et al., 2012).

Several studies have documented evidence of heightened maternal distress after the child's cancer diagnosis, particularly in the mental health outcome measures of depression and anxiety (Cernvall, Alaie, & von Essen, 2012; Jurbergs et al., 2009; McCarthy et al., 2012; Norberg, Poder, & von Essen, 2011). Dunn and colleagues (2012) found that mothers of children with cancer reported much higher levels of acute and long-term depression and anxiety symptoms. Patino-Fernandez et al. (2008) reported that more than 50% of mothers of children newly diagnosed with cancer meet the DSM-IV criteria for acute stress disorder in that the individual experiences a traumatic event which can result in posttraumatic stress disorder. Several studies have reported that mothers of children newly diagnosed with cancer continue to report symptoms of moderate to severe stress for at least 2 months after their child's cancer diagnosis, which leads to increased

risk of posttraumatic stress disorder (Cernvall et al., 2012; Poder, Ljungman, & von Essen, 2008; Stehl et al., 2009; Warner et al, 2011;).

Rodriguez et al. (2012) reported that mothers experience higher levels of stress after their child's cancer diagnosis, particularly stress involving caretaking responsibilities and how to best parent their ill child. Several studies have shown that mothers of children diagnosed with cancer report feelings of insecurity in how to care for their child and how to best prepare their child for their cancer treatment (Dunn et al., 2012; Mack et al., 2011).

Impact of the cancer diagnosis on the child. Numerous studies have demonstrated that children diagnosed with cancer often have long-term quality of life issues as well as feelings of stress that continue after the conclusion of treatment. Children, like their parents, may experience feelings of fear, anger, guilt, and grief that can be manifested in behavioral problems and long-term adjustment issues including ability to maintain relationships and ability to maintain employment (Engelen et al., 2011; Lund et al., 2011). The child's adjustment to their diagnosis and treatment is strongly correlated to the parent's adjustment to the diagnosis and treatment (Currier, Jobe-Shields, & Phipps, 2009; Davis et al., 2010; Dunn et al., 2012).

Child behaviors. Although the psychological sequelae of childhood cancer in parents and children has been well documented in the literature, very few studies have been conducted to test interventions designed to facilitate parental and child coping and enhance mental health outcomes (Dunn et al., 2012; Pai et al., 2006). Small and Melnyk (2006) reported that young children (age 1 to 7 years) often have issues expressing their feelings in words and will often experience their feelings including distress and fear as

internalizing (i.e., anxiety, depression, and somatization) and externalizing behaviors (i.e., hyperactivity and aggression). There is a relationship between early extreme levels of externalizing behaviors and later-life adjustment difficulties (i.e., maintaining long-term relationships) (Small & Melnyk, 2006; Wolfe-Christensen et al., 2009, 2010). In addition, higher levels of the children's internalizing behaviors at acute illness consistently resulted in long-term expression of anxiety, depression, and somatization (Engelen et al., 2011; Small & Melnyk, 2006) Thus there is an urgent need for intervention studies to be conducted that target improvement in parent and child outcomes in this high-risk population. Interventions focusing on educating parents about what personal emotional changes to expect, changes they might anticipate with regard to their child's behaviors, and potential changes in family dynamics can enhance parental and child coping outcomes (Goldwin, Lee, Afzal, Drossos, & Karnik, 2014, Kazak et al., 2005; Pai et al., 2006; Rodriguez et al., 2012).

Purpose of the Proposed Study and Research Questions

In order to address the substantial gap in the science of intervention research designed to enhance coping outcomes for parents of children newly diagnosed with cancer, the primary purpose of this pilot study is to assess the feasibility (timing, format, and length) and acceptability (content and general acceptability) of a three-phase manualized educational/skills-building intervention with parents of children newly diagnosed with cancer. The secondary aims are to (a) evaluate the preliminary effects of the intervention program, and (b) determine the relationships among the study's variables.

Primary aim.

Research question 1. Is a theory-based coping intervention program (i.e., COPE-PCC) which emphasizes education and skills-building feasible and acceptable for parents of children newly diagnosed with cancer?

Secondary aims.

Research question 2. What are the preliminary effects of a theory-based coping intervention program (i.e., COPE-PCC) on (a) maternal depression, maternal anxiety, and maternal beliefs regarding parenting a child with cancer; and (b) children's externalizing and internalizing behaviors?

Research question 3. What are the relationships among the coping variables prior to and immediately following the intervention program inclusive of maternal depression, maternal anxiety, maternal beliefs regarding parenting a child with cancer, and children's externalizing and internalizing behavior?

Theoretical Framework

Importance of theory to guide intervention research. Theory-based research is important in guiding nursing practice as it should explain the relationships between the variables and enhance nursing knowledge and understanding of the process by which interventions are effective (Fawcett, 2005; Johnson, 1999; Reed & Shearer, 2009). Theory should act to guide nursing research by (a) aiding in identifying the problem of interest; (b) guiding the development, design, and implementation of the intervention; (c) guiding the analysis of the study; (d) explaining the findings and identifying specific links between the activities of the intervention and the outcomes; and (e) providing a

framework that outlines evaluation of the effect of the intervention (Sidani & Braden, 1998, 2011).

The selection of the theory can be derived from the problem and population of interest (Sidani & Braden, 1998, 2011). The theoretical framework for this intervention was based on self-regulation theory (Johnson, 1999; Johnson & Leventhal, 1983) and control theory (Carver, 1979; Carver & Scheier, 1982). Both theories are based on response and adaptation to a stressful healthcare event and together may guide intervention research regarding a parent's response to their child's new cancer diagnosis. For parents of children with cancer, the stressful healthcare event is the child's cancer diagnosis. After the parent is told their child has cancer, they must then emotionally respond to their perceptions and feelings about their child's diagnosis. Parents of children with cancer usually have little or no preparation for their response to their child's cancer diagnosis (Kazak et al., 2012).

Using self-regulation and control theory as the theoretical framework for the intervention provides a mechanism to design the intervention and a means of explaining the process through which the intervention works to positively impact the desired outcomes of increased maternal beliefs about their ability to parent their child after the cancer diagnosis and decreased maternal depression and anxiety.

This study is built on the research supported COPE intervention for parents of critically ill and hospitalized children, which is based on self-regulation and control theories. The COPE program does not require a mental health provider to deliver it and has two decades of research to support its efficacy in reducing short- and long-term

stress, anxiety, and posttraumatic stress disorder symptoms in parents of critically ill and hospitalized children (Melnyk et al., 2004).

Findings from five RCTs using COPE indicated that parents who received COPE versus those who received attention control programs reported significantly less parental stress, depression, anxiety, and fewer posttraumatic stress symptoms during as well as up to 12 months following hospitalization. Additionally, children of parents who received the COPE program had fewer internalizing and externalizing behavior problems 12 months following hospitalization than children of parents who received an attention control program. Therefore, it is plausible that COPE adapted for parents of newly diagnosed cancer children also could produce similar positive outcomes (Melnyk et al, 2004, Melynk, Feinstein, & Fairbanks, 2006). Because of the positive findings from these studies, COPE was adapted specifically for parents of children with cancer and termed COPE-PCC.

Self-regulation theory. Self-regulation theory proposed by Johnson and Leventhal (1983) was derived from Dr. Johnson's work regarding preparing patients for invasive healthcare procedures and surgery. Self-regulation theory (Johnson & Leventhal, 1983) was developed in a cyclic process during which propositions supported by data were retained, propositions not supported by data were altered, and new propositions were added when research produced unexpected findings. This cyclic process allowed for refinement of the theory (Johnson, 1999; Johnson & Leventhal, 1983). Also, self-regulation theory is a mid-range theory, based on its limited scope, limited variables, and its ability to be tested and applied to practice (Walker & Avant, 2005). Self-regulation

theory is a theory that explains the relationship between the concepts of healthcare experiences, coping, and health outcomes.

In self-regulation theory, the stressor being experienced results in the development of a schema or perception of what changes will occur as a result of the stressful event (Johnson, 1999; Johnson & Leventhal, 1983). This cognitive schema allows the individual to develop a coping strategy that prepares the individual to deal with the actual experience. Self-regulation theory also contends that providing individuals with concrete information about what they will see, hear, and feel during an upcoming stressful procedure or event will assist them in forming a cognitive schema that will help them to match what is occurring with what was expected. As a result of knowing what to expect, individuals can develop coping strategies to deal with it. Melnyk (1994) extended self-regulation theory to parents of hospitalized/critically ill children by preparing parents for their children's behavioral and emotional responses early in an unanticipated hospitalization, which enhanced their cognitive beliefs about types of behaviors to expect in their children to demonstrate and how best to help them to cope with the stressful experience. As a result, parent and child coping outcomes improved (Melnyk, 1994; Melnyk, Alpert-Gillis, Hensel, Cable-Billing, & Rubenstein, 1997; Melnyk et al., 2004;). Using this ungirding theory, the intervention in this study is designed to assist mothers in developing a cognitive schema regarding what child behaviors to expect in response to the new cancer diagnosis and strengthen their beliefs about their parenting role. It was believed that once the parents develop a cognitive schema roughly delineating the potential responses that they and their child might demonstrate following a new cancer diagnosis, and through the behavior-skills portion of

the intervention information, the parents would be able to develop strategies to cope with anticipated emotional and behavioral responses. As a result, it is anticipated that the parents of children newly diagnosed with cancer who received this information will demonstrate enhanced coping skills and report fewer depressive and anxiety symptoms.

Psychosocial interventions driven by self-regulation theory often include preparatory or anticipatory information (Melynck et al., 2004). In this case, the information may include typical changes to be expected in the diagnosed children's emotions and behaviors. Utilizing self-regulation theory which supports the use of concrete information to prepare for an event before it occurs, this intervention will include medical play in which the mother and child will engage in role playing for an upcoming event (i.e., medical procedure) to promote positive rehearsal which should result in preparation for the emotional and behavioral responses of the child to the actual event. This information was developed based upon the research literature that has outlined the responses children by who have experienced a cancer diagnosis (Harper et al., 2013; Melnyk et al., 2004; Norberg et al., 2011). According to self-regulation theory, concrete and objective anticipatory information offered to parents of the affected children will strengthen the parents' awareness, understanding, and interpretation of the child responses and provide them with concrete suggestions of parenting behaviors that they could provide to facilitate their child's coping.

The ultimate goal of using self-regulation theory as the theoretical framework for this intervention is to assist the mothers in forming a cognitive schema/stronger beliefs about the typical emotions and behaviors to expect in themselves and their children, which should result in improved maternal coping outcomes (e.g., fewer anxiety and

depressive symptoms). Since emotion is contagious according to the emotional contagion hypothesis (VanderVeer, 1949), the children of mothers who receive the coping intervention are expected to have fewer externalizing and internalizing behaviors.

Control theory. Like self-regulation theory, control theory is a mid-range theory, based on its ability to be tested in research and the ability to directly apply the concepts to practice (Walker & Avant, 2005). Control theory contends that discrepancy between a current state (e.g., parenting a child newly diagnosed with cancer) and a pre-existing standard or goal state (parenting a healthy child) should motivate behaviors to help an individual to once again reach their standard or goal (Carver, 1979; Carver & Scheier, 1982). However, in stressful or unfamiliar situations, there are often barriers that block one's ability to engage in behaviors to reach the standard or goal such as uncertainty, stress, and lack of knowledge. Anxiety, environmental constraints, or a novel situation may inhibit action. After the diagnosis of their children's cancer, mothers can have difficulty assuming their usual parental role and may experience a discrepancy between their typical parenting standard and their actual role. Normally, the discrepancy should motivate the mother to implement behaviors that would decrease the incongruity. However, due to heightened anxiety, uncertainty regarding their ability to parent a child with cancer, and decreased confidence or perceived lack of skills in how to parent a child newly diagnosed with cancer, mothers may find it difficult to initiate behaviors to reduce this discrepancy. Anxiety or a novel situation also may inhibit action because the individual may not be able to identify and focus on the aspects of the experience toward which to direct action. As a result, an intervention that provides education, information, and behavior-skill development of parenting behaviors specific to this novel situation, in

combination with information that reduces ambiguity about their children's behaviors and emotions after the cancer diagnosis, is expected to help the mother engage in activities that helps them to best parent their child with cancer. By providing information to the mother and activities that they can engage in with their child with cancer, it is thought that the mother will be able to return to their standard or goal parenting state. Therefore, it is anticipated that mothers who receive this intervention will be highly involved in their children's care as they usually would be better able to help their children adapt to the cancer diagnosis and its many related treatments, and view this diagnosis as less of a barrier to their ability to enact their usual parenting role.

Similar to the positive outcomes from previous studies with COPE, it is anticipated that this COPE-PCC intervention will increase maternal beliefs which will result in improved maternal coping outcomes (depression and anxiety) and improved children behavioral outcomes (Melynk et al., 1997, 2004, 2006).

Operationalization of the Theoretical Framework

Building on the positive outcomes from previous versions of COPE and by utilizing self-regulation and control theories as the theoretical basis for an intervention, an intervention that helps mothers to anticipate their and their child's emotional and behavioral adjustment to the cancer diagnosis and how to facilitate their children to adapt to the stressful experience should strengthen the mother's belief in their parenting role, which should result in improved maternal coping outcomes that include decreased depression and anxiety and enhanced child behavioral outcomes (see Figure 1 for hypothesized effects of COPE-PCC on maternal coping and child behavioral outcomes).

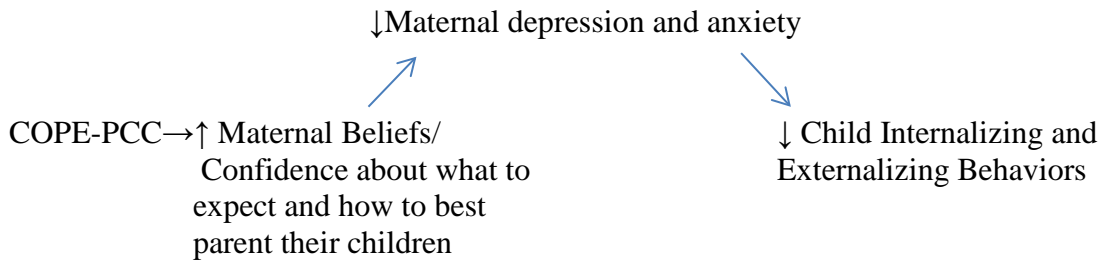


Figure 1. Hypothesized effects of COPE-PCC on the outcomes of maternal coping and child behaviors.

Based on the theoretical framework, it is expected that teaching mothers about what to expect in their own and their children’s emotions and behaviors after the cancer diagnosis as well as how they can help their children to cope with their illness is expected to result in the mothers having stronger beliefs/confidence about what to expect and how to best parent their child during this traumatic experience. This increase in beliefs/confidence in parenting abilities should result in a decrease in maternal depression and anxiety. In addition, since mothers are expected to have less anxiety and be better able to understand and meet their children’s needs, their children should have improved externalizing and internalizing behaviors after the intervention.

Mediating Variables

One important consideration in designing an intervention to facilitate coping in mothers of children with cancer is to determine what variable or variables may mediate the effects of the intervention on the study’s outcomes. Mediating variables provide the explanations of mechanisms through which the interventions work (Melnik & Fineout-Overholt, 2005). In a previous study with parents of children with cancer, parental beliefs

about their ability to parent a child with cancer were identified as a critical mediator of parental coping with the cancer diagnosis (Kazak et al., 2005).

Melnyk (1994) first developed a scale to tap parental beliefs/confidence about parenting a hospitalized child so that she could explore beliefs as a mediator of the effects of her COPE intervention on parental coping outcomes. In the 1994 and subsequent studies, Melnyk found that parental beliefs mediated the effects of her COPE intervention on parental outcomes, such as state anxiety and depressive symptoms (Melnyk 1994; Melnyk et al., 1997, 2004). For this study, the scale to measure beliefs in mothers of children with cancer is adapted and operationalized from Melnyk's Parental Belief Scale (PBS) and is expected to mediate maternal depression and anxiety. Previous research with the COPE intervention found that parents with greater belief/confidence in their parenting abilities had fewer feelings of stress, anxiety, and depressive symptoms (Melnyk, 1994; Melnyk et al., 1997, 2004, 2006).

Outcome Variables

Outcome measures are the standards for evaluating the preliminary effects of this small pilot intervention study. The selection, measurement, and analysis of the outcome variables should be guided by the theoretical foundation and are crucial to the validity of the study's conclusions or the true effects of the intervention and should be guided by the theoretical foundation (Sidani & Braden, 1998, 2011). Four outcome variables will be measured in this pilot study. Maternal coping outcomes will be operationalized and measured as maternal reports of depression and anxiety. Child coping outcomes will be operationalized and measured as internalizing and externalizing behaviors from maternal reports.

Maternal outcome variables.

Depression. Depression is often a common emotional response by mothers to their child's cancer diagnosis and is often related to the uncertainty of the child's current and future health status (Cernvall et al., 2012; Goldwin, Lee, Afzal, Drossos, & Karnik, 2014; Davis et al., 2010). Mothers of children diagnosed with cancer often know that their child will die without treatment, but may also die with treatment (Bayat et al., 2008; Cernvall et al., 2012; Davis et al., 2010; Norberg & Boman, 2013; Warner et al., 2011). Using self-regulation and control theory, depression may increase following the development of a negative cognitive schema of the actual event and inhibit attainment of a goal parenting state (Carver, 1979; Carver & Scheier, 1982; Johnson, 1999; Johnson & Leventhal, 1983). The one intervention study that measured depression in parents of children with cancer suggested that parents had noticeable reduction in depression symptoms as reported on the Beck Depression Inventory (BDI) after receiving a coping intervention (Svavarsdottir & Sigurdardottir, 2006).

Anxiety. Johnson (1999; Johnson & Leventhal, 1983) identified higher levels of anxiety in patients who did not develop an effective cognitive schema to deal with a healthcare event than patients who had formed a more realistic cognitive schema that helped facilitate the anticipation of a healthcare event. Control theory also contends that anxiety can inhibit a person's ability to obtain a standard or goal state, in this case enacting their usual parenting behaviors with their child (Carver, 1979; Carver & Scheier, 1982). The theories used as the theoretical foundation for this study underscore the need for measuring the critical variable of anxiety in parents of children newly diagnosed with cancer. Numerous studies report that persistent anxiety is common among parents of

children diagnosed with cancer and is often related to the parent's and the child's adjustment to the cancer and its associated treatments (Dunn et al., 2012; Bayat et al., 2008; Harper et al., 2013; Rosenberg et al., 2013; Tufan, Doksat, & Yalug, 2011). Feelings of anxiety can impact a parent's ability to make medical decisions and meet the caregiving demands for their child (Warner et al., 2011). Although the literature suggests that parents of children newly diagnosed with cancer have an increased risk of developing anxiety, anxiety was only measured in four of the 10 current coping intervention studies for parents of children newly diagnosed with cancer. The studies that did measure anxiety before and following an intervention found that parents who received a coping intervention had a reduction in their self-reported feelings of anxiety, further underscoring the need to measure anxiety as an outcome variable for this intervention. Furthermore and perhaps most importantly, in intervention studies that use self-regulation theory as the guide for the intervention reports of anxiety symptoms decrease significantly (Melnyk et al., 2004).

Maternal belief in their parenting role. Mothers often experience lack of confidence in their belief about their ability to parent their child after the cancer diagnosis related to the uncertainty and lack of confidence in their parental role in the complex medical setting and their ability to meet the parenting needs of their acutely ill child (Flury et al., 2011). Parents may feel that they do not have the skills needed to care for their child newly diagnosed with cancer (Warner et al., 2011). Using control theory as the theoretical basis for the intervention, this intervention will provide information focused on parenting a child with cancer which should result in a goal state of increased confidence in parenting a child with cancer. In addition, a major component of the COPE

program is to remove barriers that might inhibit parents' ability to participate in their child's complex healthcare needs (i.e., the myriad of medical treatments associated with the cancer diagnosis).

Child outcome variables. Children, like their parents, may experience feelings of anxiety and depression following their cancer diagnosis, which can be manifested in emotional and behavioral problems (Anthony et al., 2013; Fedele et al., 2011; Geest et al., 2014). This study will include the emotional and behavior responses of toddler, preschool age, and early school age children (2 to 8 years old) as the outcomes of interest that represent the coping outcomes of the children. The most common age range (2 to 8 years old) that encompasses children diagnosed with childhood cancers is the toddler, preschool age, and early school age children (Centers for Disease Control and Prevention, 2014). Also, this age range tends to have similar emotional and behavioral responses to their new cancer diagnosis and thus requires similar parental interventions, whereas older children are likely to have different emotional and behavioral responses due to their different level of development (Kurtz & Abrams, 2011). Inclusion of a wider age range would require different intervention materials be developed for children of different ages and their parents to facilitate coping (Kurtz & Abrams, 2011). This study will look at specific behaviors that are common in young children (age 2 to 8 years): (a) internalizing behaviors (i.e., withdrawal, depression, and anxiety); and (b) externalizing behaviors (i.e., aggression and hyperactivity) (Anthony et al., 2013; Caspi & Shiner, 2006; Fedele et al., 2011; Geest et al., 2014; Kurtz & Abrams, 2011; Small & Melnyk, 2006).

Internalizing behaviors. Internalizing behaviors (i.e., anxiety, depression, and somatization) are behaviors that reflect the child's internal environment and are common

behavioral responses to a stressful event including hospitalization and acute illness (Anthony et al., 2013; Caspi & Shiner, 2006; Kurtz & Abrams, 2011; Small & Melnyk, 2006). Young children (age 1-7 years) may manifest internalizing behaviors by crying, being sad, and worrying. The child with internalizing behaviors may appear to be withdrawn, anxious, and depressed (Anthony et al., 2013). Although there is descriptive research regarding behaviors in children with acute illnesses, there is very little research published regarding parental response to those behaviors and child behavioral outcomes following parent-focused interventions (Rakow et al., 2012; Wolfe-Christensen et al., 2009; 2010).

Externalizing behaviors. Externalizing behaviors (i.e., hyperactivity and aggression) are those behaviors the child exhibits in response to their outward environment, otherwise referred to as acting out behaviors, and are a common emotional response by young children to a stressful event including acute illness and its required medical intervention (Caspi & Shiner, 2006; Goldwin, Lee, Afzal, Drossos, & Karnik, 2014; Kurtz & Abrams, 2011; Small & Melnyk, 2006; Wolfe-Christensen et al., 2009; 2010). For young children, externalizing behaviors can be manifested as temper tantrums, screaming, and uncooperative behaviors. For example, the child who screams at the nurse or throws things at the nurse can have a delay in their medical treatment (Anthony et al., 2013).

Research suggests that children who have high levels of internalizing or externalizing behaviors at baseline are more likely to have an acceleration of these behaviors after an acute unanticipated hospitalizations (Small & Melnyk, 2006; Small, Melnyk, & Sidora-Arcoleo, 2009). Like internalizing behaviors, there is very little

research on the specific behavioral responses that include externalizing behaviors in children diagnosed with cancer (Wolfe-Christensen et al., 2009, 2010).

This pilot study will advanced the science and fill a gap in the literature as it describes specific internalizing and externalizing behavioral manifestations of young children newly diagnosed with cancer. Moreover, the intervention is designed to help mothers to anticipate the behaviors that their child may exhibit ranging from withdrawal to aggression, thus assisting the mothers to refine their existing cognitive schema of the anticipated behavioral responses and facilitate the mothers to better cope if these behaviors are manifested. The desired outcome of this intervention is to decrease anxiety and depressive symptoms, and to facilitate increased adaptive behavioral responses in their children.

Significance of the Proposed Research

Impact on clinical practice. This study fills a gap in theory-based coping interventions for parents of children newly diagnosed with cancer. Although there are currently no widely used psychosocial interventions for parents of children with cancer, findings from the few available interventions for this population indicated that giving parents some type of psychological intervention did improve their outcomes (Pai et al., 2006; Peek & Melnyk, 2010). Most of the prior intervention studies with parents of children newly diagnosed with cancer required a mental health provider to deliver the intervention. In contrast, the intervention in this study is designed and manualized so that it can be implemented by healthcare providers, including nurses and social workers, which increases its availability to all parents and children in this high-risk population. This study adapts the COPE program, a well-researched and theory-based program to be

used in mothers of children newly diagnosed with cancer (COPE-PCC). The adapted COPE-PCC three-phase intervention will be conducted in the clinical setting and is designed to help mothers anticipate typical changes in their children's emotions and behaviors after the cancer diagnosis as well as to provide information to mothers regarding how they can help their children to cope with their illness (Melnyk, 1994; Melnyk et al., 1997, 2004). It is hypothesized that this intervention, like the COPE intervention program on which it is based, will result in decreased stress as well as decreased depression and anxiety in mothers of children newly diagnosed with cancer by providing concrete objective information regarding mothers' and children's potential emotional and behavioral responses and how mothers can best assist their children in coping with this stressful diagnosis and its associated treatment.

Impact on health policy. Health policy is an important part of the healthcare system and is important to review in developing an outcome goal for a specific population (McLaughlin & McLaughlin, 2008). An intervention designed to facilitate coping in parents of children newly diagnosed with cancer and their child should result in improved short- and long-term mental health outcomes for the parent and child which should subsequently result in reduced costs associated with mental health treatments for this high-risk population (Alderfer et al., 2009; Melnyk et al., 2004). Also like similar findings from the previous COPE interventions, the potential for decrease in negative children's behaviors has positive implications for clinical practice including potential for improvement in the child's mental health within the context of the current limitations in mental health services for children (Melnyk et al., 2004). Because maternal coping behaviors are likely to influence their child's coping behaviors, this may impact the

child's adherence to treatment; an intervention to improve coping may result in improved adherence to treatment and possible improved healthcare outcomes (Engelen et al., 2011; Siham, 2013). In addition, as mothers experience improved coping outcomes they may become stronger advocates for their children and other children diagnosed with cancer resulting in increased support and advocacy for childhood cancer research (Felicity et al., 2012).

Summary

Although the psychological effects of a cancer diagnosis in children and their mothers is well documented, there are very few intervention studies that have been conducted with the goal of improving coping outcomes in both mothers and their children (Pai et al., 2006; Peek & Melnyk, 2010). This educational/skills-building coping intervention for parents of children newly diagnosed with cancer will build on the evidence-based COPE program which is a theory-based manualized intervention program based on self-regulation and control theories that has been shown to reduce short- and long-term stress, anxiety, and posttraumatic stress disorder symptoms in parents of critically ill and hospitalized young children and the maladaptive internalizing and externalizing behaviors of the children (Melnyk, 1994; Melnyk et al., 1997, 2004). Therefore, it was hypothesized that the COPE intervention program adapted for mothers of children with cancer (COPE-PCC) will result in similar outcomes for this high-risk child and parent population.

CHAPTER 2. BACKGROUND LITERATURE

This chapter provides an overview of existing literature regarding (a) the interventions that currently exist to facilitate coping in parents of children with cancer, (b) strength of the evidence, and (c) limitations of the current intervention research in order to identify the gaps in the current research.

Literature Review on Coping Interventions for Parents of Children with Cancer

The first step in identifying gaps in the current research is a systematic search and critical analysis of the current interventional literature (Melnyk & Fineout-Overholt, 2005; Sidani & Braden, 1998, 2011). The databases Medline, CINAHL, and Psych Info were searched to identify psychosocial interventions for parents of children with cancer. The keywords used in the search process were *parents*, *childhood cancer*, and *interventions*. The search was limited to English language.

Results

A total of 15 intervention studies and one meta-analysis of coping interventions for parents of children with cancer were found, with one article specifically focused on psychological interventions for parents with children undergoing bone marrow transplant (see Appendix A). Three articles were obtained from Medline, six articles from CINAHL, one article from Cochrane, and six articles from Psych Info. Eleven of the studies were RCTs, two were quasi-experiments, two were pre-experiments, and one study was a meta-analysis of psychological interventions for children with cancer and their parents.

Sample

Six studies included only mothers in the intervention (i.e., two pilot studies, two replication studies, and two RCTs), five studies included fathers and mothers, two studies included parents and adolescent survivors of cancer (i.e., one pilot study and one replication study), and two studies included mothers, fathers, and grandparents. There were a variety of interventions including a web-designed intervention, a multidisciplinary intervention for distress, a guided written disclosure, and a series of in-person support sessions that included all-day workshops.

Setting

Eight studies were conducted in outpatient clinics at university hospitals in the United States. One study was conducted in an inpatient environment in Iceland, one study was conducted in an inpatient environment in Malaysia, one study in an outpatient clinic in Israel, and one study was conducted in an inpatient setting in the Netherlands. Two studies were conducted as a joint study in inpatient settings in five hospitals in the United States and one hospital in Israel.

Recruitment and Retention

Although the majority of the coping interventions focused on parents of newly diagnosed children, there was no consensus on the definition of what constituted newly diagnosed. Seven studies did not define the term *newly diagnosed*, while eight studies defined newly diagnosed as 2 months from diagnosis. All childhood cancer diagnoses (e.g., Hodgkin's, leukemia) were included in the intervention with the only exclusion criteria being terminal diagnosis and secondary cancer diagnosis. Additionally, the age criteria for the children in the studies ranged from 0-17 years of age in two studies, less

than 18 years of age in one study, 2 to 16 years of age in one study, 10 to 17 years of age in one study, 11 to 19 years of age in one study, and there was no mention of age in six of the studies reviewed. Intervention studies conducted with children of a large age range and/or their parents cannot include developmentally-specific information that would assist a parent to anticipate emotional and behavioral responses in their child or provide developmentally appropriate information to facilitate parents engaging with their children to facilitate coping.

Intervention Content and Duration

Current coping interventions for parents of children newly diagnosed with cancer have a great deal of variability in the content and duration of the interventions. The content of the interventions included (a) a three-session guided writing intervention in which mothers wrote about their emotional responses to their child's cancer diagnosis; (b) a two-session web-based support site focusing on practical issues of caring for a child with cancer and social support needs of the parent; (c) two interventions consisting of an eight-session problem-solving skills for mothers in which the mothers were given written information on strategies for completing the complex tasks often associated with a child's cancer diagnosis (i.e., paying bills, completing chores, and attending to other family members); (d) a four-session post-treatment intervention focused on adjusting to life after cancer; (e) a six-session intervention administered by an psychologist in sessions 1, 3, and 5, and a nurse in sessions 2, 4, and 6, focusing on sources of maternal distress after a child's cancer diagnosis; and (f) an eight-session intervention focusing on parental assertiveness in caring for their child in the medical arena and problem-solving skills such as the parent returning to work and the child returning to school. The duration of the

current coping interventions, like the content, had a great deal of variability and ranged from one instructional session to eight educational sessions with only one intervention specifically including booster interventions in the study's design (Pai et al., 2006).

Timing of the Interventions

Timing of the current coping interventions for parents of children with cancer varied and ranged from 12 studies focusing on facilitating coping during the child's treatment phase and three focusing on the survivor/post-treatment phase. Timing of the interventions ranged from within 24 hours after diagnosis to 1 year after completion of treatment with follow-up measurements ranging from 21 days to 9 months. None of the interventions addressed timing for the initial or follow-up intervention sessions (Pai et al., 2006).

Validity

Internal validity of a study is the study's ability to infer that it was the intervention that produced a change in the study's outcomes and not extraneous/confounding variables (Kazdin, 2003; Sidani & Braden, 1998, 2011). The internal validity of the currently available intervention studies is limited by the lack of standardization in the interventions, lack of standardization in the measurements, and high attrition rates in the participants. Several of the studies reviewed also were limited by their small sample sizes and the homogeneity of the sample, which limits their external validity (i.e., the ability to generalize the findings from the sample to the greater population).

Use of Theoretical Framework in Prior Intervention Studies

Only three of the studies appraised included a theoretical framework, which limits interpretation of the study findings. None of the three studies that included a theoretical framework explained the use of the theory to guide the intervention development. Two studies used cognitive-behavioral theory and family therapy (Kazak et al., 1999; Stehl et al., 2009). Another intervention to facilitate coping in parents of children with cancer used the Calgary family intervention model as the theoretical framework for the study (Svavarsdottir & Sigurdardottir, 2006). Self-regulation and control theory were chosen as the theoretical basis for designing and evaluating the outcomes for the current proposed study.

Measures of Intervention Fidelity

Fidelity of an intervention is the intervention being delivered as planned, being delivered in the same manner to all participants, and adhering to the theory of the intervention (Keller, Fleury, Sidani, & Ainsworth, 2009). A study's fidelity is enhanced by the use of a manualized intervention. Only three of the current intervention studies used a manualized intervention and only three used a theory as the basis for the development of intervention, which limits the ability to assess the fidelity of the intervention. The fidelity of the previously conducted interventions studies was not reported in subsequent publications.

Outcome Variables Measured

The theoretical framework of a study should guide the intervention and selection of the outcome variables in the study. Only three of the current coping interventions used a theoretical framework for designing and implementing the intervention, which makes

selection and analysis of the outcome variables difficult. State-Trait Anxiety Index (STAI) was the most used measure and was used in five of the 15 current coping interventions. Several of the studies used scales specifically created for the study and did not report reliability and validity of the scales (Pai et al., 2006). This is a well-developed instrument with strong published validity and reliability psychometrics thus strengthening the study. However, several of the studies used scales specifically created for the study and did not report reliability and validity of the scales (Pai et al., 2006). Also, child outcomes were measured in only one of the previously mentioned studies; therefore it is unclear if a reduction in parent adverse coping outcomes had a positive effect on the children. Table 1 includes the outcome measures of the current intervention studies for parents of children with cancer.

Timing of Outcome Measures

All of the studies used a pre- and posttest design although timing of the posttests ranged from immediately following after completion of the intervention to 8 months after completion of the intervention. One study looked at the long-term effect of the intervention and measured the outcome variables 1-year post-intervention (Svavarsdottir & Sigurdardottir, 2006). Therefore, it is unclear that the intervention studies impacted parental coping longitudinally or that any child outcomes were affected.

Table 1

Outcomes Measures from Previous Studies

Author/Year	Significant Between Group Findings	Post-traumatic Stress	Emotional Distress	Anxiety	Personal Well-being	Coping	Family Hardiness	Depression	Child Behaviors
Sahler et al., 2013	One group design			√				√	
Fedele et al., 2013	One group design				√	√			
Mullins et al., 2012	One group design		√						
Marshland et al., 2013	One group design				√				√
Othman et al., 2009	↑				√				
Stehl et al., 2000	↔	√			√				
Duncan et al., 2007	One group design	√							
Svavarsdottir et al., 2006	One group design					√	√	√	
Kazak et al., 2005	↑	√			√				
Sahler et al., 2005	↑		√						√
Kazak et al., 2004	↑	√							
Sahler et al., 2002	↑		√						
Streisand et al., 2000	↑	√							
Kazak et al., 1999	↑	√			√				
Hoekstra-Weebers et al., 1998	↔	√							

Note. ↔ No significant change; ↑ improvement in symptoms with the intervention; ↓ worsening of symptoms with the intervention; √ outcome measure.

Major Findings

Based on this evidence review, there are few published studies on interventions to decrease anxiety, depressive symptoms, and improve coping/mental health outcomes in parents of children with cancer. The few published studies on psychosocial interventions for parents of children with cancer have been conducted with convenience samples with varying numbers of participants with sample sizes ranging from 8 mothers to 309 mothers. Most of the current intervention studies did not have attention control groups which weakens their internal validity (i.e., the ability to say that the intervention caused a change in the outcomes, not other extraneous variables). Findings from this evidence review support the urgent need for larger theory-based RCTs with attention control groups for parents of newly diagnosed children with cancer in order to improve both their own and their children's coping/mental health outcomes. However, a review of these studies indicated that giving parents some type of psychological intervention did improve their outcomes. These psychosocial interventions included allowing time for the parents to express their feelings, as well as stress reduction and coping strategies that included recognizing and validating the parents' feelings of anxiety, depression, and stress. The review of the current literature suggests that psychosocial interventions should begin within 2 to 16 weeks after diagnosis with scheduled booster interventions to improve parent and child coping outcomes. I have built upon this overall synthesis of the science to test a psychological intervention with mothers of young children (2 to 8 years) newly diagnosed with cancer using a pilot study to design to test the feasibility and acceptability of a theory-based coping intervention.

Booster interventions of the studies that were appraised included reviewing the impact of the diagnosis on the child's behavior and parental role (Stehl et al., 2009). Booster interventions are useful in strengthening the intervention effects and reinforcing the expected outcomes. It should be noted that none of the intervention studies addressed the change in parental role in childhood cancer. In addition, no interventions were designed to prepare parents for what to expect in their children's responses to the diagnosis of childhood cancer or how parents can help the child cope with the diagnosis.

The key strength from the prior intervention studies demonstrated that parents who received a psychosocial intervention had improved coping/mental health outcomes. The limitations from previous studies with this population include (a) lack of theory-based interventions, which weakens explanations of the process through which the interventions worked to improve outcomes; (b) use of convenience samples; (c) lack of attention control groups which limits the internal validity of the studies; and (d) non-manualized training and education protocols, which limits reproducibility in multiple healthcare settings. The current pilot study will build on prior coping interventions for parents of children newly diagnosed with cancer and will address the current limitations by (a) use of a manualized intervention, (b) randomization to attention control group and intervention group, and (c) utilization of theory to design and guide intervention.

Although each of the intervention studies had limitations, they all documented a reduction in one or more coping negative outcomes in parents of children with cancer who had received a psychosocial intervention (see Appendix A). In addition, each study provides and supports the development of future psychosocial interventions.

Parents' Responses to the Cancer Diagnosis of Their Child

The experience of having a child diagnosed with cancer is a stressor to the parent of the child and can result in a range of emotional responses in the parent. These emotional responses can be related to the parents' experiences with the information regarding the cancer diagnosis and its associated treatment, watching their child experience pain, dealing with the emotional responses of others to their child's cancer diagnosis, and negative employment and financial consequences of their child's cancer diagnosis (Warner et al., 2011). Emotional responses in parents of children newly diagnosed with cancer include anger, avoidance, grief, and intrusive thoughts (Davis et al., 2010). These emotional responses can result in the parent not attending to their own needs and their child's emotional and physical needs (Hoekstra-Weebers et al., 2012).

Young Children's Behavioral and Emotional Responses to Illness

Toddlers, preschoolers, and early school age children diagnosed with cancer experience a unique disruption of their childhood and can have a variety of behavioral and emotional responses to their acute illness and diagnosis. Since young children are unable to verbalize their feelings, some common behavioral responses in toddlers, preschoolers, and early school-aged children are manifested as acting out behaviors including biting, kicking, and temper tantrums (Aldiss, Horstman, O'Leary, Richardson, & Gibson, 2009; Small & Melnyk, 2006; Wolfe-Christensen et al., 2009).

Small and Melnyk (2006) found that young children (age 1 to 7 years) were at high risk for post-hospital behavioral sequelae, especially when confronted with an acute illness and unanticipated/unplanned hospitalization. Since young children often have difficulties expressing their feelings in words, they will often express their feelings

including distress and fear as internalizing and externalizing behaviors. There is a relationship between early extreme levels of externalizing behaviors and later-life difficulties. Also higher levels of the children's baseline internalizing behaviors consistently predicted later internalizing behaviors that increased following the hospitalization experience. Some investigators have suggested that the internalizing behaviors of young children are less stable over time than externalizing behaviors (Small & Melnyk, 2006; Wolfe-Christensen et al., 2009). In addition, young children may exhibit negative behavior changes after hospitalization which may be manifested as (a) separation anxiety, (b) regression, (c) apathy or withdrawal, (d) hyperactivity, (e) aggression, (f) loss of newly acquired developmental skills, (g) developmental delays, and (h) posttraumatic stress (Small & Melnyk, 2006; Wolfe-Christensen et al., 2009, 2010).

CHAPTER 3. METHODOLOGY

The methodology section of a research study describes how a study was designed to control for confounding variables and strengthen the internal validity of a study.

Within the methods section, researchers describe the process used to analyze the data collected must be consistent with the study aims, study design, expected or achieved sample size, measurement tools, and resultant data.

Study Aims

The primary aim of this study was to examine the overall feasibility and acceptability of a theory-based manualized, educational/skills-building coping intervention for mothers young of children (age 2 to 8 years) diagnosed with cancer (COPE-PCC). The secondary aims were to evaluate the preliminary effects of the manualized theory-based intervention and to assess the relationships among the study variables.

Study Design

This pilot study used a one-group repeated measures design to (a) assess the feasibility and acceptability of a theory-based manualized, educational-behavioral skills building intervention (i.e., COPE-PCC) for mothers of young children 2 to 8 years of age; (b) evaluate preliminary effects of the intervention on mother's depression, anxiety and beliefs about their ability to parent a child with cancer; and (c) evaluate the preliminary effects of the COPE-PCC program on children's externalizing and internalizing behaviors.

Setting

The study was conducted in two children's hospitals in the pediatric oncology department. The first intervention session was conducted in the acute care hospital setting and the second and third intervention sessions were conducted in both the acute care setting and pediatric oncology outpatient clinic where the child was receiving continued oncology care. In both the inpatient and outpatient clinic settings, the interventions were delivered in a quiet, private room, and childcare was provided for the child and any siblings as needed.

Sample

The sample for this feasibility study consisted of 15 mothers of children newly diagnosed with cancer. The sample size was small since this was a pilot study with the primary purpose of testing the feasibility, acceptability, and preliminary effects of the adapted theory-based manualized intervention for parents of children newly diagnosed with cancer. This was deemed to be an adequate sample size for a pilot study whose purpose was to determine effect sizes (or how large of an impact that was produced by the intervention) for the intervention on the outcomes variables so that a power analysis could later be completed to determine the sample necessary to yield significant results in a full-scale RCT (Cohen, Cohen, West, & Aiken, 2003).

Non-probabilistic convenience sampling was used in an effort to include study participants whose race, socioeconomic status, and ethnicity are representative of the parents and children in these clinical settings. The ethnic breakdown of the patient population at one recruitment site was as follows: Caucasian 67.9%, Latino 21.5%, black 5%, Asian 2.9%, and other 2.7%. The ethnic breakdown of the patient population at the

second recruitment site was Caucasian 74.2%, Latino 1.8%, black 21.4%, Asian 3%, and other 1.5%. While this represents some site differences, the total ethnic make-up of the study participants mirrors that of young children nationally who are diagnosed with cancer.

Rationale for Inclusion/Exclusion Criteria

The inclusion criteria included diagnosis of childhood cancer within the 2 months of the child's cancer diagnosis. The age range for the children was 2 through 8 years of age, which is the most common age of diagnosis for childhood cancers (Centers for Disease Control and Prevention, 2014). More importantly, children 2 through 8 years are experiencing a time of rapid cognitive development and have been found to exhibit similar behavioral manifestation when hospitalized or endure multiple complex medical procedures (Small & Melnyk, 2006; Wolfe-Christensen et al., 2009, 2010). Children diagnosed with recurrent or secondary cancer and/or experiencing a terminal diagnosis (i.e., stage 4 neuroblastoma) were excluded from this pilot study.

Currently 7 to 8 children meeting the inclusion criteria are diagnosed each month in each of the recruitment sites.

Recruitment and Retention

Potential participants were identified in the hospital setting within 2 months (8 weeks) of their cancer diagnosis. The study was initially introduced to potential participants by a site study coordinator through an informational brochure. If an eligible mother expressed interest, she was referred to the principal investigator (PI) at site 1 and study coordinator at site 2 and given additional information prior to enrollment in the study. The letter and brochure given to the mothers assured the mothers that their

participation was completely voluntary, that they could withdraw at any time, and that confidentiality of the data collected was maintained at all steps of the study. In addition, the letter stated that participation in the study or withdrawal from participation did not affect the care of their child. If the mother continued to express her interest in participating, a 30-minute telephone meeting with the PI/study coordinator was scheduled with the mother in the next 24 hours to further explain the study, the anticipated time involvement, and answer all questions exhaustively. After this formal and thorough consenting meeting, interested mothers were asked to read and sign the study consent form and contact information was provided if the parent developed any further questions regarding the study.

Mothers of children newly diagnosed with cancer were identified and recruited from 4/13/12 through 11/1/13 from one of two pediatric oncology units of children's medical centers. All study participants completed the intervention by 1/1/2014. The total number of participants who completed the study from both sites was 15. In previous studies conducted with this child and parent population, attrition has ranged from 10% to 60%. The intent of the inclusion criteria attended to this issue by not recruiting mothers whose child had a secondary or terminal cancer diagnosis. Also, potential study attrition was addressed by waiting, in some cases, until 2 months after the cancer diagnosis and when the initial acuity of the child's illness and medical condition had stabilized (Kazak et al., 2012).

In addition, mothers were called prior to the scheduled clinic visit to confirm their appointment and study involvement. Culturally important strategies such as personal contact between participants and PI and study coordinator during reminder phone calls

and provision of a warm professional and respectful environment was maintained for all participants.

Intervention Protocol Overview

After completion of the baseline measures, the study coordinator delivered the first COPE-PCC intervention. Session 1 was delivered within 2 months (8 weeks) of the child’s cancer diagnosis, session 2 was delivered 2 to 3 weeks after session 1, and session 3 was delivered 3 to 4 weeks after session 2. Session 1 of COPE-PCC was conducted on an inpatient hospital unit and sessions 2 and 3 were conducted at the pediatric oncology clinic during a routinely scheduled clinic visit. The PI reminded participants of upcoming appointments. Each session was delivered in 30-minute in-person sessions during which each manualized session was reviewed and questions were answered. To strengthen the fidelity of the intervention and promote intervention information retention an audio-taped CD was provided with all participants for their review and use. Table 2 outlines the timeline for the intervention.

Table 2

Timeline of Intervention (COPE-PCC)

Diagnosis confirmed Time (T0)	Time (T1) (within 2 months of diagnosis)	Time 2 (T2) (2-3 weeks after T1)	Time 3 (T3) (3-4 weeks after T2)
Screened for inclusion criteria	1 st Intervention Session	2 nd Intervention Session	3 rd Intervention Session
Informed Consent			
Baseline Data Collection	30 minutes	30 minutes	30 minutes

COPE-PCC Intervention

COPE-PCC is a three-session manualized intervention designed to be used by healthcare providers to facilitate positive coping outcomes in children newly diagnosed with cancer and their parents. The intervention is based on the COPE-PICU three-session intervention in which findings indicated that parents who received COPE versus those who received attention control information reported significantly less parental stress, depression, anxiety, and fewer posttraumatic stress symptoms during as well as up to 12 months following hospitalization and an improvement in children's behavioral outcomes (Melnyk, 1994; Melnyk et al., 1997, 2004).

This intervention was adapted for delivery to parents of children newly diagnosed with cancer and consisted of three on-site in-person sessions in which CDs were used for content delivery that were approximately 30 minutes in length. The CDs consisted of anticipatory educational and skills-building information about frequently encountered parental and child emotional responses to the cancer diagnosis; the parental role in helping the child to adapt to the illness and treatment will be integrated into the program. The program and activities were manualized to ensure that they could be reproduced in clinical practice and replicated in future research studies.

COPE-PCC sessions.

Session 1 of COPE-PCC. Session 1 occurred within 2 months of the cancer diagnosis and consisted of an in-person information session delivered via audiotaped CD which was played with the PI present and left with the participant for additional review. A written copy of all the information was also provided for the mothers to have for review and reflection. The focus of intervention session 1 was common emotions and

behaviors in mothers and their child following the child's cancer diagnosis. The parenting activities in this session consisted of identifying (a) special characteristics and coping strategies used by the children prior to the cancer diagnosis, (b) common behaviors exhibited by children exhibited after a cancer diagnosis, and (c) common emotions in parents of children with cancer.

Session 2 of COPE-PCC. Session 2 occurred 2 to 3 weeks after session 1 and focused on anticipated responses to post-cancer diagnosis in the mother and child. This in-person information session delivered via audiotaped CD intervention which was played with the PI present and left with the participant for additional review included a review of the information provided in session 1 that reinforced critical contents of the initial intervention and introduced new material. In addition, a written copy of all the information was also provided for the mothers to have for review and reflection. The new information addressed in this intervention session provided supplemental information on (a) how parents can help their child with coping with the changes associated with the cancer diagnosis and its treatment; (b) a parent-child workbook that focuses on therapeutic play for the child to gain mastery over their emotions associated with their cancer diagnosis and its associated treatments; and (c) reading and discussing *Jenny's Wish*, a story about a young girl who successfully copes with changes in her behaviors and physical appearance after an illness.

Session 3 of COPE-PCC. Session 3 occurred 3 to 4 weeks after the second intervention. This in-person information session delivered via audiotaped CD intervention which was played with the PI present and left with the participant for additional review included a review of the information provided in sessions 1 and 2 that

reinforced critical contents of the initial intervention and introduced new material. In addition, a written copy of all the information was also provided for the mothers to have for review and reflection. The new information in this intervention session focused on the impact of the diagnosis on the family and provided some concrete information regarding parenting a child diagnosed with cancer including (a) parenting behaviors found to facilitate positive coping outcomes for the children, and (b) continued parent-child workbook activities including medical play for the parent and child to do together.

Measures

Intervention feasibility measures.

Attendance log. An attendance log was maintained for each participant. This log was subsequently used to determine when participants did not continue in the study. Documentation on the attendance log included the sessions attended (session 1 through session 3), the length of time of each session, and the length of time between the previous and current session. If a mother missed a scheduled session, the session was rescheduled. Adherence to the intervention was documented by the attendance at each session and the review of what activities the mother and child had completed since the previous session. Adherence to the intervention protocol was strictly maintained and ensured that the intervention was delivered as designed and intervention fidelity was assured (Whitmer, Sweeney, Slivjak, Sumer, & Barsevick, 2005).

Attrition log. An attrition log was maintained for any participants leaving the study and included the date and reason the participant reported taking leave of the study. Attrition is a valuable resource for determining acceptable and unacceptable aspects of an intervention (Sidani & Braden, 1998, 2011). Attrition rate was based on the total number

of participants who consented to the study and the total number of participants who completed the study. Of the 16 participants who consented to participate in the study, 15 participants completed the study, which resulted in an attrition of 7% for this study. The 1 participant who withdrew from the study stated the reason for withdrawal was that their child was too sick for the mother to continue participation. Eighteen participants were approached about the study, with 2 refusing to participate in the study.

Intervention acceptability measures. Information about the acceptability of the COPE-PCC was obtained from the exit questionnaires. The exit questionnaires were completed after completion of session 3. Acceptance of an intervention is determined by the extent to which a participant remains or adheres to the intervention (Keller et al., 2009; Kline et al., 2009; Sidani & Braden, 1998, 2011).

1. Was the program with its number acceptable to you?
2. Was the program helpful in coping with your child's cancer diagnosis?
3. Would you be interested in participating in future studies like this one?
4. Describe how participation in the intervention program could have been made easier for you.
5. What other information should be included in the program?
6. How was the program helpful to you?

Fidelity of the Intervention

Monitoring fidelity or integrity of a research study is the degree to which the intervention is delivered as planned and is essential in determining the difference between what was planned and what was delivered (Keller et al., 2009; Sidani & Braden, 1998, 2011). The confidence in a study's results is based on the study's fidelity (Sidani &

Braden, 1998, 2011). The study's fidelity is important in evaluating the results of the study and is important in making any necessary revisions. Fidelity is enhanced by the use of a manualized protocol and intervention which ensures that the intervention is delivered in the same manner to all participants and enhances the ability of the study to be replicated (Sidani & Braden, 1998, 2011). Lack of fidelity of a study can be impacted in two ways: (a) deviation from implementation of intervention, and (b) different dosage of intervention for different participants (Sidani & Braden, 1998, 2011). Components of fidelity that were assessed in this study included (a) standardized delivery of the intervention via audio-taped CD, and (b) scheduled timing and dose of the intervention. The fidelity, and thus internal validity, of this proposed pilot study was enhanced by the using a manualized intervention, tracking of completion of each audio-taped CD session, and tracking that all handouts were read. These precautions greatly strengthened this single-group pilot project that was conducted in two sites.

Delivery of the intervention. A manualized protocol was developed for delivery of the intervention that outlined the intervention to be provided in each session. The PI documented the completion of each session using this manual in an intervention log and the documentation included (a) time spent on each task, (b) outline of materials used to support the interventions, (c) methods for delivering the intervention, and (d) tasks accomplished in each session. All intervention sessions included an audio-taped CD and matched written information so that mothers could listen to and read the information being provided. The parents and investigator listened to each CD together. Each mother was asked to make note of any additional times that they listened to the CD, used the storybook, and/or workbook to track dose frequency.

Timing and dose of the intervention. This intervention for mothers of children with cancer built on the previous intervention research (Kazak et al., 2012; Pai et al., 2006) by designing a manualized intervention focusing on a mother's potential emotional response to their child's cancer diagnosis and providing concrete parenting information about potential ways to help their children cope with the diagnosed illness and subsequent medical therapies. The intervention was a three-phase intervention started within 2 months after confirmation of the cancer diagnosis. Timing for the initial intervention was planned based on self-regulation theory's principle that the development of a schema will prepare the parents for what to expect may occur after the diagnosis (Johnson, 1999). The second and third follow-up interventions were scheduled during the child's routinely scheduled outpatient clinic visits and were designed to decrease attrition which has been an issue in previous studies with this population (Kazak et al., 2006; Pai et al., 2006). The timing for the start of the intervention and the duration of the intervention session are the components of the intervention dosage that were documented. Each of these aspects was based on the previously conducted review of the literature with a focus on what had effects and what components of the intervention that did not appear to have an effect. Although self-regulation theory supports the use of the intervention prior to or immediately after the stressor, previous studies have shown that beginning a coping intervention for parents of children diagnosed with cancer within 2 to 6 months after the child's cancer diagnosis has resulted in higher recruitment and retention of participants (Fedele et al., 2013; Mullins et al., 2012; Pai et al., 2006; Peek & Melnyk, 2010; Sahler et al., 2013). Additionally, other related studies have found that intervention with patients who have extremely high levels of anxiety have had limited effects due to

the patients inability to engage and synthesize the intervention information (Marshland et al., 2013; Peek & Melnyk, 2010; Stehl et al., 2009).

Receipt of intervention/manipulation checks. Receipt or processing of the intervention was measured by a manipulation check which provided information regarding how much information the subjects processed of the content delivered. After each of the three sessions, the mothers completed the manipulation check comprised of 10 multiple choice knowledge questions (five questions specific to the intervention and five questions on general childhood cancer information) covering concepts discussed during the previous sessions. We determined that if the mothers understood and processed the information given, they responded with 80% accuracy or greater (Melnyk et al., 1997; Melnyk & Fineout-Overholt, 2005). If the mothers answered with less than 80% of the questions correctly, the information was replayed for them again, and they were given the manipulation check again to be sure they processed all of the information provided.

Variables and Measures

The selection of outcome variables and the instruments to measure them is important in evaluating the effectiveness of the intervention (Sidani & Braden, 1998, 2011). The outcome variables for this study include (a) a theoretical mediating variable (maternal beliefs), (b) maternal depression, (c) maternal anxiety, and (d) child internalizing and externalizing behaviors. In order to increase validity (measures what it purports to measure) and reliability (consistency and accuracy in measuring the outcome variable) for this study, only measures that have established reliability and validity in prior studies for the population of interest were used (Sidani & Braden, 1998, 2011). In

addition, measures were administered in the same way by the PI or study coordinator and scored immediately after completion of each data collection session.

Independent variables. Based on self-regulation and control theories, a manualized educational skills-building intervention was used to provide information to parents regarding typical changes in children's emotions and behaviors after the cancer diagnosis as well as how the mothers can help their children to cope with their illness, including activities to be performed with their children. The independent variable for this study is the intervention (COPE-PCC).

Demographic variables. The demographic variables included in this study were (a) age, (b) gender, (c) race/ethnicity, (d) marital status, (e) highest level of education, (f) household income, (g) perceived family and social support, (h) history of or current presence of mental health disorders in the mother(s), (i) any history of or current chronic illness in the parent(s), (j) a prior diagnosis of mental health disorder in the child, and (k) history of a child chronic or debilitating illness prior to this diagnosis (Melnyk, 1994; Melnyk et al., 1997, 2004).

Dependent variables.

Depression symptoms. The Beck Depression Inventory-II (BDI-II) was used to measure maternal depressive symptoms. The BDI-II is a 21-item scale, with 4-point Likert-type response sets that measure the presence and intensity of various somatic, emotional, and cognitive features of depression. It has well-established construct validity and Cronbach's alphas in the high .80s (Beck, Steer, & Brown, 1996). The 4-point scale for each item of the scale ranges from 0 to 3, reflecting a set of graded options ranging from a *mild* symptom to an *extreme* symptom. Scores range from 0 to 63, with higher

scores indicative of more depressive symptoms. Cutoff scores indicate varying levels of symptomatology (0 to 13 = minimal depression; 14 to 19 = mildly depressed; 20 to 28 = moderately depressed; 29 to 63 = severely depressed). Mothers' BDI-II questionnaires were collected from intervention sites and scored promptly. Mothers with scores indicating clinically significant severe depression (scores > 29) were referred to their primary care physician. Those admitting to suicidal ideation on key indicators (item #2-pessimism; item #9-suicide ideation or intent) at a score of 2 or 3 were referred immediately to emergency care.

Anxiety symptoms. The STAI (Spielberger, 1983) was used to measure maternal anxiety symptoms. The well-known valid and reliable STAI with established construct validity is comprised of two self-report scales (Spielberger, 1983). Current feelings of anxiety are measured in the 20-item scale (A-State) that is designed to be delivered first, while an individual's anxiety *proneness* or trait is measured in the 20-item trait scale (A-Trait), which is only measured at baseline as a potential covariate. Responses to individual items range from 1 (*not at all*) to 4 (*very much so*) on the State Scale with the sum score ranging from 20 to 80. The Trait Scale response sets to individual items range from 1 (*almost never*) to 4 (*almost always*) and the resultant sum scores range from 20-80. Test-retest reliability (r) for the A-Trait scale ranged from 0.73 to 0.86 and from 0.16 to 0.54 for the A-State scale (Marshland et al., 2013). Low levels of stability for the State Scale are expected as responses to the items are thought to reflect transient environmental or situational factors existing at the time of testing. Analysis of the STAI included reverse scoring of particular items and summation of all of the individual responses for a total State and Trait Anxiety score. Examples of State Anxiety questions are, "I am tense; I am

worried,” and “I feel calm; I feel secure,” while examples of Trait Anxiety Scores questions are, “I worry too much over something that really doesn’t matter,” and “I am content; I am a steady person.” Higher total scores on both scales indicate higher levels of anxiety. In previous studies on parental coping with their child’s cancer diagnosis, Cronbach’s alpha for the A-Trait and A-State Scales has exceeded .86 in previous studies on parental coping (Othman, Blunden, Mohamad, Hussin, & Osman, 2010; Stehl et al., 2009).

Child internalizing and externalizing behaviors. The Behavioral Assessment Scale for Children-2 parent form (BASC) for children was used to measure externalizing and internalizing behaviors in children (Reynolds & Kamphaus, 2004). The BASC-2 is a norm-referenced, standardized behavioral assessment system designed to facilitate the differential diagnosis and classification of a variety of externalizing and internalizing behavioral in young children. The age-appropriate BASC-2 consists of 134 items, each having a 4-point scale ranging from 1 (*never*) to 4 (*always*) based on parental report of child psychosocial competence. The parent rating form of the BASC-2 generates scores in the areas of externalizing problems, internalizing problems, behavioral symptoms index, and adaptive skills. The internalizing composite scale includes three sub-scale scores that generate the index and include (a) anxiety, (b) depression, and (c) somatization (Reynolds & Kamphaus, 2004). The externalizing composite scale is comprised of three subscale scores that include (a) hyperactivity, (b) aggression, and (c) conduct problems. In this study only the areas of internalizing and externalizing behaviors were analyzed. Mothers were asked to complete the BASC-2 at baseline and report their child’s behavior of the previous 3 months. Mothers completed the BASC-2

again at the completion of the intervention. The BASC-2 has a Cronbach's alpha exceeding .80 in previous studies in parents of children with cancer (Wolfe-Christensen et al., 2009).

Theoretical mediating variable. The theoretical mediating variable of maternal beliefs in their parenting abilities was measured using the Parental Beliefs Scale (PBS) at T0 and T3. The PBS is a 20-item instrument that taps parent's belief about the behaviors and emotions of their child as well as their ability to assist their child in adapting to the illness and treatment. For this study, the PBS was modified to ask questions about a mother's knowledge of their child's emotional responses to the cancer diagnosis (i.e., "I know what changes in behavior to expect in my child after their diagnosis") and the maternal role during hospitalization (i.e., "I am clear about the things that I can do to best help my child"). Mothers indicated agreement with each item on a 5-point scale, ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Item scores were summed, with a possible range of scores of 20 to 100; higher scores indicated stronger beliefs. Cronbach's alpha for this scale has exceeded 0.85 in prior studies of parents with hospitalized children (Melnyk 1994; Melnyk et al., 1997, 2004).

Table 3 presents the demographic, mediating and behavioral outcome variables that were measured and the timing for measuring the variables using standardized questionnaires and measures.

Table 3

Measures for Data Collection with Parents of Children Newly Diagnosed with Cancer

Construct	Instrument	Cronbach's Alpha	Data Collection
Demographics	Demographic Questionnaire	Not applicable	T(0) Baseline
Depressive symptoms	BDI-II	>.86	T0, T3
Anxiety	STAI	>.86	T0,T3
Parental beliefs regarding their children's emotions/ behaviors and their role	PBS	>.85	T0, T3
Child internalizing and externalizing behaviors	BASC-Parent Form	>.80	T0, T3
Intervention fidelity (Process)	Task/Time/Method Report	Not applicable	T0-T3
Adherence	Attendance Roster	Not applicable	T0, T3
Receipt of intervention – Learning	Manipulation Check	Not applicable	T0-T3
Satisfaction with/ acceptability of the intervention	Exit Interview	Not applicable	T3

Evaluation of the Intervention and Protocol: Feasibility and Acceptability

A program evaluation was used to collect information about the feasibility (timing, format, and length) and acceptability (content and general acceptability) of the intervention and to inform the next study in this program of research, which will be a larger-scale RCT. The PI conducted the exit evaluation with subjects after all of the other study assessments were completed.

Data Collection

Procedures. The study was conducted in two children's hospitals and was approved by the Institutional Review Board of the hospitals and Arizona State University prior to recruitment and implementation of the intervention. A detailed, manualized protocol for the intervention was developed to standardize delivery of the intervention and was strictly followed to validity of the study (Sidani & Braden, 2011).

Data Management

The PI was responsible for the overall management of the study, development of study materials, participant recruitment, data collection, and data analysis. Subject codes were placed on all measures and all identifying mother information was only kept in a master code book to which only the PI had access. Prior to data collection, a file system with materials to be used at each session and a codebook that included each measure was established.

Coded data collection forms completed at Time 0 and Time 3 were reviewed for missing data and any missing data were coded 9999. Confidentiality was strictly maintained for all data collected in this study. The data were entered into a computerized database (SPSS) within 72 hours and were protected by computer virus and hacking protection, password protection on systems and files, and weekly backup and archiving of information. The computer was located in the locked office of the PI and access was limited to the PI, mentor, and co-mentor. Once data were entered, they were later verified for accuracy and to reduce human data-entry errors.

In addition, due to the nature of this intervention, information regarding available mental health services was provided to all study participants. Additionally, the BDI-II

was scored immediately following its administration, and mothers who reported a high level of depressive symptoms evidenced by BDI-II score of 29 or greater were advised to see their primary care providers and were provided referral information to community mental health resources. Mothers who expressed suicidal ideation were referred to the emergency room for thorough evaluation.

Data Analysis

After data cleaning, preliminary analysis included assessing the psychometric properties (reliability) of the scaled measures and calculating univariate descriptive statistics to ensure the quality of data (check distributions and examine outliers) and to describe the sample (Cohen et al., 2003).

Data reduction of questionnaires. Although multi-item questionnaires were used to measure theoretical moderating, potential mediating, and outcome variables, sum scores were used in the analyses. The data transformation functions within SPSS were used to calculate summary scores. The author's guidelines were followed for each instrument and formulas were preserved in SPSS syntax files.

Maternal responses to each of the 20 items on the State Anxiety and the 20 items on the Trait Anxiety Inventories were scored taking into account the reverse scored items (i.e., State Anxiety Inventory items #1, 2, 5, 8, 10, 11, 15, 16, 19, and 20; Trait Anxiety Inventory items #21, 23, 26, 27, 30, 33, 34, 36, and 39). Each item received 1, 2, 3, or 4 points, which were then summed and compared to gender and age reference tables provided by the authors. A standard score for each mother was then entered into an SPSS data file.

Maternal responses to each of the 21 items on the BDI-II were scored with each item receiving 0, 1, 2, or a maximum of 3 points. Total scores for each participant for this questionnaire were entered an SPSS data file.

The BASC-2 parent responses were entered into a SPSS database. Identified items were reverse scored and the subscale scores (e.g., externalizing and internalizing) were generated. At that point the composite scale scores of internalizing and externalizing behavior were generated. The gender and age reference tables provided by the authors were used to identify matching standard scores for each composite scale which were then added to the database and used for further analyses.

The PBS item scores were summed, with a possible range of scores of 20 to 100. The items reverse coded on the PBS were questions 2, 4, 6, 7, 9, 11, 14, 15, 17 and 18. Maternal responses to each the questions on the PBS were entered into SPSS and a sum score was calculated for each individual and used for the planned analyses.

Analysis plan for research question 1. Is a theory-based coping intervention program (COPE-PCC) which emphasizes education and skills building feasible and acceptable for mothers of children newly diagnosed with cancer?

Feasibility and acceptability of the COPE-PCC program were evaluated by review and descriptive analyses of feasibility and acceptability questions in the program evaluation. The intervention was considered feasible if it was delivered in the same manner and the specified time period to all participants. Feasibility was monitored by careful tracking of the mothers progress in the intervention study which included how many sessions the mothers attended and how many times they reported replaying the CD.

The intervention was considered acceptable if 70% or more of subjects responded positively to the five questions in the program evaluation. If a session was missed, the mother was telephoned and the session was rescheduled at her convenience.

Analysis plan for research question 2. What are the preliminary effects of a theory-based coping intervention program (COPE-PCC) on (a) maternal depression, maternal anxiety, and maternal beliefs about parenting a child with cancer; and (b) children's externalizing and internalizing behaviors?

Descriptive statistics and effect sizes for the intervention were computed for state anxiety, depression, and maternal beliefs. In addition, paired *t*-tests were performed for each of the outcome measures to determine preliminary efficacy of the intervention. A significance level of .10 was set instead of the traditional .05 due to the small sample size and lack of statistical power to detect change at the .05 level of significance. A small effect size from the pilot study meant that a future RCT needs a larger sample size.

Analysis plan for research question 3. What are the relationships among the coping variables prior to and immediately following the intervention program (COPE-PCC) inclusive of maternal depression, maternal anxiety, maternal beliefs about parenting a child diagnosed with cancer, and children's externalizing and internalizing behavior?

Pearson's correlations (measures the strength and linear relationship between two variables) at $\alpha = .10$ was conducted among all of the study variables. Supporting positive correlations between the COPE-PCC and maternal beliefs, and maternal beliefs and the outcome variables is the first step to assessing mediation, to be appropriately tested in a subsequent large-scale study.

CHAPTER 4. RESULTS

The primary purpose of this pilot study was to test the feasibility, acceptability and preliminary effects of a theory-based manualized intervention (COPE-PCC) to improve the mental health/coping outcomes of mothers of children diagnosed with cancer and their children. The three-session COPE-PCC intervention was delivered to mothers of children newly diagnosed with cancer. Relationships among variable were also assessed. A total of 16 mothers of children newly diagnosed with cancer (within 8 weeks of the cancer diagnosis) were recruited into the study. Fifteen participants completed the study. The data from the participant ($n = 1$) who was lost to attrition after completion of the consent forms and demographic data were not included in the baseline analysis or outcome assessments. No demographic data were collected on the subjects who declined to participate ($n = 2$) and subjects who did not meet eligibility criteria ($n = 3$).

Psychometrics

Psychometrics examines the validity and reliability of a measure (Kazdin, 2003). Reliability can be measured by Cronbach's alpha and a Cronbach's of .70 or greater is required for a measure to be considered to have adequate reliability (Kline, 2009). For this study the internal consistency reliabilities at baseline were examined and are presented in Table 4.

Table 4

Cronbach's Alpha of Study Measures

Scale	Number of Items	Cronbach's Alphas Prior Studies	Cronbach's Alphas COPE-PCC
BDI-II	21	.83-.94	.91
Anxiety (State)	40	.78-.86	.71
PBS	20	.85-.91	.85
BASC	134	.80-.95	.94

Two specific questions that indicated an increased risk for suicide on the BDI-II were examined using frequencies, percentages, and cumulative percentages. Responses on question 2 for pessimism of, "I do not expect things to work out for me," or "I feel my future is hopeless and will only get worse," and question 9, "I would like to kill myself," or "I would kill myself if I had the chance," indicated an increased risk for suicide. Table 5 describes the findings.

Based on these findings, no participants required immediate referral because they were not at imminent risk for suicide. No participants were referred for immediate psychological evaluation based on their total BDI-II scores placing them in the severe depression range. Four participants were found to score in the moderate depressive range and were monitored throughout the study. All participants were given a handout that delineated the local behavioral services available for minimal or no cost in the event that

the participant mother experienced an emotional response and they personally decided to seek attention.

Table 5

Frequencies, Percentage, Valid Percentage, and Cumulative Percentages of Items Indicating Increased Risk for Suicide on Beck Depression Inventory (BASELINE)

Item	Frequency	%	Valid %	Cumulative %
2. Pessimism				
I am not discouraged about my future.	6	40	40	40
I feel more discouraged about my future than I used to be.	9	60	60	100
I do not expect things to work out for me.	0	0	0	0
I feel my future is hopeless and will only get worse.	0	0	0	0
9. Suicidal Thoughts or Wishes				
I don't have any thoughts of killing myself.	13	86.7	86.7	86.7
I have thoughts of killing myself, but I would not carry them out.	2	13.3	13.3	100
I would like to kill myself.	0	0	0	0
I would kill myself if I had the chance.	0	0	0	0

Description of Participants

Mother demographics. Mothers in the study ranged in age from 22 to 55 years with a mean age of 32 years ($SD = 8.1$ years). Seventy-three percent of the mothers were married. Seventy-four percent of the mothers had some college or higher educational level. Sixty-seven of the mothers reported a household income of \$40,000 or more per year. Ninety-three percent of the mothers reported no previous mental health disorder and

80% of the mothers reported no history of chronic illness. Demographic information of the mothers who participated in this study is summarized in Tables 6 and 7.

Table 6

Participant Demographic Data (n = 15)

Demographic Variable	Mean	Standard Deviation	Range
Mother's age (years)	32.0	8.1	22-55
Child's age (years)	5.3	1.7	3-8
Time from diagnosis (weeks)	6.4	1.8	2-8
Number of children in household	2.0	1.0	1-4

Table 7

Demographic Data Represented as Percentages (N = 15)

Demographic Variable	Frequency	Percent
Child's Gender		
Male	7	47
Female	8	53
Ethnicity		
White, not of Hispanic origin	8	53
Black, not of Hispanic origin	4	27
Hispanic or Latino	3	20
American Indian		
Alaskan Native		
Asian/Pacific Islander		
Other		
Marital Status		
Married	11	73
Never married	2	13
Separated	1	7
Divorced	1	7
Widowed	0	0

Table 7, continued.

Demographic Variable	Frequency	Percent
Education Level		
Did not finish high school	1	7
Finished high school or got GED	3	20
Some college or training after high school	6	40
Finished college	4	27
Master's degree or doctoral degree	1	7
Household Income Per Year		
Less than \$20,000	1	7
\$20,000-\$39,000	4	27
\$40,000-\$59,000	3	20
\$60,000-\$79,000	4	27
\$80,000-\$99,000		
More than \$100,000	3	20
Maternal History of Mental Health Disorder		
Yes	1	7
No	14	93
Maternal History of Chronic Illness		
Yes	3	20
No	12	80
Child's History of Mental Health Disorder		
Yes	0	0
No	15	100
Child's History of a Prior Chronic or Debilitating Illness		
Yes	3	20
No	12	80
Other Child(ren)'s History of a Prior Chronic or Debilitating Illness		
Yes	2	13
No	13	87

Child demographics. The mean age of the child diagnosed with cancer in this study was 5.3 years ($SD = 1.7$ years), with an age range of 3 to 8 years of age. The mean time from diagnosis was 6.4 weeks ($SD = 1.8$ weeks), with a range of 2 to 8 weeks from

diagnosis. Fifty-three percent of the children were female. None of the children had a history of a mental health or behavioral disorder. Thirteen percent of the children had a prior history of a chronic or debilitating illness (non-cancer diagnosis). Forty percent of the children had a diagnosis of acute lymphoblastic leukemia, 27% had a diagnosis of lymphoma, 7% had a diagnosis of retinoblastoma, 13% had a diagnosis of rhabdomyosarcoma, and 13% had a diagnosis of Wilm’s tumor.

Table 8

Child’s Cancer Diagnosis

Diagnosis	Frequency	Percent
ALL	6	40
Lymphoma	4	27
Retino	1	7
Rhabdo	2	13
Wilm’s	2	13

Note. ALL = acute lymphoblastic leukemia, retino = retinoblastoma, rhabdo = rhabdomyosarcoma

A summary of the research findings is presented in the text and Tables 9-19. The first findings are for the acceptability and feasibility of delivering the COPE-PCC. Presented second is the overall effect of the COPE-PCC intervention, including effects on (a) maternal depression, maternal anxiety, and maternal beliefs about parenting a child with cancer; and (b) the children’s externalizing and internalizing behaviors. The third results presented are the relationships among maternal depressions, maternal anxiety, and maternal parental role beliefs, and the children’s externalizing and internalizing behaviors.

Research Question 1 and Results

Is a theory-based coping intervention program (COPE-PCC) that emphasizes education and skills-building feasible and acceptable for mothers of children newly diagnosed with cancer?

Measures of acceptability of the COPE-PCC were at 80% or higher positive response rate to questions on the exit evaluation questionnaires (i.e., Was the program with its number of sessions acceptable to you? Was the program helpful in coping with your child's cancer diagnosis? How easy was it to teach your child the coping strategies?). One-hundred percent of the mothers completed the exit evaluation and rated the program with its number of interventions sessions as acceptable. One mother commented that by attending the program, she learned new ways to cope with her child's cancer diagnosis. Other positive comments noted were:

“I received information that I didn't get anywhere else.”

“I got new information about how to help my child cope with their cancer diagnosis.”

“No one had told me how my feelings affected my child before.”

“It helped me know how to help my child.”

“I didn't know how my child would react before this.”

“This was all new information to me.”

“It was all helpful to me.”

“I liked the part about what to do at home.”

“I liked the part about it was ok to take care of myself.”

“The play activities with my child were helpful.”

“The activity book was helpful.”

“The suggestions on how to take care of myself were helpful.”

“I liked the ideas on how to help my child.”

“It was all new information and helpful.”

“I liked the medical kit for my child.”

“I liked that I could understand all of the words.”

Mothers found the COPE-PCC program and the length of the program highly acceptable. Ninety-three percent of mothers rated the program as helpful in coping with their child’s cancer diagnosis. Eighty-seven percent of the mothers would participate in a similar study in the future. One-hundred percent of the mothers would recommend this program to other mothers of children diagnosed with cancer. Seven percent of the mothers recommended that the intervention be offered earlier and that the questions asked were shorter as improvements to the program. Eighty-seven percent of the mothers rated it was very easy to teach their child the coping strategies. Ninety-three percent of the mothers rated it as somewhat to very easy for them to stay calm during stressful events after completion of the intervention. Descriptive analyses of acceptability questions in the program evaluation are presented in Table 9.

Table 9

Exit Evaluation Descriptive Responses

Parent Question	Yes (%)	No (%)
Was the program with its number acceptable to you?	15 (100%)	0 (0%)
Was the program helpful in coping with your child's cancer diagnosis?	14 (93%)	1 (7%)
Would you be interested in participating in future studies like this one?	13 (87%)	2 (13%)
Since your child has been diagnosed with cancer have you received any information about how to help your child cope with the cancer diagnosis?	2 (13%)	13 (87%)
Since your child has been diagnosed with cancer have you received any information about how mothers and their child respond to the cancer diagnosis?	2 (13%)	13 (87%)

Table 10

Exit Evaluation Coping Questions

Coping Questions	Not Easy At All	A Little Easy	Fairly/Somewhat Easy	Very Easy	Frequency	Percent
How easy was it to teach your child the coping strategies?	1	2	6	6	12	87
How easy was it for you to stay calm during stressful events?	1	1	10	3	13	73

*Frequency/percent for questions answered fairly and/or very easy

Measures of feasibility of the COPE-PCC were the attrition rate, the level of the participants' attendance at the COPE-PCC intervention sessions, and completion of the log of times the CD was reviewed. Of the original 21 participants who were referred for

the study, 18 mothers met eligibility criteria for the study, 16 were enrolled, and 15 (94%) completed the three-session COPE-PCC intervention. Attrition is the number of participants who drop from the study after they start the study. For this study 16 mothers were enrolled and 15 participants completed the study. Twenty-one mothers were identified by the nursing staff and 3 were ineligible based on exclusion criteria: 2 with a brain tumor diagnosis and 1 with a secondary cancer diagnosis. Two mothers eligible for the study declined the study after the meeting to explain the study details. One stated the reason for declining to participate in the study was the perceived time requirement for participating. The second mother declined to participate because she felt “too overwhelmed.” Another mother dropped from the study after completing the consent form and the demographics but prior to completion of remaining baseline questionnaires. The participant who withdrew from the study after consent and prior to completion of baseline measures reported that her child was too sick for them to be able participate in a study. Participants who completed the study attended all of the sessions, thereby contributing to 100% participation of the 15 participants consented and enrolled with completed baseline measures.

One unanticipated issue that occurred during this study was the lack of referral from the healthcare staff. Although a total of 36 children were newly diagnosed during the timeframe of the study, only 56% of the mothers were referred by the healthcare staff for recruitment. The primary reasons for the number of participants eligible being larger than the number of participants referred by staff and recruited for the study was the medical staff’s concern over caregiver burden.

Table 11

Eligibility for Study

Number of Children Diagnosed Age 2-8 Years	Number of Mothers Referred by Staff	Eligible for Study	Consented	Completed Intervention
36	21	18	16	15 (94%)

Table 12

Medical Staff Statements on Reluctance to Refer Participants

-
- “The mom is too overwhelmed to participant in the study.”
- “The mom can’t handle one more thing.”
- “The mom just received a devastating diagnosis and now is not the time for them to participate in a study.”
- “The child is too sick for the mom to fill out forms.”
- “The child is having a bad day.”
- “It’s hard to give them the recruitment letter for this study when they were already considering a medical study.”
- “The mom is too tired for me to give her the recruitment letter.”
- “The mom needs to complete the medical research forms before they can start another study with forms.”
- “The mom is too overwhelmed for you to give her any more information.”
- “The mom is too upset by the child’s behavior to talk about a study.”
- “It would be hard for the mom to meet another person.”
- “Now is not a good time to meet with the mom because the child is having a bad day.”
-

The intervention was initially designed for session 1 to be delivered 1 week after confirmation of the child’s cancer diagnosis, session 2 delivered 2 to 3 weeks later, and session 3 delivered 3 to 4 weeks after session 2. Introduction and delivery of the

intervention within this timeframe was very challenging. Based on the slow rate of participant accrual, the intervention delivery was modified for session 1 to be delivered within 8 weeks after confirmation of the child’s cancer diagnosis, session 2 delivered 2 to 3 weeks later, and session 3 delivered 3 to 4 weeks after session 2. The mean time for introduction of the intervention was 6.4 ($SD = 1.8$) weeks with a range of 2 to 8 weeks after confirmation of the child’s cancer diagnosis. Forty percent of the participants had children who had been diagnosed 8 weeks prior to enrollment in the study (see Table 13).

Table 13

Length of Time from Child’s Cancer Diagnosis to Start of Intervention Session 1

Number of Weeks	Frequency	Percent
2	1	6.7
4	1	6.7
5	2	13.3
6	3	20.0
7	2	13.3
8	6	40.0

Intervention fidelity.

Delivery of the intervention. A fidelity monitoring log was used as a guide to ensure that the intervention was delivered as outlined per protocol. There were no deviations from the protocol during the implementation of the intervention. All COPE-PCC sessions were delivered consistently with the intervention manual.

Receipt of the intervention. Manipulation checks were performed to assess how the mothers processed the information they received. Ten-question questionnaires were

administered to participants at sessions 2, 3, and 4 to determine if mothers were processing the information they received. Approximately 93% ($n = 15$) of the mothers answered 80% or more of the questions correctly on all three manipulation checks, which is an indicator that the intervention was adequately received and processed. The mean score on manipulation check 1 was 93 ($SD = 7.65$), 100% on manipulation check 2, and 93% ($SD = 6.94$) on manipulation check 3. The interventionist reviewed all missed questions with the participants upon their completion of the manipulation checks.

Research Question 2 and Results

What are the preliminary effects of a theory-based coping intervention program (i.e., COPE-PCC) on (a) maternal depression, maternal anxiety, and maternal beliefs about parenting a child with cancer; and (b) children's externalizing and internalizing behaviors?

The preliminary effects of the three-session COPE-PCC intervention program were examined by evaluating maternal depression with the BDI-II, maternal anxiety with the STAI, and maternal beliefs regarding their parental role with the PBS and the children's externalizing and internalizing behaviors with the BASC. Descriptive statistics and effect sizes (a measure of the strength of the change) were calculated using Cohen's d for the intervention were computed for state anxiety, depression, and maternal beliefs. Due to the small sample size, a significance level of .10 was set to analyze the data.

Fifteen participants completed the BDI-II edition and the STAI pre- and post-intervention. Paired t -tests were performed for each of the outcome measures (maternal depression, maternal anxiety, and children's behaviors) to determine preliminary efficacy of the intervention. Ratings of maternal depression significantly decreased from pre-

intervention to post-intervention with a large effect as evidenced by the mean score pre-intervention (T0) on the BDI-II of 16.9 ($SD = 3.3$) with a range of 12-23 and post-intervention mean score (T1) of 12.4 ($SD = 3.3$) with a range of 7-9. Maternal anxiety scores also significantly decreased with a large effect as evidenced by the mean score pre-intervention (T0) on the STAI of 47.6 ($SD = 3.2$) with a range of 43-53 and the post-intervention (T1) STAI score of 40.3 ($SD = 4.2$) with a range of 30-47. Maternal beliefs in their ability to parent their ill child significantly increased with a large effect based on answers pre-intervention to post-intervention with the baseline PBS (T0) mean of 54.6 ($SD = 9.1$) with a range of 46-71 and post-intervention mean score (T1) of 64.1 ($SD = 4.8$) with a range of 54-74. Table 14 shows the scores for each participant pre- and post-intervention with the statistically significant large effect sizes change in each measure.

Table 14

Pre- and Posttest Values for the Beck Depression Inventory, the State Trait Anxiety Index, the Parental Belief Scales, and the Behavioral Assessment Scale for Children (n = 15)

	T0Mean (SD)	T1Mean (SD)	Effect Size	P Value
BDI-II	16.9(3.3)	12.4(3.0)	1.4+++	.001**
STAI (State)	47.6(3.2)	40.3(4.2)	1.9+++	.02*
PBS	54.6(9.1)	64.1(4.8)	1.3+++	.002**
Behaviors				
Externalizing	101.5(14.0)	91.8(5.2)	1.5+++	.003**
Internalizing	137.3(24.0)	122.3(10.9)	1.3+++	.01*

Note. ** = significant at the .001 level * = significant at .05 level
 + = small effect size, ++ = medium effect size, +++ = large effect size

The BASC was used to examine the child externalizing and internalizing behaviors. Fifteen participants completed the BASC pre- and post-intervention. Findings indicated a decrease in the externalizing and internalizing behaviors post-intervention with a large effect size. The BASC externalizing composite scores were obtained from the aggression subscale scores and the hyperactivity subscale scores. The BASC internalizing composite scores were obtained from the anxiety subscale scores, the depression subscale scores, and the somatization subscale scores. The mean for the BASC externalizing composite score behaviors decreased from a pre-intervention mean of 101.5 ($SD = 14$) to a post-intervention mean of 91.8 ($SD = 5.2$) with a large effect size. The mean for the BASC internalizing composite score behaviors decreased from a pre-intervention mean of 137.3 ($SD = 24$) to a post-intervention mean of 122.3 ($SD = 10.9$) with a large effect size. Table 15 shows the means for the BASC composite and subscale scores pre- and post-intervention.

Table 15

Pre- and Post-intervention Scores for the BASC (n = 15)

	Pre-intervention <i>M(SD)</i>	Post-intervention <i>M(SD)</i>	Effect Size	P value
Externalizing	101.5(14)	91.8(5.2)	1.5+++	.003**
Aggression	51.7(6.7)	45.5(3.0)	1.3+++	.01*
Hyperactivity	49.7(7.7)	46.2(3.0)	.9+++	.01*
Internalizing	137.3(24)	122.3(10.9)	1.3+++	.01*
Anxiety	43.5(9.5)	39.3(5.0)	.7++	.01*
Depression	51.0(9.2)	41.2(3.5)	1.1+++	.02*
Somatization	44.3(6.1)	41.7(3.6)	1.0+++	.002**

Note. ** = significant at the .001 level * = significant at .05 level + = small effect size, ++ = medium effect size, +++ = large effect size

T scores were calculated and percentiles for the externalizing and internalizing composite scores for the BASC pre- and post-intervention. Percentile scores greater than the 59% are considered *at risk* which warrants monitoring for potential behavioral problems (Reynolds & Kamphaus, 2004). The BASC composite subscales that had percentiles in the *at risk* category pre-intervention were the somatization subscale (64%) and depression (66%), and those percentiles decreased post-intervention (somatization 44% and depression 56%). Seven children had *at risk* scores on the somatization subscale (T score greater than 59%) prior to the intervention and 3 children had *at risk* scores on the somatization subscale (T score greater than 59%) post the intervention. Five children had *at risk* scores on the depression subscale (T score greater than 59%) prior to the intervention and 2 children had *at risk* scores on the depression subscale (T score greater than 59%) post the intervention. Table 16 shows the T scores and percentile for the BASC pre- and post-intervention.

Table 16

BASC Externalizing and Internalizing T Scores and Percentiles

Subscale & Composite Scales	BASC Pre- Intervention		BASC Post-intervention	
	T Score	Percentile	T Score	Percentile
Externalizing Composite Scale				
Aggression	44	33	42	24
Hyperactivity	50	56	47	47
Internalizing Composite Scale				
Anxiety	48	48	46	39
Depression	53	66	50	56
Somatization	53	64	48	44

Research Question 3 and Results

What are the relationships among the variables prior to and immediately following the intervention (COPE-PCC) inclusive of maternal depression, maternal anxiety, maternal beliefs about parenting a child with cancer, and children's externalizing and internalizing behaviors?

The sample size for this study was small and the effects are all preliminary based on the small sample size. Also, due to the small sample size the significance level of .10 was set to analyze the data.

Pearson's correlations which measures the strength and linear relationship between two variables set at an alpha = .10 was conducted among all of the study variables (maternal depression, maternal state anxiety, maternal beliefs, and children's behaviors) and were examined pre-and post-intervention. Table 17 shows the correlations among study variables pre-intervention, and Table 18 depicts the correlates among study variables post-intervention. When examining the relationship among variables at baseline, maternal beliefs demonstrated a strong negative significant correlation between maternal depression ($r = -.51, p < .05$) and maternal state anxiety ($r = -.55, p < .05$). In addition, there was a strong positive significant correlation between maternal depression and maternal state anxiety ($r = .58, p < .05$) at baseline. Maternal state anxiety had a positive significant correlation to trait anxiety at baseline ($r = .44, p < .05$).

When examining the correlations among variables post-intervention, a strong negative significant correlation was found between maternal beliefs between maternal depression ($r = -.54, p < .05$) and anxiety ($r = -.67, p < .05$). In addition, there was a

strong positive significant correlation between maternal depression and maternal anxiety ($r = .55, p < .05$) post-intervention.

When examining the correlations among variables pre-intervention, a strong negative significant correlation was found between maternal beliefs and children's internalizing ($r = -.48, p < .05$) and externalizing behaviors ($r = -.45, p < .05$). When examining the correlations among variables pre-intervention, a strong positive significant correlation was found between depression and children's internalizing ($r = .45, p < .05$) and externalizing behaviors ($r = .52, p < .05$). The correlations among variables pre-intervention, a strong positive significant correlation was found between state anxiety and children's internalizing ($r = .44, p < .05$) and externalizing behaviors ($r = .42, p < .05$) and trait anxiety and children's internalizing ($r = .42, p < .05$) and externalizing behaviors ($r = .43, p < .05$).

When examining the correlations among variables post-intervention, a strong negative significant correlation was found between maternal beliefs and children's internalizing ($r = -.44, p < .05$) and externalizing behaviors ($r = -.45, p < .05$). When examining the correlations among variables post-intervention, a strong positive significant correlation was found between depression and children's internalizing ($r = .50, p < .05$) and externalizing behaviors ($r = .54, p < .05$). The correlations among variables post-intervention, a strong positive significant correlation was found between state anxiety and children's internalizing ($r = .43, p < .05$) and externalizing behaviors ($r = .44, p < .05$).

Table 17

Correlations Among Study Variables Pre-Intervention

	Depression	Anxiety State	Anxiety Trait	Beliefs	Behaviors Externalizing	Behaviors Internalizing
Depression		.58*	.56*	-.51*	.52*	.45*
Anxiety State	.58*		.44*	-.55*	.42*	.44*
Anxiety Trait	.56*	.44*		-.42*	.43*	.42*
Beliefs	-.51*	-.55*	-.42*		-.45*	-.48*
Behaviors Externalizing	.52*	.42*	.43*	-.45*		.50*
Behaviors Internalizing	.45*	.44*	.42*	-.48	.50*	

*Correlation is significant at the 0.1level (2-tailed)

Table 18

Correlations Among Study Variables Post-Intervention

	Depression	Anxiety State	Beliefs	Behaviors Externalizing	Behaviors Internalizing
Depression		.58*	-.54*	.54*	.50*
Anxiety State	.58*		-.67*	.44*	.46*
Beliefs	-.54*	-.67*		-.45*	-.44*
Behaviors Externalizing	.54*	.44*	-.45*		.53*
Behaviors Internalizing	.50*	.46*	-.44	.53*	

*Correlation is significant at the 0.1level (2-tailed)

CHAPTER 5. DISCUSSION

Summary of Findings

The primary aim of this study was to pilot test a theory-based manualized intervention for mothers of children aged 2 to 8 years newly diagnosed with cancer and to determine the feasibility and acceptability of the intervention for this population. The outcomes included maternal depression, maternal anxiety, and children's behaviors. The secondary aims were to:

1. Examine the preliminary effects of a theory-based coping intervention program (COPE-PCC) on (a) maternal depression, maternal anxiety, and maternal beliefs about parenting a child with cancer; and (b) children's externalizing and internalizing behaviors?; and

2. Explore the relationship among the variables prior to and immediately following the intervention program inclusive of maternal depression, maternal anxiety, maternal beliefs about parenting a child with cancer, and children's externalizing and internalizing behavior?

Also, the internal consistency of the instruments (BDI-II, STAI, PBS, and the BASC) for this population was assessed.

Interpretations of the findings are presented in this chapter. This chapter also discusses the study limitations and strengths, the theoretical considerations, and implications for future research and clinical practice.

Feasibility

Feasibility is an important first step in designing an intervention study. Feasibility studies identify what modifications may be needed prior to undertaking a large-scale

study (Bowen et al., 2009). Feasibility studies are used to determine whether an intervention is appropriate for further testing by assessing whether or not the intervention and its findings are significant and maintainable. Bowen et al. (2009) also suggest that a feasibility study can be employed in a population that has been identified as needing a unique topic. Although the coping needs of childhood cancer in parents and children has been well documented and includes posttraumatic stress symptoms, depressive symptoms, and anxiety, there are very few interventions to enhance mental health/coping outcomes in parents and their children after the childhood cancer diagnosis, which was the basis for this feasibility study (Fedele et al., 2013; Flury et al., 2011; Hoekstra-Weebers et al., 2012; Sahler et al., 2013; Stehl et al., 2009).

Using recommendations for the focus of feasibility studies suggested by Bowen et al. (2009), feasibility for this study can demonstrated in several focus areas:

(a) acceptability, (b) demand, (c) implementation, (d) practicality, (e) adaptation, (f) integration, (g) expansion, and (h) limited-efficacy testing of the preliminary effects of the study variables.

Acceptability. Bowen et al. (2009) define the acceptability of a study as the degree to which the intervention is satisfactory or acceptable to the recipients. The exit evaluation questionnaire responses, intervention logs, and interventionist field note documentation were used to determine acceptability and found that the mothers perceived the program to be informative and helpful. The mothers' positive acceptance of the intervention was evident in positive responses to the exit evaluation questions including, "Was the program with its number acceptable to you?," "Was the program helpful in coping with your child's cancer diagnosis?," and, "Would you be interested in

participating in future studies like this one?” All of the participants stated they would recommend the program to other mothers of children diagnosed with cancer. The majority of the participants rated the intervention strategies as easy to use. One participant commented on the length of the BASC and the length of time required to complete the BASC.

In future clinical trials, the questions to address acceptability should include an open-ended question on how the intervention was acceptable or not acceptable to the participants. In addition, a future large-scale RCT should address one important area of acceptability which is the level of satisfaction of the intervention group compared to an attention control group (Bowen et al., 2009).

Demand. One measure of feasibility was the demand of the COPE-PCC intervention in the pediatric oncology population. Currently there are only 15 intervention studies to facilitate parental coping in parents of children diagnosed with cancer which addresses the initial demand for the study (Kazak et al., 2012; Peek & Melnyk, 2010). For this study, demand was based on the level of the participants’ attendance in the COPE-PCC intervention sessions and the completion of the log of times the CD was reviewed. Also, demand was identified in exit evaluation comments as evidenced by positive comments after completion of the intervention (i.e., “I received information that I didn’t get anywhere else,” “I learned new ways to cope with her child’s cancer diagnosis,” “I wish I had gotten this information sooner after my child’s cancer diagnosis”).

Implementation. One measure of feasibility was the implementation of the COPE-PCC intervention as designed. Implementation was examined based on the

attrition rate and delivery of the implementation as planned. Attrition rate was low for this sample and only 1 participant who consented declined to complete the baseline measures and did not start the intervention. Although the sample size was small, all of the participants who completed session 1 remained in the study and completed all of the intervention sessions and the post-intervention questionnaires.

One issue with initial implementation of the study was the initial timing of the planned intervention. Although the initial study was designed to recruit mothers of children within 1 week of their cancer diagnosis, this time period proved to be problematic. After several months of lack of recruitment of participants, the initial period of recruitment was extended to 2 months from the child's cancer diagnosis. Extending the initial intervention to within 2 months of the cancer diagnosis was based on a review of the previous literature which demonstrated a low recruitment rate and a high attrition rate in parents of children diagnosed with cancer to participate in research studies immediately after the cancer diagnosis (Pai et al., 2006, Sahler et al., 2013).

Another issue of initial implementation was the initial age limitations of the children diagnosed with cancer for the study. Many of the children currently being diagnosed with childhood cancer are age 5 to 8 years, and they were excluded from this study based on the initial age restrictions. Expanding the age limit to 8 years of age increased the potential benefits for the current coping study and resulted in recruitment of more participants to the study.

Practicality. Practicality of the COPE-PCC was evaluated by delivery of the intervention and was monitored by compliance to the weekly fidelity logs of session

content. The intervention was delivered at 100% and there were no deviations from the manualized intervention.

Adaptation. The COPE-PCC intervention was adapted from the research supported COPE intervention for parents of critically ill and hospitalized children, which is based on self-regulation and control theories. In prior studies, the delivery of COPE to parents of hospitalized and critically ill children was found to strongly increase parental beliefs to facilitate mental health/coping outcomes in critically ill young children and their parents (Melnik et al., 2004). Because of the positive findings from these studies, COPE was adapted specifically for parents of children with cancer. The outcome measures of BDI-II, STAI, and the BASC-2 were adapted from the COPE and the PBS was modified to cancer specific terminology (i.e., I am NOT sure about how my child will behave when painful things are done to him [or her] in as part of their cancer treatment). The COPE manual was adapted to include specific information concerning the mother and their child's emotional and behavioral response to the cancer diagnosis.

Integration. According to Bowen et al. (2009), integration assesses the ability of the intervention to be integrated into the existing infrastructure. One unexpected issue with integration was the reluctance of the healthcare staff to refer mothers. The healthcare staff voiced concern about caregiver burden and the mother's current level of distress as evidenced by comments such as the mother is "too overwhelmed to participate," and "the mom is too stressed to participate." This concern was not validated by the positive results in decreased maternal depression, maternal anxiety, and child externalizing and internalizing behaviors. One mother commented that she wished the intervention had been started earlier after her child's cancer diagnosis.

Integration for this study was also examined with manipulation checks to assess how the mothers processed the information they received. Participants completed 10-question questionnaires after completion of sessions 1, 2 and 3. Participants scored higher than 90% on each of the manipulation checks, which demonstrated that the participants were processing the information they received.

Expansion. The positive findings from the COPE-PCC feasibility study supports its use as the basis for full-scale study testing the COPE-PCC using a randomized clinical trials with an attention control group that measure mediating variables (i.e., parental beliefs/confidence in parenting skills) so that the explanations of mechanisms through which the interventions work can be determined. In addition, moderating variables should be measured in order to determine under what conditions the interventions work best (e.g., parents in two-parent families, parents with high stress levels). Also, there is a need to study the long-term outcomes associated with interventions in order to determine sustainability of intervention effects. In addition, future studies should continue to incorporate the measurement of child outcomes. Although the current evidence identifies vast differences in the timing of interventions from 24 hours after diagnosis until 1 year post-chemotherapy, future studies should focus on delivering interventions within the first 2 months of diagnosis in order to allay adverse outcomes early. Based on the outcomes for this pilot study, interventions should be designed to prepare parents for what to expect in their children's responses to the diagnosis of childhood cancer and how parents can help the child cope with the diagnosis.

Limited-efficacy testing. Study findings support preliminary efficacy of the COPE-PCC intervention in increasing maternal beliefs about their parenting abilities and

decreasing maternal anxiety and depression and decreasing children's internalizing and externalizing behaviors.

Preliminary effect of COPE-PCC on maternal depression, anxiety, and beliefs. The preliminary effect of the COPE-PCC on maternal depression, anxiety, and beliefs about their ability to parent a child with cancer was examined by evaluating the mothers' level of depression, anxiety, and their beliefs pre-intervention and post-intervention. The mean score of maternal depression on the BDI-II decreased from the pre-intervention to post-intervention with a large positive effect (1.4). The mean score of state maternal anxiety on the STAI decreased from the pre-intervention to post-intervention with a large positive effect (1.9). The mean score of maternal beliefs in their ability to parent their ill child as evidenced by the PBS increased from the pre-intervention to post-intervention with a large positive effect (1.3). Utilizing self-regulation theory (which supports the use of concrete information to prepare for an event before it occurs) and control theory (which postulates that an individual's lack of confidence or perceived lack of skills and/or abilities can cause negative emotions that may interfere with coping efforts), COPE-PCC mothers who were provided information to increase their confidence and/or skills about parenting their child with cancer had an increase in their beliefs about their ability to parent their child after their child's cancer diagnosis. In addition, control theory postulates the discrepancy between the current and desired state will motivate a change in behavior (Carver, 1979; Carver & Scheier, 1982; Johnson, 1999; Johnson & Leventhal, 1983; Melnyk et al., 2004). Similar to COPE on which this intervention was based, COPE-PCC mothers were provided information to increase their beliefs about parenting their child with cancer and their ability to support their children more

effectively after their child's cancer diagnosis, which resulted in a goal state of decreased maternal depression and anxiety (Melnik et al., 2004).

Although the sample size is small, these findings support further large-scale testing of the COPE-PCC intervention in a RCT to assess the effect on maternal beliefs, maternal depression, and maternal anxiety.

Preliminary effect of COPE-PCC on child's behavior. The mean score of child externalizing and internalizing behaviors on the BASC decreased from the pre-intervention to post-intervention with a large positive effect (externalizing effect size = 1.5 and internalizing effect size = 1.3). Similar to COPE (on which this intervention was based), the COPE-PCC intervention strengthened mothers' beliefs in the common behaviors and emotions to expect from themselves and their child after the child's cancer diagnosis. This increase in maternal beliefs enhanced the mother's ability to facilitate their children's adjustment to the cancer diagnosis, which resulted in decreased children's internalizing and externalizing behaviors (Melnik et al., 2004). Also, children's negative behaviors improved as maternal coping outcomes improved, as evidenced by decrease in maternal depression and anxiety correlated with decrease. As postulated by self-regulation theory, COPE-PCC helped to increase the mother's beliefs/confidence in their parenting abilities, which resulted in the mother's ability to be emotionally supportive to their child after the cancer diagnosis, which in turn resulted in decreased negative behaviors in the children.

Although the sample size is small, these findings support further large-scale testing of the COPE-PCC intervention in a RCT to assess the effect on children's internalizing and externalizing behavior after their cancer diagnosis.

Theoretical Mediating Variable: Beliefs

The proposed mediating variable for this study was maternal beliefs. Although the small sample size makes it difficult to adequately test the mediation of belief, the post-intervention means of maternal depression and anxiety decreased as the post-intervention mean of maternal beliefs increased. This negative correlation supports the use of the COPE-PCC with belief as the mediating variable in a large-scale RCT to determine the effect of the intervention on maternal depression and anxiety symptoms after their child's cancer diagnosis and to conduct mediational testing (Melnyk, 1994; Melnyk et al., 2004).

Strengths. A strength of this study was the use of a theory-based and previously efficacious intervention adapted to a new population (i.e., mothers of children newly diagnosed with cancer). Another strength of this study was the use of measures that have known reliability and validity for the population of interest. Also, the participants all had children newly diagnosed with cancer and either had anxiety and depression or had the potential to develop anxiety and depression. Another strength of this study was that it was built on previous research for this population. Lastly, while this was a single-group pre- and post-test design, there was significant attention paid to the fidelity of the intervention to maximally control for confounding variables.

Limitations. The findings from this study should be interpreted in the context of several limitations that may have influenced the results. The first limitation is the use of a one-group pre- and post-test design which threatens the internal validity of the study. Additional limitations of this pilot study included use of self-report measures, a small convenience sample, and the PI not being blinded to study participants, which can all limit the generalizability of the study findings. Another limitation of this study was the

use of a convenience sample which limits the generalizability of the study findings on the potential for (a) homogeneous characteristics of the sample, (b) inadequate representation of minorities, and (c) inadequate representation of socioeconomic status.

The lack of an attention control group with randomization also is a threat to the internal validity of the study or the ability to say the COPE-PCC intervention was the reason for the outcomes in this study.

Despite these limitations, the aggressive evaluation of the feasibility and acceptability of the intervention was a necessary first step in this program of research, which was critical in refining the intervention and study protocol in order to inform a future larger-scale randomized controlled pilot trial of a coping intervention in parents of children diagnosed with cancer. In addition, the large effect sizes of intervention on the material and child coping outcomes provide encouraging results that support the testing of the intervention in a large-scale RCT.

Implications for Clinical Practice

This pilot test of a coping intervention for mothers of children newly diagnosed with cancer demonstrated that the intervention did improve mothers' coping outcomes as evidenced by decreased measures of depression and anxiety post-intervention and decreased child negative behaviors as evidenced by decreased internalizing and externalizing behaviors in the children. Therefore, clinicians should consider incorporating this type of intervention with parents of children newly diagnosed with cancer once these findings are verified with an internally valid study that provides generalizable evidence. This pilot study suggests that clinicians may consider initiating psychosocial interventions within 2 months after the cancer diagnosis to potentially

improve coping outcomes. Any additional sessions of the intervention should review the impact of the cancer diagnosis on the parent and child's emotional and behavioral response to the cancer.

Also, this pilot study demonstrated a decrease in negative children's behaviors after the intervention which has positive implications for clinical practice including potential for improvement in the child's mental health within the context of the current limitations in mental health services for children (Melnyk et al., 2004).

Implications for Theory

Self-regulation and control theory were the theoretical basis for the adaption of COPE for implementation in mothers of children newly diagnosed with cancer (COPE-PCC). Self-regulation theory posits that concrete information about a healthcare event can result in development of a cognitive schema regarding what to expect as the event unfolds. This schema then results in decreasing the discrepancy between what is expected and what actually occurs. Control theory contends that a change in discrepancy between the desired state and the current state results in behaviors to decrease the discrepancy.

Utilizing self-regulation theory and control theory, the COPE-PCC program provided audiotaped CDs with matched written information to the mothers regarding their and their children's probable emotional and behavioral responses to their cancer diagnosis. Providing information about what mothers could expect in regards to their and their child's emotional and behavioral response resulted in the mothers developing a schema prior to the actual emotional response and allowed the mothers to decrease the discrepancy between what they expected and what actually occurred. The results of this study suggest as mothers were prepared for what to expect, their beliefs/confidence about

their parenting abilities increased and their depression and anxiety decreased. Also, as mothers were prepared on what changes to expect in their child's behaviors, they reported a decrease in their child's internalizing and externalizing behaviors. The findings support the use of self-regulation and control theory as the theoretical basis for COPE-PCC.

Implications for Future Research

Future intervention studies with parents of newly diagnosed cancer patients should include full-scale randomized clinical trials with an attention control group that measures mediating variables so that the explanations of mechanisms through which the interventions work can be determined. In addition, moderating variables should be measured in order to determine under what conditions the interventions work best (e.g., parents in two-parent families, parents with high stress levels). Also, there is a need to study the long-term outcomes associated with interventions beyond 9 months in order to determine sustainability of intervention effects. In addition, future studies also should continue to incorporate the measurement of child behavioral outcomes. Based on the outcomes for this small pilot study, interventions should be designed to prepare parents for what to expect in their children's responses to the diagnosis of childhood cancer or how parents can help the child cope with the diagnosis.

Another implication which anecdotally arose from this pilot study which should be considered in the design of future research is the barrier to recruitment from the pediatric oncology staff. A number of mothers meeting the enrollment criteria were not presented with the study information because the staff felt the mothers were "too overwhelmed to participate in a study," which was not validated in the exit evaluations that all of the participants completed. Although these perceptions were not validated, a

large-scale study should be conducted and exit evaluation could be used to determine the mothers' actual perception of their ability to participate in a study. Also, the positive findings in increased maternal beliefs, decreased maternal depression and anxiety, and decreased children's internalizing and externalizing behaviors can be presented to the staff to facilitate recruitment.

Conclusions

This small pilot study suggests that a theory-based coping intervention (COPE-PCC) is acceptable and feasible to deliver to mothers of children newly diagnosed with cancer.

Continued implementation and refinement of strategies learned in COPE-PCC has the potential to improve the coping outcomes in mothers of children newly diagnosed with cancer as evidenced the positive findings in this small sample.

Since the only participants in this study were mothers, further research with both parents would expand the generalizability of study findings to both mothers and fathers. Further research will enhance the body of coping knowledge regarding the effect of the COPE-PCC intervention in this high risk population, thus adding to nursing science.

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APPENDIX A

PSYCHOSOCIAL INTERVENTIONS FOR PARENTS OF CHILDREN WITH
CANCER

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
<p>Sahler, Dolgin, Phipps, Fairclough, Askins, Katz, Noll, & Butler</p> <p>USA</p> <p><i>Specificity of problem-solving skills training in mothers of children newly diagnosed with cancer: results of a multisite randomized clinical trial (2013)</i></p>	<p><i>Purpose:</i> To evaluate the efficacy of a problem-solving intervention for mothers of children newly diagnosed with cancer.</p> <p><i>Sample:</i> 309 mothers of children diagnosed with cancer within 2 to 16 weeks. Mothers had to be able to read and speak either English or Spanish and live within 50 miles of the hospital to participate.</p> <p><i>Setting:</i> 4 university hospitals in the USA</p>	<p>Randomized controlled trial (RCT)</p> <p><i>Experimental Intervention:</i> An eight 1-hour session intervention for mothers of children newly diagnosed with cancer that focused on problem-solving skills.</p> <p><i>Control intervention</i> Standard care</p>	<p>Parents completed The Social Problem-Solving Inventory-Revised and the Profile of Mood States Scale at baseline, immediately post intervention and 3 months post-intervention.</p>	<p>There authors reported significant improvement in scores on the problem-solving skills mothers in the intervention group. There were no reported significant differences in scores Profiles of Mood.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Randomization to study group Large sample size <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Lack of specified theoretical framework • Lack of long-term follow-up • No child measure

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
<p>Fedele, Hullman, Chaffin, Kenner, Fisher, Kirk, Eddington, Phipps, McNall-Knapp, & Mullins</p> <p>USA</p> <p><i>Impact of a parent-based interdisciplinary intervention for mother on adjustment in children newly diagnosed with cancer</i> (2013)</p>	<p><i>Purpose:</i> To evaluate the feasibility and acceptability of a brief inter-disciplinary intervention for mothers of children newly diagnosed with cancer.</p> <p><i>Sample:</i> 52 families of children from age 2 to 17 years newly diagnosed with cancer. The mothers had to speak English have phone access and the child had to be receiving chemotherapy</p> <p><i>Setting:</i> University hospital in the USA</p>	<p>RCT</p> <p><i>Experimental Intervention:</i> A 12-session intervention for mothers of children newly diagnosed with cancer that focused on reducing stress. Interventions 1, 3, 5, 7, 9 and 11 were administered by a psychologist and intervention 2, 4, 6, 8, 10 and 12 were administered by a nurse.</p> <p><i>Control intervention</i> Standard care</p>	<p>Parents completed Symptom Checklist 90-Revised and the Behavior Assessment System for Children, 2nd edition: Parent Report Scale at baseline and immediately postintervention.</p>	<p>There authors reported significant reduction in internalizing behaviors in mothers that received the intervention.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Randomization to study group • Child measures <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Lack of specified theoretical framework • Lack of long-term follow-up

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
<p>Mullins, Fedele, Chaffin, Hullmann, Kenner, Eddington, Phipps, & McNall-Knapp</p> <p>USA</p> <p><i>A clinic-based interdisciplinary intervention for mothers of children newly diagnosed with cancer: A pilot study (2012)</i></p>	<p><i>Purpose:</i> To evaluate the feasibility and acceptability of a brief inter-disciplinary intervention for mothers of children newly diagnosed with cancer.</p> <p><i>Sample:</i> 52 families of children from age 2 to 17 years newly diagnosed with cancer. The mothers had to speak English have phone access and the child had to be receiving chemotherapy</p> <p><i>Setting:</i> University hospital in the USA</p>	<p>RCT</p> <p><i>Experimental Intervention:</i> A six-session intervention for mothers of children newly diagnosed with cancer that focused on reducing stress. Interventions 1, 3 and 5 were administered by a psychologist and interventions 2, 4 and 6 were administered by a nurse.</p> <p><i>Control intervention</i> Standard care</p>	<p>Parents completed The Intensity of Treatment Rating, Parent Perception of Uncertainty Scale, Symptom Checklist 90-Revised, Impact of Events Scale-revised and Care of my Child with Cancer Scale at baseline and immediately post-intervention. The parents also completed patient satisfaction surveys at the beginning of each intervention session and after completion of the last intervention session.</p>	<p>The authors did not report the specific results of the pre- and post-intervention questionnaire results, but did report the feasibility and acceptability results which demonstrated both were achieved with this study.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Randomization to study group <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Lack of specified theoretical framework • Lack of long-term follow-up • No child measure

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
<p>Marsland, Long, Howe, Thompson, Terask, & Ewing</p> <p>USA</p> <p><i>A pilot trial of a stress management for primary caregivers of children newly diagnosed with cancer: Preliminary evidence that perceived social support moderates the psychological benefit of intervention (2013)</i></p>	<p><i>Purpose:</i> To evaluate the feasibility and acceptability of a stress management intervention for caregivers of children newly diagnosed with cancer.</p> <p><i>Sample:</i> 45 families of children from age 2 to 17 years newly diagnosed with cancer. The mothers had to speak English have phone access and the child had to be receiving chemotherapy</p> <p><i>Setting:</i> University hospital in the USA</p>	<p>RCT</p> <p><i>Experimental Intervention:</i> Six face-to-face intervention sessions, six telephone contacts, and access to a website for caregivers of children newly diagnosed with cancer that focused on stress management</p> <p><i>Control intervention</i> Standard care</p>	<p>Parents completed the Beck Depression Inventory, the State-Trait Anxiety Inventory, the Perceived Stress Scale and the Impact of Event Scale at baseline and post-intervention and the Interpersonal Support Evaluation List at baseline.</p>	<p>The authors reported that there was no significant reduction in stress in the intervention group, but caregivers who reported perceived lower support had an improvement in psychological benefit after the intervention.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Randomization to study group <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Lack of specified theoretical framework • Lack of long-term follow-up • No child measure

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
<p>Othman, Blunden, Mohamad, Hussin, & Osman</p> <p>Malaysia</p> <p><i>Piloting a psycho-education program for parents of pediatric cancer patients in Malaysia (2010)</i></p>	<p><i>Purpose:</i> To evaluate a psycho-education program for parents of children with cancer in Malaysia</p> <p><i>Sample:</i> 79 parents with children with cancer. All of the parents were married, Malay, and Muslim. No average age was documented.</p> <p><i>Setting:</i> Government hospital in Malaysia</p>	<p>Quasi experimental</p> <p><i>Experimental intervention:</i> Standard care plus four 50-minute information sessions on childhood cancer and coping strategies.</p> <p><i>Control intervention</i> Standard care</p>	<p>Parents completed 5 self-assessment scales: The Knowledge Assessment Scale, State Anxiety Scale (STAI), Strain Questionnaires (SQ), Strength and Difficulties Questionnaire (SDQ) and Parents' Activities with Children (PA). The scales were mailed to the families 4 to 8 months after intervention.</p>	<p>Parents in the experimental intervention group reported increased knowledge and decreased anxiety.</p> <p>The authors reported the effect size for the intervention was small.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • 100% of the parents completed the questionnaires <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Lack of true attention control group to control for the time and attention spent with the parents in the experimental group • Study location of Malaysia may limit applicability to parents in the US • Convenience sample, no long-term follow-up

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
<p>Stehl, Kazak, Alderfer, Rodriguez, Hwang, Pai, Boeving, & Reilly</p> <p><i>Conducting a randomized clinical trial of an psychological intervention for parents/caregivers of children with cancer shortly after diagnosis (2009)</i></p>	<p><i>Purpose:</i> To evaluate the feasibility of a brief psychological intervention for parents of children newly diagnosed with cancer.</p> <p><i>Sample:</i> 82 families of children from birth to 17 years newly diagnosed with cancer. Families had to be comprised of 2 parents/ caregivers to participate</p> <p><i>Setting:</i> University hospital in the USA</p>	<p>RCT</p> <p><i>Experimental Intervention:</i> A three-session intervention program (Surviving Cancer Competently Intervention Program-Newly Diagnosed) for parents/caregivers of children newly diagnosed with cancer. Timing for interventions included initial intervention started 24 hours to 6 days after diagnosis and all three sessions completed within first month of diagnosis. Interventions were provided by four psychology fellows and a PhD nurse.</p> <p><i>Control</i></p>	<p>Parents completed the Acute Stress Disorder Scale (ASDS), the Impact of Event Scale-Revised (IES-R), and the State-Trait Anxiety Inventory (STAI). The ASDS was completed prior to intervention and 1 month after intervention. The IES-R was administered after the intervention. The STAI was administered prior to intervention and a shortened version was administered 1 month after the intervention.</p>	<p>There were no reported significant differences in scores on the ASDS, IES-R, and the STAI for parents in the intervention group and the control group.</p> <p>The authors reported the effect size for the intervention was small.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Theoretical framework-Cognitive-Behavioral Theory and Family Therapy • Follow up RCT of previous intervention study with larger sample size • Use of valid and reliable instruments <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Narrow inclusion criteria (requirement for 2 parents or caregivers) • Final retention rate of 23% for the intervention, which threatens the internal validity of the study

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
		<i>Intervention:</i> Standard psychosocial care			<ul style="list-style-type: none"> • Use of psychology fellows and a PhD nurse may limit use of the intervention in institutions where these professionals are lacking
<p>Duncan, Gidron, Rabin, Gouchber, Moser, & Kapelushnik</p> <p>Israel</p> <p><i>The effects of guided written disclosure on psychological symptoms among parents of children with cancer (2007)</i></p>	<p><i>Purpose :</i> To evaluate the efficacy of three 15-minute guided writing sessions</p> <p><i>Sample:</i> 8 parents of children diagnosed with cancer within 2 months prior to study entry.</p> <p><i>Setting:</i> University hospital in Israel</p>	One group pre-and posttest pre-experimental design	Parents completed the revised Posttraumatic Diagnostic Scale (PTDS) at baseline and 1 month after guided writing intervention.	Guided writing intervention showed a decrease in parental posttraumatic stress symptoms but no change in parental depression. The effect size for PTSS was 0.84(large) and there was no effect for depression.	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Easily replicated • 100% completion of questionnaire <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Small sample size • Location in Israel, which may limit applicability to parents in the US • No attention control group, which threatens the internal validity of the study • No long-term follow-up

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
<p>Svavarsdottir & Sigurdardottir</p> <p>Iceland</p> <p><i>Developing a family-level intervention for families of children with cancer (2006)</i></p>	<p><i>Purpose:</i> To evaluate the feasibility and efficacy of a family-level intervention for parents of children age 0-18 years newly diagnosed with cancer</p> <p><i>Sample:</i> 10 families (19 parents) of children newly diagnosed with cancer. The average age of the mothers was 37.5 years and the average age of the fathers was 39.4 years.</p> <p><i>Setting:</i> University hospital in Iceland</p>	<p>One group pre- and posttest pre-experimental design</p> <p>Parents were given access to an educational and informational web site focusing on practical issues regarding their child's cancer including treatments, management of side effects, and future concerns, as well as Internet-based support and one to two in-person support interviews.</p>	<p>Parents completed self-assessment scales: Cancer Factor Index (CFI), Coping Health Inventory for Parents (CHIP), Family Hardiness Index (FHI), General Well Being Schedule (GWB), and the Family Adaptation Scale (FAS). The self-assessment scales were completed at baseline, 6 months, and 12 months after the intervention.</p>	<p>Parents self-reported improvement in well-being measures, coping behaviors, and family hardiness at both 6 and 12 months after the intervention.</p> <p>The effect size for this study was small for coping, family hardiness, and well-being.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Theoretical framework-Calgary Family Intervention Model to guide the study • Long-term follow-up (12 months after intervention) • 1% subject attrition <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Lack of control group, which weakens internal validity of the study • Small sample size • Difficult to reproduce based on constantly changing web-based intervention • Study location was Iceland, which may limit

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
					applicability to parents in the US
<p>Pai, Drotar, Zebracki, Moore, & Youngstrom</p> <p><i>A meta-analysis of the effects of psychological interventions in pediatric oncology on outcomes of psychological distress (2006)</i></p>	<p><i>Purpose:</i> To evaluate the efficacy of psychological interventions in decreasing psychological distress in pediatric oncology</p> <p><i>Sample:</i> A total of 28 studies were reviewed for interventions in pediatric oncology. 12 studies met the criteria for inclusion which included children 18 years of age or younger and/or their families, published in English.</p>	<p>Meta-analysis of preventive interventions that were designed to reduce the level of negative psychological sequelae of pediatric cancer in parents and children.</p>	<p>The meta-analysis reviewed 12 pediatric oncology intervention studies. Five studies included parental interventions but only 3 of the studies assessed parent outcomes with psychosocial interventions. The 5 parental interventions were teaching problem-solving skills, engaging in written disclosure, and teaching cognitive behavioral techniques. The delivery format varied based on the intervention.</p>	<p>Meta-analysis reported decreased parental distress in intervention groups. The authors reported the effect size as small.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Meta analysis of intervention studies <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Small number of psychological interventions to review • Diversity of intervention approaches making it difficult to analyze effects across studies and draw conclusions regarding the most potent intervention for parents of children diagnosed with cancer

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
<p>Kazak, Simms, Alderfer, Rourke, Crump, McClure, Jones, Rodriguez, Boeving, Hwang, & Reilly</p> <p><i>Feasibility and preliminary outcomes from a pilot study of a brief psychological intervention for families of children newly diagnosed with cancer (2005)</i></p>	<p><i>Purpose:</i> To evaluate the feasibility and outcomes of a pilot study that tested the effects of a new three-session intervention program for caregivers of children with cancer</p> <p><i>Sample:</i> 19 families (38 caregivers) with children aged 0-17 newly diagnosed with pediatric malignancy. 19 mothers, 18 fathers, and 1 grandmother participated. The average age of the primary caregiver was 37 and the average age of the partner was 42.</p> <p><i>Setting:</i> A children's hospital in the USA</p>	<p>Two-group RCT</p> <p><i>Experimental intervention:</i> Three 45-minute sessions of Surviving Cancer Competently Intervention Program-Newly Diagnosed (SCCIP-ND) which incorporates a CD-ROM and three discussion intervention sessions to focus on the cancer journey. The intervention started within 24 hours after the caregiver received diagnosis of the child's cancer and was administered by 2 psychology fellows and 1 psychology graduate student who had received specialized training</p>	<p>Four scales completed by caregivers: the Acute Stress Disorder Scale (ASDS) completed after the first intervention, Impact of Events Scale-Revised (IES-R) completed after the second intervention, State-Trait Anxiety Inventory (STAI) completed after the first and second intervention, and Program Evaluation Form completed after the third intervention.</p> <p>One form completed by the oncology social workers and child life specialists to track contact provided to the family to verify usual psychosocial</p>	<p>Caregivers in the intervention group self-reported a decrease in anxiety and posttraumatic stress symptoms.</p> <p>The effect size for the STAI was large (0.88).</p> <p>There is no reported effect size for the ASDS and the IES-R and no reported measures to calculate effect size.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Randomization to study group • Intervention commenced within 24 hours of diagnosis <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Small convenience sample size • Lack of specified theoretical framework • Lack of long-term follow-up • No child measures. • No reported outcomes for the IES-R and the ASDS.

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
		<p>to provide the intervention</p> <p><i>Control intervention:</i> Usual psychosocial care (social worker, written resources including information about diagnosis and treatment)</p>	<p>care for the control group.</p> <p>A scale completed by the treating oncologist blinded to patient identity to classify treatment protocol (Intensity of Treatment Rating).</p>		
<p>Sahler, Fairclough, Mulhern, Noll, Varni, Dolgin, Katz & Copeland</p> <p>USA and Israel</p> <p><i>Using problem-solving skills training to reduce negative affectivity in mothers of children with newly diagnosed cancer: report of a multi-site randomized trial (2005)</i></p>	<p><i>Purpose:</i> To evaluate the efficacy of problem-solving training skills interventions to decrease the emotional distress in mothers of children newly diagnosed with cancer. Replication study with inclusion of Spanish speaking only mother, English speaking only mother, and Hebrew speaking</p>	<p>RCT (replication study)</p> <p><i>Experimental Intervention:</i> Eight 1-hour individual sessions of specific problems identified by each mother provided by a mental health professional.</p> <p><i>Control Intervention:</i> Usual psychosocial care</p>	<p>Mothers completed Neo-Five Factor Inventory (NEO-FFI) at baseline and the Social Problem-Solving Inventory-Cancer (SPSI-C), the Profile of Mood States (POMS), the Beck Depression Inventory-II (BDI-II), and the Impact of Event Scale-Revised (IES-R) at baseline, 10-12 weeks after the intervention and 6 months after the</p>	<p>Mothers in the intervention group reported decreased emotional distress and depression immediately following the intervention that was maintained at the 6-month follow-up. The effect size for the intervention was medium.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • 10% attrition • Randomization to study group <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Lack of long-term follow-up • No child outcomes measures • Fathers not included in intervention • Intervention delivered by a mental health professional, which may not be

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
	<p>only mothers.</p> <p><i>Sample:</i> 217 mothers of children diagnosed with cancer 2 to 16 weeks before study enrollment. Spanish speaking only mothers were recruited first to obtain 20% of total sample. The average age of the mothers was 35 years. The majority of the mothers (88%) were married and 85% had a minimum of a high school education. The primary language was 66% English, 20% Spanish and 13 % Hebrew.</p> <p><i>Setting:</i> 7 children's hospitals in the USA and 1 hospital in Israel</p>		intervention.		<p>feasible in some settings</p> <ul style="list-style-type: none"> • Lack of an attention control group, which weakens the internal validity of the study

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
<p>Kazak, Alderfer, Streisand, Simms, Rourke, Barakat, & Gallagher</p> <p><i>Treatment of posttraumatic stress symptoms in adolescent survivors of childhood cancer and their families: a randomized clinical trial (2004)</i></p>	<p><i>Purpose:</i> To determine the efficacy of a cognitive-behavior based intervention to reduce symptoms of posttraumatic stress in adolescent survivors of childhood cancer and their parents</p> <p><i>Sample:</i> 150 families with children aged 11 to 19 years who had completed treatment for childhood cancer 1-10 years prior to participation. The average age of the mothers was 42 years and the fathers was 46 years.</p> <p><i>Setting:</i> University hospital in the USA</p>	<p>RCT (replication study)</p> <p><i>Experimental Intervention:</i> Interventions were conducted as a 1-day manualized program that consisted of 4 topics: how cancer has affected me and my family, coping skills, getting on with life, putting it all together. Mother, fathers, siblings, and adolescent attended individual sessions provided by therapists.</p> <p><i>Control Intervention:</i> Wait control list were invited to participate in intervention 8 to 10 months after baseline</p>	<p>Parents and survivors completed the Posttraumatic Stress Disorder Reaction Index, Impact of Event Scale, and the State-Trait Anxiety Inventory prior to intervention (T1) and 3 to 5 months later (T2).</p>	<p>Parents and survivors showed a greater decrease in posttraumatic stress between T1 and T2 than the control wait list group.</p> <p>The effect size for the intervention in this study was small.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Child outcome measures included • Inclusion of fathers <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Lack of true control group • 38% attrition • Intervention implementation by therapist may limit intervention in institutions where therapists are not readily available

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
<p>Sahler, Varni, Fairclough, Butler, Noll, Dolgin, Phipps, Copeland, Katz, & Mulhern</p> <p>USA and Israel</p> <p><i>Problem-solving skills for mother of children with newly diagnosed cancer: A randomized trial</i> (2002)</p>	<p><i>Purpose:</i> To evaluate the efficacy of problem-solving training skills interventions to decrease the emotional distress in mothers of children newly diagnosed with cancer</p> <p><i>Sample:</i> 92 mothers of children diagnosed with cancer 2 to 16 weeks before study enrollment. The average age of the mothers was 34.7 years. The majority of the mothers were married and all had a minimum of a high school education.</p> <p><i>Setting:</i> 5 children's hospitals in the USA and 1 hospital</p>	<p>RCT (pilot study)</p> <p><i>Experimental Intervention:</i> Eight 1-hour individual sessions of specific problems identified by each mother provided by a mental health professional.</p> <p><i>Control Intervention:</i> Standard psychosocial care</p>	<p>Mothers completed the Social Problem-Solving Inventory-Cancer (SPSI-C) and the Profile of Mood States (POMS). All mothers completed the SPSI-C and the POMS prior to randomization to the intervention or control group. Mothers in the intervention group completed the SPSI-C and POMS immediately after the intervention and 3 months later, while the mothers in the control group completed the SPSI-C and the POMS at 10-12 weeks and at 22-24 weeks.</p> <p>The SPSI-C was adapted from the Social Problem-solving Inventory</p>	<p>Mothers in the intervention group reported decreased emotional distress immediately following the intervention with a diminishing effect in decreased emotional distress 3 months after the intervention.</p> <p>The effect size for the intervention on problem-solving skills training was moderate (0.45-0.57) and for dysfunctional problem-solving was small 0.24-0.31).</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • 100% completion of questionnaires <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Lack of an attention control group, which weakens the internal validity of the study • Fathers not included in intervention • Intervention delivered by a mental health professional which may not be feasible in some settings

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
	in Israel		for this study.		
<p>Streisand, Rodrigue, Houck, & Graham-Pole</p> <p><i>Brief report: Parents of children undergoing bone marrow transplantation: Documenting stress and piloting a psychological intervention program</i> (2000)</p>	<p><i>Purpose:</i> To document stress and evaluate efficacy of a psychological intervention in parents of children undergoing bone marrow transplant</p> <p><i>Sample:</i> 22 mothers of children aged 2-16 years undergoing a bone marrow transplant. Most mothers were married, Caucasian, and achieved a high school education.</p> <p><i>Setting:</i> Teaching hospital in the USA</p>	<p>RCT</p> <p><i>Experimental Intervention:</i> A graduate psychology student provided one 90-minute intervention session focused on education, relaxation, and education. In addition, the parents were provided handouts and a tape of relaxation techniques.</p> <p><i>Control Intervention:</i> Standard care</p>	<p>All mothers completed the Daily Stress Inventory (DSI), the Parenting Stress Index (PSI), and a Semi-structured Interview (SSINT).</p> <p>The DSI was completed at 6 time points: baseline (2 to 4 weeks prior to admission), 7 days before transplant, day of transplant, 7 days after transplant, 14 after transplant, and 21 days after transplant. The PSI was conducted at baseline and 21 days after transplant. The SSINT which was developed for this study was conducted at</p>	<p>Mothers in the intervention group reported less stress on the DSI and PSI both prior to and 21 days posttransplant.</p> <p>On the SSINT there was no significant difference between the control and intervention group.</p> <p>The effect size for both the DSI and PSI were medium to large.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • 100% completion of questionnaires • Random assignment to groups <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Lack of long-term follow up • Small sample size • No attention control group intervention to control for the time and attention spent with the mothers in the experimental group • No child outcome measures

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
			baseline, 7 days before transplant, and 14 days after transplant, and 21 days after transplant.		
<p>Kazak, Simms, Barakat, Hobbie, Foley, Golomb, & Best</p> <p>USA</p> <p><i>Surviving Cancer Competently Intervention Program (SCCIP): A cognitive-behavioral and family therapy intervention for adolescent survivors of childhood cancer and their families (1999)</i></p>	<p><i>Purpose:</i> To determine the effectiveness of a cognitive-behavior based intervention to reduce symptoms of posttraumatic stress in adolescent survivors of childhood cancer and their parents.</p> <p><i>Sample:</i> 19 families of adolescent survivors who had previously participated in studies.</p> <p><i>Setting:</i> University hospital in the USA</p>	<p>Pre-and posttest one group design, pre-experiment</p> <p>Intervention was developed by multidisciplinary team consisting of psychologists, social workers, and nurse practitioner.</p> <p>Interventions where covering four topics: how cancer has affected me and my family, coping skills, getting on with life, putting it all together. Mother, fathers, siblings and adolescent attended individual sessions provided by therapists.</p>	<p>Parents completed 4 self-assessments (Posttraumatic Stress Disorder Reaction Index, Impact of Event Scale, State-Trait Anxiety Inventory, and Family Life Scale) prior to assessment and 6 months after the intervention.</p>	<p>Parents and adolescent survivors self-reported decreased symptoms of posttraumatic stress and anxiety.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Theoretical framework-Cognitive-Behavioral Theory and Family Therapy • Study location USA • 100% completion of questionnaires <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • Lack of a control group, which threatens the internal validity of the study • Small convenience sample size • Unable to determine effect size, based on

Author(s), Title of Study, and Year of Publication	Purpose, Sample, and Setting	Design	Outcomes with Measures and Time Administered	Findings	Strengths and Limitations
					<p>results reported.</p> <ul style="list-style-type: none"> • Intervention implementation by therapist may limit intervention in institutions where therapist are not readily available
<p>Hoekstra-Weebers, Heuvel, Jaspers, Kamps, & Klip</p> <p>The Netherlands</p> <p><i>Brief report: An intervention program for parents of pediatric cancer patients: A randomized controlled trial (1998)</i></p>	<p><i>Purpose:</i> To evaluate the efficacy of a psycho-educational program for parents of pediatric cancer patients</p> <p><i>Sample:</i> 120 parents of children newly diagnosed with cancer. The average age was 36.6 years and the majority was married.</p> <p><i>Setting:</i> University hospital in the Netherlands</p>	<p>RCT</p> <p><i>Experimental Intervention:</i> Eight 90-minute manual guided interventions at 3-week intervals</p> <p><i>Control Intervention:</i> Standard psychosocial care</p>	<p>The parents completed the Goldberg General Health Questionnaire (GHQ), the Symptom Check List (SCL), and the State-Trait Anxiety Inventory –State (STAI-S) within 14 days of enrollment (T1), immediately after completion of the intervention (T2), and 6 months after completion of the intervention (T3).</p>	<p>The study found that although there was a decrease in parental distress over time, there was no significant decrease in distress between the intervention and the control group.</p> <p>The authors reported the effect size for the intervention as medium.</p>	<p><i>Strengths:</i></p> <ul style="list-style-type: none"> • Inclusion of both mothers and fathers <p><i>Limitations:</i></p> <ul style="list-style-type: none"> • No child outcomes included • No long-term follow-up • No attention control group which limits the internal validity of the study • No theoretical framework

APPENDIX B
STUDY MEASURES

**Coping in Mothers of Children with Cancer:
Mother Demographic Question**

Directions: Please fill in the blank or check the number of the item that best answers your question.

1. Your age in years? _____

2. Number of children living in your household _____

3. Please check all races that apply to your ethnic background

White, not of Hispanic origin	_____	1
Black, not of Hispanic origin	_____	2
Hispanic or Latino	_____	3
American Indian	_____	4
Alaskan Native	_____	5
Asian/Pacific Islander	_____	6
Other	_____	7

4. Your marital status

Married	_____	1
Never Married	_____	2
Separated	_____	3
Divorced	_____	4
Widowed	_____	5

5. Your education level

Did not finish high school	_____	1
Finished high or got GED	_____	2
Some college or training after high school	_____	3
Finished college	_____	4
Master's degree or doctoral Degree	_____	5

6. Your household income per year

Less \$20,000	_____	1
\$20,000-\$39,000	_____	2
\$40,000-\$59,000	_____	3
\$60,000-\$79,000	_____	4
\$80,000-\$99,000	_____	5
More than \$100,000	_____	6

7. On a scale of “0” meaning none, to “10” meaning a lot, please rate the amount of family and social support you have. **Please circle your response.**

0	1	2	3	4	5	6	7	8	9	10
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8. On a scale of 0 meaning none, to 10 meaning a lot, please rate how serious you perceive your child’s illness?

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

9. Do you have a history of or current presence of mental health disorders?

Yes _____ 1
No _____ 2

If yes, what type of mental health disorder? _____

10. Do you have any history of or a current chronic illness?

Yes _____ 1
No _____ 2

If yes, what type of chronic illness? _____

11. Has your child has ever been diagnosed with a mental health/behavioral disorder?

Yes _____ 1
No _____ 2

If yes, what type of mental health/behavioral disorder? _____

12. Does your child have a history of a chronic or debilitating illness prior to this diagnosis?

Yes _____ 1
No _____ 2

If yes, what type of illness? _____

13. Have any of your other children been diagnosed with cancer or chronic illness?

Yes _____ 1
No _____ 2

If yes, what type of cancer/illness? _____

Beck Depression Inventory

Please pick the statement that best describes the way you have been feeling during the past two weeks including today.

1. Sadness

- 0 I do not feel sad.
- 1 I feel sad much of the time.
- 2 I am sad all the time.
- 3 I am so sad or unhappy that I can't stand it.

2. Pessimism

- 0 I am not discouraged about my future.
- 1 I feel more discouraged about my future than I used to be.
- 2 I do not expect things to work out for me.
- 3 I feel my future is hopeless and will only get worse.

3. Past Failure

- 0 I do not feel like a failure.
- 1 I have failed more than I should have.
- 2 As I look back I see a lot of failures.
- 3 I feel I am a total failure as a person.

4. Loss of Pleasure

- 0 I get as much pleasure as I ever did from the things I enjoy.
- 1 I don't enjoy things as much as I used to.
- 2 I get very little pleasure from the things I used to enjoy.
- 3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

- 0 I don't feel particularly guilty.
- 1 I feel guilty over many things I have done or should have done.
- 2 I feel guilty most of the time.
- 3 I feel guilty all the time.

6. Punishment Feelings

- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

7. Self-Dislike

- 0 I feel the same about myself as ever.
- 1 I have lost confidence in myself.
- 2 I am disappointed in myself.
- 3 I dislike myself.

8. Self-Criticalness

- 0 I don't criticize or blame myself more than usual
- 1 I am more critical of myself than I used to be.
- 2 I criticize myself for all of my faults.
- 3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

- 0 I don't have any thoughts of killing myself.
- 1 I have thoughts of killing myself, but I would not carry them out.
- 2 I would like to kill myself.
- 3 I would kill myself if I had the chance.

10. Crying

- 0 I don't cry any more than I used to.
- 1 I cry more than I used to.
- 2 I cry over every little thing.
- 3 I feel like crying, but I can't.

11. Agitation

- 0 I am no more restless or wound up than usual.
- 1 I feel more restless or wound up than usual.
- 2 I am so restless or agitated that it's hard to stay still.
- 3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

- 0 I have not lost interest in other people or activities.
- 1 I am less interested in other people or things than before.
- 2 I have lost most of my interest in other people or things.
- 3 It's hard to get interested in anything.

13. Indecisiveness

- 0 I make decisions about as well as ever.
- 1 I find it is more difficult to make decisions than usual.
- 2 I have much greater difficulty in making decisions than I used to.
- 3 I have trouble making any decisions.

Subtotal Page 1 _____ Subtotal Page 2 _____ Subtotal Page 3 _____ Total Score _____
Score of 0-13: minimal, 14-19: mild, 20-28: moderate, and 29-63: severe

14. Worthlessness

- 0 I do not feel I am worthless.
- 1 I don't consider myself as worthwhile and useful as I used to.
- 2 I feel more worthless as compare to other people.
- 3 I feel utterly worthless.

15. Loss of Energy

- 0 I have as much energy as ever.
- 1 I have less energy than I used to have.
- 2 I don't have enough energy to do very much.
- 3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

- 0 I have not experienced any change in my sleeping pattern.
- 1 I sleep somewhat less than usual. –or– I sleep somewhat more than usual.
- 2 I sleep a lot less than usual. –or– I sleep a lot more than usual.
- 3 I sleep most of the day. –or– I wake up 1-2 hours early and can't get back to sleep

17. Irritability

- 0 I am no more irritable than usual.
- 1 I am more irritable than usual.
- 2 I am much more irritable than usual.
- 3 I am irritable all the time.

18. Changes in Appetite

- 0 I have not experienced any change in my appetite
- 1 My appetite is somewhat less than usual. –or– My appetite is somewhat greater than usual.
- 2 My appetite is much less than usual. –or– My appetite is much greater than usual.
- 3 I have no appetite at all. –or– I crave food all the time

19. Concentration Difficulty

- 0 I can concentrate as well as ever.
- 1 I can't concentrate as well as usual.
- 2 It's hard to keep my mind on anything for very long.
- 3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

- 0 I am no more tired or fatigued than usual.
- 1 I get more tired or fatigued more easily than usual.
- 2 I am too tired or fatigued to do a lot of the things I used to do.
- 3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

- 0 I have not noticed any recent changes in my interest in sex.
- 1 I am less interested in sex than I used to be.
- 2 I am much less interested in sex now.
- 3 I have lost interest in sex completely.

Subtotal Page 1 _____ Subtotal Page 2 _____ Subtotal Page 3 _____ Total Score _____
 Score of 0-13: minimal, 14-19: mild, 20-28: moderate, and 29-63: severe

State-Trait Anxiety Inventory (STAI)

There are no right or wrong answers; give the answer that seems to describe your present feelings best.

	Not at all	Somewhat	Moderately so	Very much so
	1	2	3	4
1. I feel calm	1	2	3	4
2. I feel secure	1	2	3	4
3. I am tense.	1	2	3	4
4. I am regretful.	1	2	3	4
5. I feel at ease.	1	2	3	4
6. I feel upset.	1	2	3	4
7. I am presently worrying over possible misfortunes.	1	2	3	4
8. I feel rested.	1	2	3	4
9. I feel anxious.	1	2	3	4
10. I feel comfortable.	1	2	3	4
11. I feel self-confident.	1	2	3	4
12. I feel nervous.	1	2	3	4
13. I am jittery.	1	2	3	4
14. I feel "high strung."	1	2	3	4
15. I am relaxed.	1	2	3	4
16. I feel content.	1	2	3	4
17. I am worried.	1	2	3	4
18. I feel over excited and "rattled."	1	2	3	4
19. I feel joyful.	1	2	3	4
20. I feel pleasant.	1	2	3	4
21. I do not feel pleasant	1	2	3	4
22. I feel nervous and restless.	1	2	3	4
23. I feel satisfied with myself.	1	2	3	4
24. I wish I could be as happy as others seem to be.	1	2	3	4
25. I feel like a failure.	1	2	3	4
26. I feel upset.	1	2	3	4
27. I am calm cool and collected.	1	2	3	4
28. I feel that the difficulties are piling up so that I cannot overcome them.	1	2	3	4
29. I worry too much over something that really doesn't matter.	1	2	3	4
30. I am happy.	1	2	3	4
31. I have disturbing thoughts.	1	2	3	4

	Not at all	Somewhat	Moderately so	Very much so
	1	2	3	4
32. I lack self-confidence.	1	2	3	4
33. I feel secure.	1	2	3	4
34. I make decisions easily.	1	2	3	4
35. I feel inadequate.	1	2	3	4
36. I am content.	1	2	3	4
37. Some unimportant thought runs through my mind and bother me.	1	2	3	4
38. I take disappointments so keenly that can't out them out of my mind.	1	2	3	4
39. I am a steady person.	1	2	3	4
40. I get in a state of tension or turmoil as I think over my recent concerns.	1	2	3	4

**Parental Beliefs Scale for Hospitalized Children
(Bernadette Mazurek Melnyk, 1991)**

Below are 20 statements that relate to you and your child's hospitalization. Hospital experiences differ for every parent. There are some parents who are not so sure about their children's needs and how they can best meet them while they are in the hospital, while other parents are more sure about how to help their children through this experience. Keep in mind that your confidence (how sure you are) about helping your child deal with being in the hospital may be different from the confidence you usually have in dealing with your child at home. There are no right or wrong answers to the following statements or how you feel while your child is in the hospital. Please circle the number that best describes your agreement or disagreement with each statement.

1. I know what changes in behavior to expect in my child while he (or she) after my child's cancer diagnosis.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

2. I do NOT know what my child's emotions will be like while he (or she) after their child's cancer diagnosis.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

3. I am sure that what I do for my child will be what is best to help him (or her) deal their cancer diagnosis..

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

4. I am NOT sure about how my child will behave when painful things are done to him (or her) in as part of their cancer treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

5. I know what changes in behavior to expect in my child AFTER he (or she)'s cancer diagnosis.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

6. I am NOT sure about what I can do to best help my child get through the painful things that are done to him (or her) as part of their cancer treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

7. I do NOT understand why my child is behaving the way he (or she) after their cancer diagnosis.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

8. I am sure I can meet all of my child's emotional needs while he (or she) is in treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

9. I do NOT know what my child will think about the things that are done to him (or her) as part of their cancer treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

10. I am clear about the things that I can do to best help my child deal with their cancer diagnosis.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

11. I am NOT sure how my child will act towards me while he (or she) during their treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

12. I know how my emotions will affect my child while he (or she) during their treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

13. No matter how my child behaves during their cancer treatment he (or she), I am sure I will be able to handle it.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

14. I am NOT sure of what things I can do to best help my child deal with his (or her) illness.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

15. I am NOT sure about what I can do to make my child feel most secure while he (or she) during their cancer treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

16. I feel confident in telling the nurses and doctors about what will best help my child while he (or she) is receiving cancer treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

17. I am NOT sure about how my child will behave when things frighten him (or her) in during their treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

18. I do NOT know what I can do to best help my child deal with frightening things during their treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

19. I feel confident in asking the doctors and nurses questions about my child's illness.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

20. I know how to prepare my child for things that will frighten or hurt him (or her) during their treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

BASC Sample Document

Remember: N – Never S – Sometimes O – Often A – Almost Always									
1. Shares toys or possessions with other children.					20. Congratulates others when good things happen to them.				
2. Speaks in short phrases that are hard to understand.	N	S	O	A	21. Argues when denied own way.	N	S	O	A
3. Gets colds.	N	S	O	A	22. Holds a grudge.	N	S	O	A
4. Compliments others.	N	S	O	A	23. Worries about parents.	N	S	O	A
5. Acts without thinking.	N	S	O	A	24. Complains about being teased.	N	S	O	A
6. Has a short attention span.	N	S	O	A	25. Has headaches.	N	S	O	A
7. Eats things that are not food.	N	S	O	A	26. Avoids other children.	N	S	O	A
8. Seems unaware of others.	N	S	O	A	27. Is unable to slow down.	N	S	O	A
9. Has trouble making new friends.	N	S	O	A	28. Is fearful.	N	S	O	A
10. Gets sick.	N	S	O	A	29. Recovers quickly after a setback.	N	S	O	A
11. Sleeps with parents.	N	S	O	A	30. Provides full name when asked.	N	S	O	A
12. Breaks other children's things	N	S	O	A	31. Vomits.	N	S	O	A
13. Misses school or daycare because of sickness.	N	S	O	A	32. Begins conversations appropriately.	N	S	O	A
14. Pouts.	N	S	O	A	33. Has poor self-control.	N	S	O	A
15. Provides own telephone number when asked.	N	S	O	A	34. Listens carefully.	N	S	O	A
16. Says, "Nobody likes me."	N	S	O	A	35. Says, "I'm afraid I will make a mistake."	N	S	O	A
17. Acts out of control.	N	S	O	A	36. Babbles to self.	N	S	O	A
18. Seeks revenge on others.	N	S	O	A	37. Is shy with other children.	N	S	O	A
19. Worries about what parents think.	N	S	O	A	38. Complains about health.	N	S	O	A

Remember: N – Never S – Sometimes O – Often A – Almost Always									
39. Decides what clothing to wear without help.	N	S	O	A	65. Shows fear of strangers.	N	S	O	A
40. Calls other children names.	N	S	O	A	66. Makes frequent visits to the doctor.	N	S	O	A
41. Complains of being cold.	N	S	O	A	67. Needs help putting on clothes.	N	S	O	A
42. Is easily frustrated.	N	S	O	A	68. Hits other children.	N	S	O	A
43. Communicates clearly.	N	S	O	A	69. Tries new things.	N	S	O	A
44. Is sad.	N	S	O	A	70. Stares blankly.	N	S	O	A
45. Interrupts others when they are speaking.	N	S	O	A	71. Says all letters of the alphabet when asked.	N	S	O	A
46. Annoys others on purpose.	N	S	O	A	72. Changes moods quickly.	N	S	O	A
47. Offers help to other children.	N	S	O	A	73. Acts strangely.	N	S	O	A
48. Gets very upset when things are lost.	N	S	O	A	74. Bullies others.	N	S	O	A
49. Threatens to hurt others.	N	S	O	A	75. Encourages others to do their best.	N	S	O	A
50. Whines.	N	S	O	A	76. Worries.	N	S	O	A
51. Worries about what other children think.	N	S	O	A	77. Loses temper too easily.	N	S	O	A
52. Cries easily.	N	S	O	A	78. Is chosen last by other children for games.	N	S	O	A
53. Has ear infections.	N	S	O	A	79. Has a hearing problem.	N	S	O	A
54. Makes friends easily.	N	S	O	A	80. Listens to directions.	N	S	O	A
55. Cannot wait to take turn.	N	S	O	A	81. Has fevers.	N	S	O	A
56. Is too serious.	N	S	O	A	82. Is shy with adults.	N	S	O	A
57. Adjusts well to new teachers or caregivers.	N	S	O	A	83. Is overly active.	N	S	O	A
58. Provides home address when asked.	N	S	O	A	84. Is cruel to animals.	N	S	O	A
59. Needs help tying shoes.	N	S	O	A	85. Is easily soothed when angry.	N	S	O	A
60. Says, “please” and “thank you.”	N	S	O	A	86. Answers telephone properly.	N	S	O	A
61. Needs too much supervision.	N	S	O	A	87. Needs help using zippers.	N	S	O	A
62. Pays attention.	N	S	O	A	88. Politely asks for help.	N	S	O	A
63. Worries about things that cannot be changed.	N	S	O	A	89. Fiddles with things while at meals.	N	S	O	A
64. Bangs head.	N	S	O	A	90. Is easily distracted.	N	S	O	A

Remember: N – Never S – Sometimes O – Often A – Almost Always									
91. Worries about making mistakes.	N	S	O	A	113. Adjusts well to changes in family plans.	N	S	O	A
92. Acts confused.	N	S	O	A	114. Is able to describe feelings accurately.	N	S	O	A
93. Readily starts up conversations with new people.	N	S	O	A	115. Has trouble fastening buttons on clothing.	N	S	O	A
94. Has stomach problems.	N	S	O	A	116. Volunteers to help with things.	N	S	O	A
95. Fails to wash hands when needed.	N	S	O	A	117. Throws tantrums.	N	S	O	A
96. Teases others.	N	S	O	A	118. Is easily annoyed by others.	N	S	O	A
97. Adjusts well to changes in routine.	N	S	O	A	119. Says, “I’m not very good at this.”	N	S	O	A
98. Shows feelings that do not fit the situation.	N	S	O	A	120. Chews clothing or blankets.	N	S	O	A
99. Responds appropriately when asked a question.	N	S	O	A	121. Wets bed.	N	S	O	A
100. Is easily upset.	N	S	O	A	122. Has sore throats.	N	S	O	A
101. Says things that make no sense.	N	S	O	A	123. Has trouble eating with a fork.	N	S	O	A
102. Needs help bathing self.	N	S	O	A	124. Disrupts the play of other children.	N	S	O	A
103. Uses appropriate table manners.	N	S	O	A	125. Adjusts easily to new surroundings.	N	S	O	A
104. Tries to be perfect.	N	S	O	A	126. Does strange things.	N	S	O	A
105. Is clear when telling about personal experiences.	N	S	O	A	127. Sets fires.	N	S	O	A
106. Refuses to join group activities.	N	S	O	A	128. Is negative about things.	N	S	O	A
107. Falls down.	N	S	O	A	129. Has toileting accident!	N	S	O	A
108. Pays attention when being spoken to.	N	S	O	A	130. Needs to be reminded to brush teeth.	N	S	O	A
109. Complains of pain.	N	S	O	A	131. Has eye problems.	N	S	O	A
110. Clings to parent in strange surroundings.	N	S	O	A	132. Is nervous.	N	S	O	A
111. Interrupts parents when they are talking on the phone.	N	S	O	A	133. Is unclear when presenting ideas.	N	S	O	A
112. Has seizures.	N	S	O	A	134. Quickly jams group activities.	N	S	O	A

**Evaluation of the Creating Opportunities
For Parent Empowerment Program**

1) Was the program with its number acceptable to you?

Please circle your response.

1 = Yes

2 = No

2) Was the program helpful in coping with your child's cancer diagnosis?

Please circle your response.

1 = Yes

2 = No

3) On a scale of "0" to "3" how easy was it to teach your child the coping strategies?

Please circle your response.

0 = not easy at all

1 = a little easy

2 = fairly/somewhat easy

3 = very easy

4) How easy was it for you to stay calm during stressful events?

Please circle your response.

0 = not easy at all

1 = a little easy

2 = fairly/somewhat easy

3 = very easy

5) Would you be interested in participating in future studies like this one?

Please circle your response.

Yes or No

6) Since your child has been diagnosed with cancer have you received any information about how to help your child cope with the cancer diagnosis?

Please circle your response.

Yes or No

If yes, who did you receive the information from?

7) Since your child has been diagnosed with cancer, have you received any information about how mothers and their child respond to the cancer diagnosis?

Please circle your response.

Yes or No

If yes, who did you receive the information from?

8) Describe how participation in the intervention program could have been made easier for you.

9) What other information should be included in the program?

10) How was the program helpful to you?

11) Would you recommend this program to other mothers of children diagnosed with cancer?

APPENDIX C
SUPPLEMENTAL STUDY MATERIALS

Adherence Log

ID #: _____

Session #: _____

Session Length: _____

	DATE	PRESENT Yes No	RESCHEDULED DATE
Review of CD Review of handout			
Review of CD Review of handout Review parent-child workbook Reading and discussing book with your child			
Review of CD Review of Handout Review parent-child workbook Reading and discussing book with your child			

ID #: _____

Session #: _____

Manipulation Check #1

Please complete the following multiple-choice questions.

1. The most common age for childhood cancers is
 - a) Age 2-5 years
 - b) Age 5-9 years
 - c) Age newborn to 1 year
 - d) Age 9-18 years

2. What are common behaviors in children exhibited after the cancer diagnosis?
 - a) Irritable, angry, sad
 - b) Happy, playful, energetic
 - c) Cooperative, talkative, outgoing
 - d) Independent, positive, eager to please

3. Chemotherapy is
 - a) Treatment of cancer with drugs
 - b) Treatment of cancer with radiation
 - c) Treatment of cancer with drugs and radiation
 - d) Treatment of cancer with surgery

4. Children diagnosed with cancer may react to the diagnosis by
 - a) Being angry at their parent
 - b) Cooperating with procedures
 - c) Maintaining same behaviors as before diagnosis
 - d) Engaging in activities with the medical staff

5. Parents are often anxious after their child's cancer diagnosis, and to decrease their child's anxiety they should
 - a) Tell their child they are anxious
 - b) Cry in front of their child
 - c) Not leave their child's bedside
 - d) Avoid crying in front of their child

6. Bone marrow
 - a) Produces blood cells
 - b) Is the hard part of the bone
 - c) Is not important in cancer treatment
 - d) Is not affected by cancer treatment

7. The term cancer means
 - a) Uncontrolled growth of cells in the body
 - b) Leukemia
 - c) Benign process
 - d) Uncontrolled growth of cells in the bone marrow

8. In order to help the child feel secure in the hospital
 - a) You should bring toys from home
 - b) Buy them all new toys while in the hospital
 - c) Do not set limits
 - d) Change your routines

9. A CBC is
 - a) Complete blood count
 - b) Comprehensive bone chemistry
 - c) Not a medical term
 - d) Complete bone count

10. Common behavioral responses in children with cancer may include
 - a) Child angry at parent
 - b) Child always cooperative with medical staff
 - c) Child having no fears
 - d) Child separating easily from parent

ID #: _____

Session #: _____

Manipulation Check #2

Please complete the following multiple-choice questions.

1. Parents can help their child cope with the cancer diagnosis by
 - a) Changing the routine to make the child happy
 - b) Encourage your child to talk about their feelings
 - c) Ignore your child's "acting out" behaviors
 - d) Buying the child new toys

2. Neutropenia means
 - a) Your child's white blood counts are low
 - b) Your child's red blood counts are low
 - c) Your child's platelet counts are low
 - d) Your child has no risk of infection

3. To help your child cope with the cancer diagnosis it is best to
 - a) Let your child sleep in your bed
 - b) Let your child sleep in their own bed
 - c) Let the child sleep with their sibling
 - d) Let the child sleep wherever they want

4. ANC stands for
 - a) Absolute neutrophil count
 - b) Is not an abbreviation
 - c) Avoid crowds
 - d) Absolute number of cells

5. Platelets are the part of the blood that
 - a) Fight infection
 - b) Clot the blood
 - c) Give you energy
 - d) Not part of the blood

6. One way parents can help their child cope with the cancer diagnosis is to
 - a) Encourage the child to talk about their feelings
 - b) Avoid discussing the cancer diagnosis
 - c) Pretend that the child doesn't have cancer
 - d) Ignore any change in your child's behavior

7. One medication to help with nausea and vomiting is
 - a) Zofran
 - b) Tylenol
 - c) Benadryl
 - d) Motrin

8. Children with cancer have painful procedures; to help your child cope with these it is best to
 - a) Tell your child that the procedures are to help them get better
 - b) Tell your child that the nurse is being mean
 - c) Help the nurse hold your child down for the procedure
 - d) Leave the room when your child is having a procedure

9. White blood cells are the part of the blood that
 - a) Fight infection
 - b) Clot the blood
 - c) Give you energy
 - d) Not part of the blood

10. Children with cancer may have regression after the cancer diagnosis. Regression is
 - a) The child acting older than their age
 - b) The child reverting to earlier behaviors
 - c) The child hitting at nurses
 - d) The child being cooperative

ID #: _____

Session #: _____

Manipulation Check #3

Please complete the following multiple-choice questions.

1. Bactrim is a medication used to prevent
 - a) PCP
 - b) Relapse
 - c) Anemia
 - d) Nausea

2. Parents can help their child cope with the cancer diagnosis by
 - a) Keep the same rules of the house
 - b) Stop disciplining your child
 - c) Discourage your child from playing
 - d) Crying in front of their children

3. A carcinogen is
 - a) A chemical that causes cancer
 - b) A chemical that prevents cancer
 - c) A chemical that treats cancer
 - d) Not related to cancer

4. One way parents can help their child cope with the cancer diagnosis is to
 - a) Encourage the child to engage in medical play
 - b) Discourage your child from medical play
 - c) Discourage your child from talking about their feelings
 - d) Pretend that the child doesn't have cancer

5. Red blood cells are the part of the blood that
 - a) Fight infection
 - b) Clot the blood
 - c) Give you energy
 - d) Not part of the blood

6. Acute means
 - a) The disease occurred over a short period of time
 - b) The disease occurred over a long period of time
 - c) The disease occurred at birth
 - d) Does not occur in childhood cancer

7. To help your child cope with the cancer diagnosis you can
 - a) Avoid talking to your child about what is happening
 - b) Blow bubbles to blow away the pain
 - c) Avoid letting your child play with their siblings
 - d) Avoid letting your child's friends visit

8. Afebrile means
 - a) Your child's temperature is high
 - b) Your child's temperature is low
 - c) Your child's temperature is normal
 - d) Not a medical term

9. Medical play
 - a) Includes letting your child give you a "shot"
 - b) You should avoid medical play with your child
 - c) Shouldn't be done with toys
 - d) Can upset your child

10. Parents can help their child cope with the cancer diagnosis by
 - a) Changing the routine to make the child happy
 - b) Telling your child it is ok to be sad
 - c) Ignore your child's "acting out" behaviors
 - d) Stop disciplining your child

ID #: _____

Session #: _____

Attrition Log

DATE	REASON(S) FOR LEAVING STUDY
	<p>1. Please check the response(s) that reflects your reasons for leaving the study.</p> <p>____ There were too many sessions.</p> <p>____ The sessions were too long.</p> <p>____ There was too much paperwork to complete.</p> <p>____ I was too overwhelmed to participate in the study.</p> <p>____ I was too busy taking care of my child to participate in the study.</p> <p>____ My child was too busy for me to participate in the study.</p>
	<p>2. If your reason for leaving the study is not listed above, please use this space to provide your reason for leaving the study.</p>

APPENDIX D

COPE-PCC INTERVENTION MANUAL PROTOCOL

ID #: _____

Session #: _____

Time 1 Contact

(Within 8 weeks of cancer diagnosis/prior to session 1)

Protocol

- ____ Obtain signed consent. Leave blank copy for mother.
- ____ Have mother complete the State and Trait Anxiety Inventory and the Beck Depression Inventory Index.
- ____ Have mother complete the demographic questionnaire.
- ____ Review each questionnaire to make sure that subject has completed all questions on the questionnaires.
- ____ Score the Beck Depression Index and complete scoring sheet. Refer immediately if score is in the severe range.
- ____ Write subject's code number and date on all questionnaires.

ID #: _____

Session #: _____

Time 2 Contact

Intervention Session 1

(Within 1 week of cancer diagnosis)

Protocol

- ____ Have mother complete the PBS and the BASC-2 parent form. Have mother review child's behavior for the last 6 weeks.
- ____ Give the mother the written information and have them listen to intervention session 1 of the CD.
- ____ Show the mother the Time 1 activities in the workbook for them to complete.
- ____ Review each questionnaire to make sure that subject has completed all questions.
- ____ Write subject's code number on all questionnaires.
- ____ Give mother log sheet to record any additional times that CD and written material was reviewed.
- ____ Payment of \$10 gift card (for each contact) to mothers for first two contacts. Get signed receipt.

ID #: _____

Session #: _____

Time 3 Contact

Intervention Session 2

(Within 3-4 weeks of cancer diagnosis)

Protocol

- ____ Have mother complete manipulation check #1.
- ____ Score manipulation check #1. If a mother answers less than 80% of the questions correctly, the information will be replayed for them again.
- ____ Review the log sheet for any additional times that session 1 CD and written material was reviewed.
- ____ Give the mother the written information and have them listen to intervention session 2 of the CD.
- ____ Show the mother the Time 2 activities in the workbook for them to complete.
- ____ Write subject's code number on manipulation check #1.
- ____ Payment of \$10 gift card to mothers for contact. Get signed receipt.

ID #: _____

Session #: _____

Time 4 Contact

Intervention Session 3

(Within 4-5 weeks of cancer diagnosis)

Protocol

- ____ Have mother complete manipulation check #2.
- ____ Score manipulation check #2. If a mother answers less than 80% of the questions correctly, the information will be replayed for them again.
- ____ Review the log sheet for any additional times that session 2 CD and written material was reviewed.
- ____ Give the mother the written information and have them listen to intervention session 3 of the CD.
- ____ Show the mother the Time 3 activities in the workbook for them to complete.
- ____ Write subject's code number on manipulation check #2.
- ____ Payment of \$10 gift card to mothers for contact. Get signed receipt.

ID #: _____

Session #: _____

Time 5 Contact

Completion of Post Intervention Questionnaires

(1-2 weeks after completion of intervention session 3)

Protocol

- ____ Have mother complete the State and Trait Anxiety Inventory and the Beck Depression Inventory Index.
- ____ Have mother complete the PBS and the BASC-2 parent form. Have mother review child's behavior since diagnosis.
- ____ Score the Beck Depression Index and complete scoring sheet. Refer immediately if score is in the severe range.
- ____ Review each questionnaire to make sure that subject has completed all questions on the questionnaires.
- ____ Have mother complete manipulation check #3.
- ____ Score manipulation check #3. If a mother answers less than 80% of the questions correctly, the information will be replayed for them again.
- ____ Review the log sheet for any additional times that session 3 CD and written material was reviewed.
- ____ Write subject's code number on manipulation check #3 and all questionnaires.
- ____ Have mother complete program evaluation.
- ____ Payment of \$10 gift card to mothers for contact. Get signed receipt.

Scoring of BDI-II and Referral Criteria

The BDI-II is scored by adding the ratings for the 21 items. Each item is rated on a 4-point scale ranging from 0-3. If the subject has made multiple choices for an item, the choice with the highest rating is used. The score range is 0-63.

Special attention must be paid to item 2) Pessimism and 9) Suicidation. These two items are predictive of eventual suicide attempts. If the scores on these two items are a 2 or 3 this needs to be reported.

Score cut off guidelines:

0-13 Minimal depression

14-19 Mild depression

20-28 Moderate Depression

29-63 Severe Depression

Criteria for making a referral:

- 1) If the mother has achieved a **score of 29 or above (severe depression range)** or more, a referral will be made immediately at **any** contact point in the study.
- 2) If the mother has **answered items 2 and/or 9 at a score of 2 or 3**, a referral will be made immediately, at **any** contact point in the study.
- 3) If the parent has achieved a **score of 20-28 (moderate depression range)** at **any** contact point in the study, this will be documented and monitored.

Procedure for making a referral for depression:

- 1) Notify the mother about the concern about their current mood and feelings and that I will be sharing the results of the BDI-II with either their Primary Care Provider.
- 2) Complete two referral letters. One letter remains in the research folder and one letter mailed to the provider designated by the mother.

BDI-II Total Score: _____

BDI-II Score for Critical Items: Item 2: _____ Item 9: _____

Referral Needed: No: _____ Yes: _____

Preferred Care Providers Name: _____

Preferred Care Providers Address: _____

Date Referral Letter Sent: _____

APPENDIX E
COPE-PCC MANUAL



**Creating Opportunities for Parent
Empowerment**

**A Program for Mothers and Their
Child Diagnosed with Cancer**

Child's Name: _____

Mother's Name: _____

AUTHORS

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COPE CHILDHOOD CANCER PROGRAM

Session 1

Diagnosis of a child with cancer is usually a very stressful event for parents and the child. This situation is stressful because parents are uncertain about their child's health and are in an unfamiliar place with unfamiliar people. Parents also tend to be stressed by their child's behavior and emotions, and because they do not know how best to help their child cope with the experience. Therefore, this information will focus on how you can stay involved in your child's care and help him or her to cope with cancer and its treatment. After their cancer diagnosis, children are faced with many things that may frighten them. Some of these things include unfamiliar places and people, new routines and painful procedures (such as getting shots or having blood drawn).

First, the best person to provide your child with love, comfort, and support during hospitalization and treatment is you. Since young children's greatest fear while hospitalized is being separated from their parents, visiting with your child as often as your family situation allows will be comforting and reassuring for him or her. You are encouraged to stay with your child as much as possible. Topics to talk about that could be comforting might include familiar people and places as well as favorite toys, dolls, pets or activities. Reading a familiar storybook also can be very soothing.



Sometimes parents are uncertain or anxious about touching or holding their children because of various tubes and monitoring equipment. If you are feeling this way, talking to your child to reassure him or her will be even more important. As time goes on, you will get more comfortable with touching and stroking your child. If you desire to hold your child, do not hesitate to tell his or her nurse you would like to do so. Many times this can be arranged, even if your child has various tubes and monitoring

equipment. Also, your child is going to have many procedures and it is helpful for you to be the “safe” person during procedures. You should continue to provide comfort to your child including holding their hand, rocking them, and other home routines. In addition, it is helpful to inform the staff of the way in which your child likes certain things done, your child’s normal routines at home, and words your child commonly uses for toileting or favorite activities.



With time, as you are becoming more comfortable, feel free to participate more in your child’s care. This might include: bathing or turning your child; preparing your child for procedures by telling him or her what is about to happen; and assisting the nurses with certain procedures. If you are present during a painful procedure, it is important that you do not help hold your child down. Your role should only be to

provide support to your child with a reassuring voice, stroking him or her gently, or trying to distract him or her from the procedure.



Since young children feel safe when they are surrounded by familiar people and things, it is a good idea to bring in items from home to place on your child's bed or in his or her room. A favorite doll, stuffed animal, toy or blanket, and family pictures can be very comforting, especially when you must leave your child. Tape recordings of you or other family members talking, singing, or telling favorite stories also can be brought in to the hospital and played for your child. Your child may benefit from listening to familiar music tapes as well. In addition, feel welcome to ask your child's nurses about what else you can do to help comfort your child.

You can be assured that you will be told frequently about your child's condition and any changes that occur. However, if you want additional information or feel that the information you are receiving is not clear, feel free to ask questions of the doctors and nurses. They do understand that you are very concerned about your child and that you may want to have certain information repeated over and over again.

Children are often more anxious when their parents are upset, so it is important for you to try to control your own anxiety when you are with your child. This is often difficult. However, it will be easier to control your emotions when you are with your child if you can talk to or cry to someone about your feelings outside of your child's room where he or she cannot overhear you. In order to offer your child the best possible support, you will need to get support from others. Although you will want to be with your child as much as your family situation allows, you will need to eat and get some rest so that you will have enough strength to support your child through this experience.



You also may need to leave your child to take care of other responsibilities, such as caring for your other children. You can be assured that, if you are taking a break to get some food and rest or need to leave to go home, the staff will make you aware of any major changes in your child's condition. Therefore, it is important to let the staff know how to contact you and to give them the name of another family member or friend if you cannot be reached at your home telephone.

When you do leave your child, he or she may react with crying, whining or excessive clinging, which will make your separations more difficult. To help your child cope with separations, you can tell him or her, in advance, when you are going to be leaving and when you will return. Because young children cannot tell time, you can connect your return with some meaningful event, such as when it gets dark or becomes light outside. You also can ease your separations by making sure your child has a comforting blanket or toy and by leaving something behind that belongs to you, such as a sweater. In addition, if possible, it may be helpful to arrange for a familiar person to stay with your child while you are away

Due to your child's attempts to cope with this frightening experience, you may see changes in his or her usual behaviors as he or she starts the treatment for their cancer. When they become ill, many young children return to doing things that they did when they were younger. Some of these things include sucking their thumbs, whining, wetting or soiling, and clinging to their parents. Young children react this way when stressed because these behaviors take them back to a time in their lives when they felt more comfortable and secure.

Other behaviors you may see in your child might include: being uncooperative and demanding; acting confused; excessive crying or whining; and being withdrawn, irritable, angry or sad. One behavior that is often confusing for parents is when their children show anger toward them. Young children behave in this way because it is difficult for them to understand why their parents cannot "make things all better."



Children also frequently cry or act more uncooperative when their parents are with them. As a result, parents might think that it may be better for their child if they do not visit often. However, it is important for you to understand that children often show more anger and upset in the presence of their parents because they feel more safe and comfortable with them. From this information, you can see that there are many things that you can do to help your child cope with this experience. Although you will not be able

to protect your child from pain due to treatments or procedures, you can comfort him or her a great deal by your presence, reassuring voice, and touch. As your child's parent, you are the best person to offer your child the emotional support he or she needs to successfully deal with this experience.

Keep in mind that these behavioral changes, although sometimes frustrating to watch and deal with, are healthy ways in which young children cope with the stress of their diagnosis. By knowing what behaviors to expect from your child and how he or she is feeling about having cancer, you will be better able to provide the support your child needs for a successful adjustment. Therefore, this information will focus on helping you recognize and understand children's common behavior changes after their diagnosis. You will also receive information regarding specific things that you can do to help your child cope with this stressful experience.

As young children deal with being sick, it is common for them to have temper tantrums or get angry at their parents and others around them. Some children throw objects, scream loudly, or say unkind things to their parents. They may also try to hit their parents or push them away when they try to comfort them. Young children may behave in this way because it is difficult for them to understand why their parents cannot "make things all better." Children are also able to express angry feelings more easily when they feel comfortable and secure with people who love them.

Children are usually not allowed to decide what happens to them while they are in the hospital. So, in an attempt to gain control over their situation, they may refuse to cooperate during procedures, such as receiving their medicine or having their blood pressure taken. It is for this reason that children often become bossy and demanding with their parents and hospital staff. Some children even refuse to eat or drink hoping to overcome feelings of helplessness and gain some control over their experience.

The stress of their diagnosis and being in the hospital may also cause children to return to doing things that they did when they were younger. Some of these things include sucking their thumbs, wetting or soiling, and whining or clinging to their parents.



In fact, children may also depend on their parents to do things for them that they usually do for themselves at home, such as feeding themselves or brushing their teeth. This is called regression and happens because when children are stressed they feel the need to go back to a time in their lives when they felt more comfortable and secure. Children may also try to get the extra attention they need by behaving in this way.

Young children may react to their sickness by withdrawing from people and activities. Some may be very sad and show no interest in their surroundings. For example, your child may show no desire to play, spend most of the day sleeping, or want to watch television constantly.

A major fear of young children diagnosed with cancer is being separated from their parents. Because they do not understand the concept of time, young children often worry about if and when their parents will return. This is why children will often cry and cling when they see their parents getting ready to leave the hospital.

Many of the behavior changes that parents see in their children may continue for weeks or months after their diagnosis. Even if your child's behavior does not change after their diagnosis and first hospital stay, you may see these behavior changes at home where he or she feels most safe and comfortable.

After the cancer diagnosis, it is common for young children to have more fears, such as fear of separating from their parents and fears of the dark, strange noises or imaginary monsters. Along with being more fearful, children may become more irritable, restless or have more sleep problems. Many children also continue to do things that they did when they were younger and try to depend on their parents to do more things for them. Some children continue to withdraw by not wanting to play with things or people they enjoyed before their hospital experience. Children may also show an increase in activity and aggressive behaviors after they are home. In addition, it is common for young children to continue to have angry outbursts at their parents and refuse to cooperate with them. All of these behaviors are ways that children try to work

through their feelings about their illness and the frightening things that were done to them.

As you can see, young children behave in many different ways while they are sick. Each child is an individual and may respond in his or her own way. It is important for you to remember that the behaviors your child shows after their diagnosis are usually normal and healthy attempts to deal with the stressful experience.

There are many things that you can do to help your child cope with his or her illness. In fact, it is very important for you to stay involved in your child's care. After all, you are the best person to give your child love and support through this experience.

Separation from parents is a major cause of stress for children diagnosed with cancer under seven years of age. Therefore, being with your child as often as your family situation allows and participating in routine care such, as feeding and bathing, will help your child feel more comfortable and secure. When you do have to leave the room or the hospital, it is important to tell your child that you are leaving and that you will return after some meaningful event, such as breakfast or lunch. If your child is sleeping when you are ready to leave, it is helpful to awaken him or her to prevent feelings of being abandoned if he or she should wake up when you are not there. Remember, in these and other situations, it is best to be honest with your child. This will maintain a trusting relationship and further increase your child's feelings of security. You can also ease your separations by leaving behind something that belongs to you, such as a sweater or by making sure that your child has a comforting blanket or toy.

It is important for the hospital staff to know your child's routines as well as likes and dislikes so they can make your child as comfortable as possible. Therefore, you are encouraged to offer this type of information to the staff. Since it is you who best knows your child, it is important that you also tell the nurses and doctors about your child's needs or what helps him or her the most during stressful times. Bringing in security objects from home such as a favorite blanket, a stuffed animal or a toy will also help your child feel more comfortable and secure.

Letting your child make decisions about when or how things are done will increase his or her feelings of control. When children feel as if they have some

control over what is happening to them, they tend to be more cooperative. For example, it might be helpful to give your child choices about play activities or what clothes to wear. If your child wants to continue doing things that he or she does at home (such as dressing, washing or teeth-brushing), encourage this to continue.

While in a hospital, many young children have painful things done to them, such as getting shots or having their blood drawn. It is important for you to tell your child that these things are done to help him or her to get better. If your child asks you if something is going to hurt and you know that it will, it is important to be honest so that your child will continue to trust what you say. However, you can also tell your child that, together, there are things you can do to lessen the hurt. Because children need to have certain places where they feel safe and secure, such as their hospital room or playroom, feel welcome to encourage hospital staff to perform painful procedures in the treatment room on the unit whenever possible.

If your child is going to have something painful done, it is very helpful to ask the nurses to explain to you what will be done. This so you can help to prepare your child for it in words that you know he or she will understand. Children respond best to procedures when they know what they will see, hear and feel. It is also helpful for children to see what will be done by first showing them on a doll or stuffed animal.

You want to be there only to give comfort and support. Some of the helpful things you can do during a medical procedure is holding your child's hand and gently rubbing or stroking him or her. Talking in a soothing or sympathetic manner and telling your child what is happening during the procedure may also be helpful. Giving him or her a favorite blanket or doll to hold during the procedure may provide some comfort.



Distraction can be an important way to help your child through painful procedures. Examples of this would be telling your child to look at a toy, such as a finger puppet, or a picture on the wall. You also can distract your child by having him or her blow on something, like a pinwheel, and telling him or her to

“blow the hurt away.” Counting, singing or saying the alphabet with your child are other ways to distract your child. In addition, you can tell your child to think about favorite things or favorite places. You also can reassure your child by saying “you can do it” or “you are doing a great job.” Once the procedure is over, you can be there to comfort, support, and praise your child.

Play is a necessary part of a child's life and should continue during hospitalization. Through play, a child can release his or her anxieties and escape from the reality of a stressful hospital experience. Therefore, you will want to keep your child involved with play activities as much as possible. If your child is permitted, it is a good idea to make routine visits to the playroom.

Since young children have difficulty putting into words how they really feel, it is also helpful to play with your child for the purpose of getting him or her to express feelings about their diagnosis. Using puppets, dolls or stuffed animals is an excellent way to do this. You can help your child deal with feelings about their cancer diagnosis by getting him or her to describe how his or her dolls or stuffed animals are feeling about being sick and in the hospital. Role play, such as letting your child pretend to be a doctor or nurse while you pretend to be a patient, is another way your child can deal with feelings about their treatments. For example, letting your child pretend to give you a shot or draw your blood with a toy syringe will help him or her to work through feelings about these frightening procedures. It is also helpful to continue this type of play after your child goes home from the hospital.

Because parents' emotions often affect their children, it is important for you to try to control your own fears and anxieties when you are with your child. If your child sees that you face situations calmly, he or she will take comfort in being with you. Also, showing your child that you have trust and confidence in the nurses and doctors will help your child to feel more secure with them.

Many parents whose children have been diagnosed with cancer become very protective of their children after hearing the diagnosis. As a result, children may not be allowed to participate in their usual activities. This can encourage children to become overly dependent on their parents and other adults at a time in their development when it is important to foster independence.

Also, some parents hesitate to discipline their children following the cancer diagnosis because they feel very badly about everything their children have been

through. However, keep in mind that young children want and need to have consistent limits placed on their behaviors, even after the diagnosis. For example, as previously discussed, some children are very angry during and after the cancer treatment experience. While it is important to encourage them to express their anger in appropriate ways, children should not be allowed to hit others or damage property when they are angry. Keep in mind that limits provide children with a sense of safety and security.



Young children with cancer might

- Fear being separated from parents
- Be afraid of and upset by painful medical procedures
- Yell, scream, throw tantrums, refuse to cooperate, or withdraw
- Cling to parents
- Become aggressive
- Be angry or sad that their normal play and exploration are restricted

How to help your child

- Give very simple explanations of what is happening and repeat them often.
- Comfort your child when he or she is upset or scared.
- Offer choices when possible.
- Do not tolerate biting, hitting, kicking, or other aggressive behavior.
- Teach it's ok to have angry feelings such as talking, drawing, or pounding a pillow.
- Encourage doll play and other play to rehearse or repeat worrisome or painful experiences.

- Discourage whining and tantrums.
- Create ways to be physically activity.
- Try to stick to a schedule for meals, naps, and play.
- Teach staff about what works to get your child's cooperation.
- Reward good behavior when your child cooperates with tests and procedures.
- Give simple explanations for a parent's crying and sadness. For example, "I just feel a little sad and a little tired today. It makes me feel better to cry and get it all out of my system. Now I feel better."
- Don't forget humor; laugh together when possible

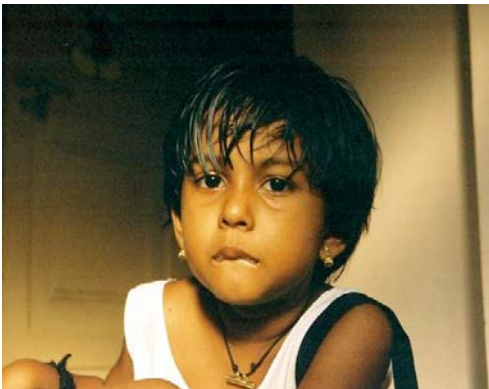
As you can see, there are many things that you can do to help your child deal with their cancer diagnosis. As your child's parent, you know what works best with your child in stressful or frightening situations. So, continue to do the things that you have found helpful in the past and make the hospital staff aware of what they can do to better support your child through this experience. Remember, with your comfort and support, your child can cope successfully with the cancer diagnosis and be better able to deal with future stressful experiences.

COPE CHILDHOOD CANCER PROGRAM
HOME INFORMATION
Session 2

It has been about a week since your child's cancer diagnosis. You will be planning to go home and it is common for you to feel the typical "ups and downs" that most parents have on going home after the cancer diagnosis.

It is normal for you to continue to see changes in your child's behaviors and emotions that are different from the way he or she acted before becoming ill. These changes may worry or frustrate you at times, but it is important to remember that they are usually healthy ways in which young children cope with a stressful experience. By knowing what behaviors and emotions to expect in your child in the weeks and months following the cancer diagnosis, you will be able to help him or her to adjust successfully.

When children have been through a stressful experience, they usually feel more comfortable and safe in showing their emotions once they are at home. That is why children's behaviors are often more difficult or become more intense after they leave the hospital. This information will discuss common reactions that children have following the cancer diagnosis and how you can respond to them to promote healthy coping.

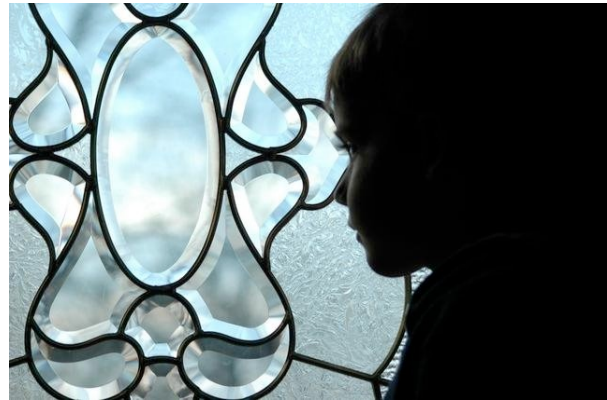


Because it could take weeks or months for your child to understand and cope with their cancer diagnosis, you can expect him or her to regress or do things that he or she did as a younger child. Some of these things might include thumb sucking, wetting or soiling, or frequently clinging to you. This happens when children are stressed and feel the need to go back to a time in their lives when they felt more secure. In order to help children to feel more secure, it is

important for parents to reassure their children that they love them and will take care of them. Encouraging your child to cuddle with his or her favorite stuffed animal or blanket can help your child feel safe and comforted as well. It also is important to encourage your child to continue doing things for him or herself and to try new things. Helping your child feel secure and confident will result in him or her acting less like a younger child and more like a child of his or her own age.

After the cancer diagnosis, it is common for children to feel sad. Along with looking sad, your child may seem withdrawn from others or less interested in things that he or she usually enjoys. Encouraging your child to talk about his or her feelings can help. In addition, you may want to ask your child to “show” you how he or she feels because sometimes it is hard for young children to express themselves with words. Letting your child know that it is okay to feel sad will help your child cope with those feelings better.

After letting your child know that it is okay to feel sad, you may want to do things that may help him or her to feel better, such as having him or her play with a friend or listen to favorite music.



Because your child had many painful and frightening things done as part of their cancer treatment, you may see that he or she is now afraid of things that never frightened him or her in the past. For example, your child may be afraid of separating from you, hearing strange noises, or have fears of the dark and imaginary monsters.

In addition, since bedtime is a form of separation from you, your child could have difficulty going to and staying asleep. There are many things that you can do to help your child reduce his or her fears. Having familiar daily routines, such as a regular bedtime, can help your child feel that life is safe and predictable. Letting your child know the plans for the day also can help him or her feel more secure and less fearful because he or she knows what to expect. It is especially important to tell your child, in advance, when you will be leaving him or her to go out, when you will be returning, and who will be taking care of him or her. For example, “I will be going out after breakfast and be back after lunch. Aunt Ann will be taking care of you while I am out.” Also, spending time with your child as he deals with his illness reassures him or her that you will continue to have special time together, whether he or she is sick or healthy.

Your child also may be more active, irritable, and restless following their cancer diagnosis. He or she might even become more aggressive. In addition, you

may find that your child frequently gets angry and upset at you. Even though you were there to love and support your child through the hospital experience, he or she may still not understand why you did not prevent it from happening. Helping children label their angry feelings and express them appropriately is an important skill that children of this age are learning. You can help your child to learn this skill by labeling feelings for him or her. For example, when your child is mad, you can say, "I can see that you are feeling very angry," and help him or her to express these feelings in appropriate ways. You can ask your child to act out their feelings with their medical kit. During the medical play ask your child how they feel when they have to have their blood drawn.

As you know, play is an important part of children's lives. Through play, your child can release his or her anxieties and escape from the recent stress of their diagnosis. It will be helpful to spend time playing with your child everyday. Besides regular play activities, it is important that you continue to encourage your child to use the play medical kit that he or she received in the hospital. For example, set aside times to let your child pretend to be a doctor or nurse while you or a stuffed animal are the patient. Even if you did this many times while in



the hospital, it is important for your child to continue to play this way. Adults often need to tell and retell a stressful experience after it has happened (for example, having an operation). This is because people get more comfortable with an experience each time that they talk about it. However, sometimes children have a hard time putting their experiences into words. Through repeated medical play, your child can "retell" his or her story about what

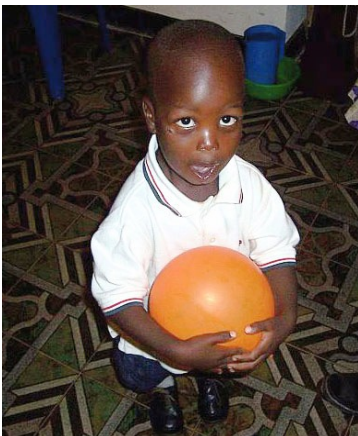
happened and continues to happen as part of their cancer treatment. This medical play can help your child work through the painful and frightening things that are

part of their cancer treatment. Therefore, continuing to use medical play with your child could speed up his or her emotional recovery.

While accepting all feelings is important, it is important to set limits on behaviors that are not appropriate. For example, if your child hits you when he or she is angry, it is important to stop this behavior and say, "People are not for hitting, tell me with your words if you are angry." Accepting your child's angry feelings, teaching your child how he or she can appropriately express his or her feelings, and setting limits on inappropriate behaviors will result in fewer behavioral problems.

Because your child has had very little control since their cancer diagnosis, he or she may try to have more control at home. For example, your child may refuse to cooperate with what you ask him or her to do. This uncooperative behavior can be a child's way of trying to overcome feelings of helplessness. While setting limits on inappropriate behavior is necessary, you can give your child a sense of control in age-appropriate ways. For example, giving your child certain choices can help him or her to feel as if he or she has some control over things that happen. Choices appropriate to young children might include which color cup they want to use for lunch, whether they take their teddy bear or their stuffed lion in the car, and whether they would like to have apple or orange juice when taking their medicine.

Many children think they did something wrong to cause their cancer diagnosis. These feelings of guilt are often the reason for some of the difficult behaviors and emotions you may be seeing in your child. Therefore, it is important for you to continue to tell your child that he or she did nothing wrong to cause their cancer.



As you can see, there are many things that you can do to continue to help your child cope with their cancer diagnosis. Remember, you are the best person to give your child the love and support he or she needs to fully recover from this stressful experience. There are even more ways that you as a parent can promote this recovery. Along with responding to your child's possible reactions to their cancer diagnosis, there are some general strategies you can use to further help his or her adjustment.

You also can help your child express feelings about what has and continues to happen to him or her with the use of puppets, dolls, or stuffed animals. For example, you can use the puppet your child received in the hospital to talk about the cancer treatment experience. Encourage your child to use the puppet to show you what happens during their cancer treatment and to talk to you about how the puppet feels about their treatment. It is usually easier for young children to let you know how they are feeling indirectly, by talking about how their puppet or doll feels. You also can use the puppet or a stuffed animal to correct any wrong ideas that your child may have about their cancer diagnosis and continued treatment. For example, your child may tell you that the puppet had to have a painful procedure done because he or she was bad. You could then reassure the puppet and your child that the procedure was done to help the puppet to get better and not to punish him or her.

It is important to encourage your child to be independent, confident, and to try new things. This can be difficult for parents after a child has been diagnosed with cancer. Many parents become very protective of their children once they have been diagnosed with cancer. For example, some parents do not want to leave their children with others or let them do things for themselves. Other parents put their children in bed with them to sleep at night. However, treating children as fragile or sickly makes it difficult for children to see themselves as independent and capable.

Also, in an effort to protect their children from experiencing any further upset after the cancer diagnosis, parents have difficulty disciplining their children. However, continuing to set limits on inappropriate behavior is very important. Children who grow up over-protected tend to become dependent on others to do things for them that they could do for themselves. These children also tend to be demanding and difficult to control. Remember, the goal of discipline is not punishment, but it is to teach a child appropriate ways to behave and to get along with others. Even if it is hard for you, try to encourage your child to do things for him or herself. Also, continue to discipline and set limits with your child when needed. Dealing with your child in these ways will help him or her to feel confident, secure, and good about him or herself.

COPE CHILDHOOD CANCER PROGRAM
Family Information
Session 3

It is now 4 weeks since your child was diagnosed with cancer and you and your family have had many changes. It is important to maintain your family's routine as much as possible. If you have other children, you may find that it takes time for them to adjust to their brother or sister having cancer. In fact, you may see similar behaviors and emotions in your other children since they, too, were probably stressed by the diagnosis and the change in your child's appearance. Your love and support also will be very important in helping your other children to get over the stressful experience.



Many of the ideas discussed already will be very useful when dealing with your other children as well. Spending special time playing and talking with your other children will reassure them that you know they need you too!

A child with cancer changes the family dynamics, and these changes can be especially difficult for the healthy siblings. After spending so much time and emotional energy looking after the child with cancer, some parents find that they don't have energy left to spend with their other children. Many parents find it difficult to think about the experience from the viewpoint of the healthy siblings. While it is natural for parents to want to focus on the child with cancer, it is important to remember that healthy siblings need their parents more than ever to help them cope with the emotions and changes caused by cancer.

Cancer creates an instant crisis in the lives of the whole family. Normal daily life stops. Parents must be away from work so they can be with their child. Siblings might need to be cared for by relatives or neighbors. The child with cancer becomes the major focus of family time and attention, and all other concerns are put on hold.

To add to the stress, all of this happens in a very short time. In the first days and weeks after the diagnosis, parents who have been through it describe feeling as if they are on an emotional roller coaster, or in a bad dream. Just about all

parents going through this difficult time seem to have the same feelings after their child's cancer diagnosis. It is not uncommon for you to feel shock, disbelief, fear, guilt, sadness, anxiety, and anger after your child's cancer diagnosis

Shock

No one is ever prepared to hear that their child has a cancer. At first, depending on their knowledge or personal experience with cancer, you may be afraid that your child is going to suffer and perhaps die. It is not common for mothers to say that they feel confused or are unable to hear, remember, or think clearly when the doctor explains their child's diagnosis or treatment plan. This numbness helps you slowly get used to the painful feelings. It gives you time to absorb and face these emotions and hard decisions.

What can help you get through the shock?

- Knowing that this is a normal reaction.
- Seeking comfort from one another or from other family members or friends.
- Remembering that feelings of shock will pass with time.

Disbelief and Denial

When first told your child has cancer, it might seem unbelievable. Your child may not seem sick enough, or look sick enough, to have such a serious disease. You may question whether the lab could have made a mistake or if the test results really belong to another child. Denial and disbelief is a normal feeling after your child's cancer diagnosis and will pass with time.

What can help you get through the disbelief stage?

- Getting answers to all your questions to resolve your doubts.
- Asking for help in understanding the diagnosis and the treatment plan.

Fear and Anxiety

It is normal to feel anxious and fearful when facing unfamiliar events and outcomes that we can't control. And nearly everyone has a fear of cancer. Also, protecting your child is the normally your job. Now you must trust others to take

care of their child. That's hard to. Also, facing major changes in daily life is upsetting, and you might worry that you might not be up to all that will be asked to do at home to take care of your child.

What can help you cope with fear?

- Getting information about your child's cancer diagnosis and treatment plan
- Openly discussing you fear and anxiety
- Taking as much control as possible of everyday events and decisions.
- Accepting that some things cannot be controlled.
- Finding strength in religious beliefs or spiritual practices.

Guilt

Feelings of guilt may come up soon after you accept that their child really does have cancer. You may feel guilty because it has always been your job to protect your child from danger. You may have already questioned what you might have done that caused their child to have this life-threatening disease.

Although it is normal to try to understand the causes of a problem, the fact is that right now no one knows exactly what causes most cancers. You are not at fault for your child's cancer. It is important that you do not let guilty feelings distract you from the many tasks they must face when their child has cancer.

What can help you deal with guilt?

- Talking with your child's cancer treatment team about feelings of guilt.
- Accepting that there may never be an answer to the question of what caused your child's cancer.
- Realizing that finding a reason for something isn't going to change the fact that it has happened.

Sadness and Depression

Of course you felt sad when your child was diagnosed with cancer. You, like every parent has hopes and dreams that your children's lives will be healthy, happy, and carefree. Cancer and its treatment changes that dream. You may grieve for the loss of some of those hopes. In grieving, you may feel hopeless about your child's recovery. You may also feel sad when you think about the hard days of treatment that lie ahead. Your feelings will affect how your child feels about their cancer and its treatment.

What can help you deal with sadness, depression, and grief?

- Finding ways to express their feelings, such as talking or crying.
- Asking for support from each other, family, or friends

Taking care of yourself: eating right, getting rest, and caring about how they look.

Anger

You may feel angry that your child had been diagnosed with cancer. When someone we love is attacked, even by illness, it is easy to want to blame someone, or ask "Why me?" or "Why us?" You also feel upset, knowing the things your child will face, including the tests and painful procedures.

You may resent your partner over past or current issues that now affect your child's treatment. Anger also maybe directed at family or friends who make thoughtless remarks or who are too busy to provide support. You may feel angry with the sick child whose illness is causing so many problems or who is not cooperating with the doctors and nurses. Some mothers hide their anger or even deny that they feel that way because they think such feelings are "not nice." Other times mothers express their anger in explosive and hostile ways, taking it out on other people. It is important to express your anger in healthy ways

What can help you deal with anger?

- Accepting that anger is a normal part of this process.
- Understanding the root of the anger in each situation.

- Expressing anger effectively
- Seeking physical release of tension (walking, exercising, or sports).
- Finding private space to vent feelings by shouting, screaming, or crying.
- Expressing feelings by keeping a journal or writing a letter (to keep, not to send).
- Letting anger go, accepting that there may be no one to blame, and finding ways to use the energy to help yourself, your child, and your family.

Taking care of yourself

You may find it hard to eat or sleep at first. You may not have the energy you need for routine daily tasks or for facing all you need to do. Mothers often report feeling overwhelmed by their child's diagnosis. You may have these unpleasant



feelings now and again throughout your child's cancer treatment. It is important for you find ways to maintain some quality of life for yourself, the rest of your family, and your child with cancer during this time.

It is important to remember to take care of yourself so that you can better handle your and your child's coping with the cancer diagnosis. It is important to remember to eat, sleep, exercise, and take breaks from caring for your child. Taking care of yourself also reassures your child that routines are the same and that mom is OK, despite their illness. Remember to take care of yourself as you take care of your child.

Taking care of your marriage/partner

If you are married or have a committed partner you may have already had disagreements and felt angry at your partner. Cancer treatment places enormous pressure on a marriage. Couples may be separated for long periods of time, emotions are high, and coping styles differ. Initially, family life is shattered. Couples must simply survive the first few overwhelming weeks, then work together to rearrange the pieces in a new pattern.

Here are suggestions to help you and your partner:

- Share medical decisions.
- Take turns staying in the hospital with your child in.
- Share responsibility for home care.
- Accept differences in coping styles.
- Seek counseling

Taking care of your child/family

Don't be afraid to discipline. Many mothers are reluctant to set limits after their child has been diagnosed with cancer. However, just like any other child, the child with cancer needs discipline and structure from you. Setting limits on unacceptable behavior, maintaining normal routines as much as possible and avoiding overindulgence provides children with structure and security. This is very reassuring to a child. This may seem impossible, particularly if you have feelings of guilt. Setting limits in regards to your child's behavior will increase your child's adjustment to his/her illness and maintain normalcy in your child's life. You should be sure that discipline is consistent, both between you and your partner and from day to day.

Children need to know what to expect from you and what behavior is expected from them. Recommended discipline techniques include praising appropriate behavior and using time-out with young children.

Maintain family routines as much as possible. Children typically do best when their daily routines are predictable and consistent. You should, as much as possible, maintain regular family routines (e.g., wake-up times, mealtimes, bedtimes, regular activities, etc.). Of course, this is not always possible, but an effort should be made to maintain regular routines and schedules for all family members

Common emotions experienced by siblings. If you have other children, remember that they are experiencing a variety of feelings about their siblings cancer diagnosis—many of them similar to those experienced by you and other adults. A sibling’s age, maturity, and personality all affect their reactions and may include these common and normal emotional responses.



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Common behaviors observed in siblings

Children often lack the emotional maturity and experience to understand their emotions and may not have words to describe how they feel. Because children often don’t talk about how they are feeling, they frequently express their feelings and needs through behavior. The following behaviors are common and normal among siblings of children with cancer:

- Misbehaving or acting out in negative, attention-seeking ways at home or school
- Increased separation anxiety, such as acting “clingy” or not wanting to leave mom or dad or go to school
- Withdrawing from the family or wanting to be alone
- Regressing or acting younger, such as a preschooler wanting to go back to diapers or an older child using baby language or sucking his or her thumb
- Demanding or entitled behaviors, such as wanting new toys from every trip to the store or demanding special foods
- Increased physical symptoms, such as headaches, stomachaches, or bedwetting
- Having trouble sleeping and/or nightmares

- Being moody and irritable, including temper tantrums, fighting with parents or siblings, or crying a lot
- Performing worse academically or having difficulty concentrating
- Demonstrating “extra good” behavior—some children try to take care of the rest of the family by being behaving well and suppressing their own feelings.

Talk to siblings about cancer

Give them age-appropriate, accurate, and honest information without being overly frightening. Provide frequent updates and encourage them to ask questions. You should be honest that cancer is a serious illness, but that the doctors are doing everything possible to help the sibling with cancer get better. Appropriate information helps children feel less anxious and prepares them to answer questions from teachers and friends.

Reassure siblings

Children need to know that they did not cause the cancer and that it is not contagious. Although it can be challenging to focus on other family members when a child has cancer, don't forget about the needs and concerns of siblings. Remember you can help your other children cope by spending time with them and talking about their feelings.

Being in the hospital and hearing the cancer diagnosis was stressful for you and your child. As a result, you both will need others to help you cope with all that you have experienced.



Talking to family and friends about your experience, getting some rest, and doing things that you enjoy will help you cope and give you the strength you need to take care of yourself and your family. Remember, understanding what changes you may see in your child and knowing how to respond to him or her will allow you to help your child's coping with their cancer diagnosis.

Because of your love and continued support, your child should have a successful adjustment and be better prepared to deal with life's future challenges.

ACTIVITIES WORKBOOK INTRODUCTION

This workbook is designed to be part of the COPE Program (Creating Opportunities for Parent Empowerment) for parents of children diagnosed with cancer. Along with this workbook, information has been shared with you regarding how children respond to being seriously ill and in the hospital and how parents can assist their child in coping with this experience. We encourage you to review the information again whenever you feel it may be helpful to do so. The parent and child activities in this workbook are designed to assist you in putting into action some of the ideas presented to you in the written and audiotaped information.

We hope you find the activities in the workbook helpful and enjoyable. These activities are one way of spending special time with your child during this stressful experience. The activities will help your child understand that you know it has been a very hard time for him or her and that you want to help him or her cope with feelings and worries.

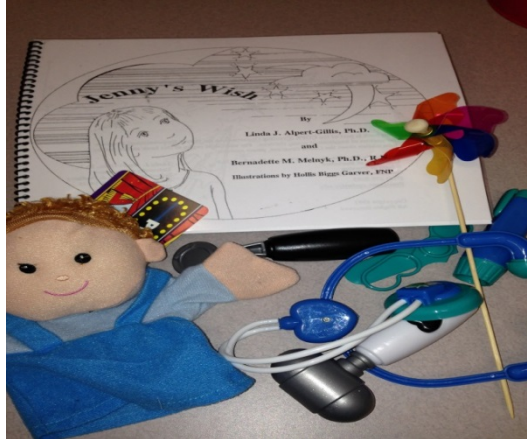


Parent and Child Activity 1

Sharing a book: *Jenny's Wish*

Materials Needed:

Jenny's Wish by L. J. Alpert-Gillis & B. M. Melnyk
Finger Puppets
Pinwheel



This parent-child activity involves sharing a book written especially for young children in the hospital and their families. The book, “Jenny’s Wish,” has several purposes which include: 1) providing children with information; 2) helping children understand and express their feelings about their hospitalization; 3) promoting age-appropriate coping skills; 4) encouraging children and parents to talk about each child’s own negative and positive hospital experiences; 5) and reassuring children that their wish to go home will come true.

It will be very helpful to talk with your child about the ideas presented in the book, both as you read the story and any time afterwards. Talking about the story as you read it can help your child attend to the issues raised and help him or her to personalize the information that he or she is hearing.

You can use the story as an opportunity to talk with your child about several issues, such as:

- The hospital is the best place for him or her to get better
- Being in the hospital is not his or her fault
- Painful procedures are to help him or her get better

- All children feel sad and mad about being sick in the hospital and having procedures
- All feelings are okay

It will be very helpful to read the book many times. As you know, children often like to hear the same story again and again. Listening to the same book helps children achieve a sense of mastery over the story and gain a sense of comfort from the familiarity of the story. Children also benefit from having the story repeated in order to process all of the information they hear. If you have other children, they too can benefit from hearing and talking about the story.

Along with talking about the book, there are other things that you can do to help your child benefit from the book. In the story, Jenny and her mother make a list of things Jenny can do when things are hard for her in the hospital. As you read about these things, you and your child can practice them (for example, your child can hug a favorite stuffed animal when he or she is upset). Other things the book talks about may be especially helpful to your child during painful procedures, such as: distracting your child with finger puppets or other objects in the room; and encouraging him or her to blow on a pinwheel to blow his or her pain away. The things listed in the book have been found to be helpful to many young children in frightening situations and may be very helpful to your child. Also, you and your child can make your own list or poster about what helps him or her when things are difficult in the hospital. You may want to hang your list on the wall so nurses, doctors, and others will know what most helps your child.

Your child will continue to benefit from reading the book once he or she is home from the hospital. It will be helpful to read the book from time to time throughout your child's cancer treatment over the months that follow. The book is one way of helping your child understand and cope with his or her cancer treatment.

The book also can help your child share his or her experience with you and others. You also may want to help your child make his or her own book in which your child is the star! This can be another way your child can achieve mastery over the experience and "tell" his or her very own story to others.

Parent and Child Activity 2: Medical Play

Materials Needed: Toy Medical Kit*



One effective and fun way to help your child cope better with his or her cancer diagnosis and hospitalization is with “medical” play. Medical play means playing with toy medical equipment such as syringes, bandages, and stethoscopes. Medical play is useful in at least five different ways.

By becoming more familiar and comfortable with toy medical equipment, your child may become more relaxed and less frightened by the procedures he or she must have during their cancer treatment.

Medical play also gives children an opportunity to be the one in charge. By pretending to be a doctor or nurse, your child gets to be the one to decide how many shots his or her patient gets rather than being the one to get the shots. Experiencing a feeling of control over what is happening, even in play, may help your child feel less helpless and more powerful.

Another way in which medical play is helpful is by encouraging your child to play out what has happened to him or her again and again. Adults often tell and retell an experience that has been very hard for them, such as giving birth, having an operation, or being in a military battle. People do this because each time that they retell their experience, they get more comfortable with what happened to them. Young children often have a hard time putting their experiences into words. So, one way you can help them “retell” their stories is to help them play and replay their cancer diagnosis and hospitalization with toys.

Medical play also may help your child cope with the strong feelings he or she has about being their cancer diagnosis and treatments. Sometimes children are overwhelmed by the procedures they must face and have a hard time understanding or expressing their feelings of fear, anger, and confusion. By giving them the chance to play out some of the things that have happened to them, they can explore and deal with the feelings they have had during those times.

Children's play also lets you better understand how they think about what is happening to them. Children often are confused about their illness, medical treatments, and the behavior of those around them. By watching and listening to your child's play, you may have the chance to correct your child's ideas about the experience. For example, sometimes children feel they have done something wrong to cause their illness. If you hear your child saying to a stuffed animal that it is sick because it is bad, then you can assume your child feels that way about him or herself. Telling the stuffed animal, and your child, that he or she is good and that sometimes people just get sick or hurt will help your child feel better about him or herself.

It will be helpful to guide your child's play, especially at first. Sometimes children may be hesitant to use the toys at first. That's fine. Be sure to encourage your child to handle the toys from time to time while reassuring him or her that these are toys and will not hurt him or her.

Below are a few of the ways children can use the toys.

- Let your child hold and look at the toys
- Suggest that your child pretend to be a doctor or nurse and that one of his or her dolls or stuffed animals is sick
- Suggest that your child pretend to be a doctor or nurse and you will pretend to be a patient in the hospital
- Suggest that your child pretend to be a doctor or nurse and examine him or herself.

You can encourage medical play by showing your child how to use the toys by pretending to be a doctor or nurse yourself and examining a doll or stuffed animal.

Some children may show a lot of feelings when playing with medical toys because they have strong feelings about their diagnosis and it's treatment. As a parent, you can use this type of play to let your child know that all of his or her feelings are okay, even angry feelings. As talked about in the information you received, children in the hospital sometimes feel very angry. If your child shows angry feelings during medical play, he or she may be less likely to show it in inappropriate ways, such as hitting or being uncooperative. At such times, you can say "I can see fluffy wishes to go home, he hates this place."

Medical play is often helpful while children are in the hospital and when they get home. You may find that your child wants to use the toy medical equipment with you more often when he or she gets home. This is usually because children feel much more comfortable at home. Therefore, it is a good idea to encourage medical play with your child frequently, both during and following hospitalization.

Enjoy sharing this special time with your child.



*Please note that the toy medical equipment you received is labeled for children three years of age and older. Therefore, if your child is under three years of age and you choose to use these materials, it is necessary that you closely supervise your child's play and only allow your child to play with these toys when you are using them with him or her.

Parent and Child Activity 3: Puppet Play

This parent and child activity involves puppet play to assist you in helping your child to talk about feelings related to his or her cancer diagnosis.

A puppet is a wonderful way of helping your child express feelings that may be too difficult for him or her to share directly. It also may allow him or her to show negative feelings that he or she thinks you might not like. Again, it is important to tell your child that all feelings are okay (although all ways of expressing feelings are not). Your child may get silly when using a puppet because sometimes children just get silly or because he or she may be anxious about the issues being discussed. Try to provide a calm, fun atmosphere. Also, if your child is not ready to deal with certain issues, you can come back to them another time or day.

You can introduce puppet play to your child in the following way:

WELL, I HAVE A NEW FRIEND. (You can bring the puppet out from behind your back). ***HE/SHE IS SICK TOO. HE/SHE HAS THE SAME THING THAT YOU HAVE:_____.***

You can first help your child to choose a name for the puppet and then decide on some things about the puppet, (for example, the puppet's favorite foods, games, or books). It is helpful to make the puppet a boy if your child is a boy and a girl if your child is a girl so that your child sees the puppet as more similar to him or herself.

Then, you can introduce the topic of feelings. Here, the puppet will be called Snuggles:

SNUGGLES HAS A LOT OF FEELINGS ABOUT BEING SICK AND IN THE HOSPITAL. MAYBE WE COULD FIND OUT HOW SNUGGLES IS FEELING RIGHT NOW. WOULD YOU LIKE TO HELP SNUGGLES TALK?

Encourage your child to take the puppet and "help" the puppet share his or her feelings (for example, what the puppet is worried about, happy about, or angry about). As your child uses the puppet to talk about feelings and experiences, make sure to label his or her feelings.

For example, (*“Oh, I see he really feels sad when his mother has to leave the hospital for a while,”* or *“Our friend really wishes she was all better and didn’t have to go the hospital,”* or *“The puppet is really angry when she has to have another shot”*).

If your child does not feel comfortable using the puppet at first, you can start by using the puppet yourself. However, try to involve your child as much as possible in the activity. You may want to say something such as the following.

Parent: **SNUGGLES, HOW ARE YOU FEELING RIGHT NOW?**

Snuggles: **NOT VERY GOOD. I DON’T KNOW MANY PEOPLE HERE.**

Parent: **IT SOUNDS LIKE YOU WISH YOU COULD GO HOME.**

Snuggles: **I DO. I WISH I WAS HOME NOW.**

Parent: **SOMETIMES KIDS FEEL LONELY WHEN THEY ARE SICK AND IN THE HOSPITAL.**

Snuggles: **I FEEL LONELY SOMETIMES. RIGHT NOW, I AM STARTING TO FEEL HAPPIER BECAUSE I AM MAKING NEW FRIENDS!**

Parent: **I GUESS BEING IN THE HOSPITAL IS PRETTY HARD BUT SOME THINGS MAKE IT A LITTLE BETTER, LIKE MAKING NEW FRIENDS.**

Snuggles: *(The puppet can give you and your child a hug).*

Issues you can talk about using the puppet include: the puppet’s feelings about painful procedures, such as having his or her blood drawn; things the puppet likes to do and does not like to do in the hospital; what the puppet plans to do when he/she gets home; who is the puppet’s favorite nurse or doctor; which nurse or doctor he/she does not like; and what helps the most when he/she does not feel well.

Once at home, you can use the puppet to talk about many issues, such as the following: the puppet’s worst time in the hospital; the best

thing about being in the hospital; and how the puppet feels at different times during their treatment.

It is helpful to use the puppet frequently. Children learn through play. Some children find it a great way to play out their situation, to overcome challenging issues, and to communicate. Remember to keep the puppet's identity the same every time you use it, (for example, someone who also is recovering from the same type of cancer as your child). This will help your child use it to deal with his or her feelings about their cancer diagnosis.

