

Parents and Children Coping with Pediatric Cancer:  
The Impact of Coping and Communication on Emotional Distress of Pediatric Cancer Patients

Angela Rebecca Shears

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### Abstract

Children who are diagnosed with cancer and their families must learn to cope with and communicate about the cancer diagnosis, treatment and its side effects, and hospital stays. Parents are their primary support; they are there to help them cope with and understand this new experience. Mothers and adolescents reported on emotional distress, coping, and communication. Results showed that secondary control coping is related to less emotional distress in pediatric cancer patients and that parents are more likely to communicate about information if they think it is important. Open communication is important in reducing emotional distress, but if problems in communication are already present, they override the impact of open communication. Implications, limitations, and areas of future research are discussed.

Parents and Children Coping with Pediatric Cancer: The Impact of Coping and Communication  
on Emotional Distress of Pediatric Cancer Patients

Each year, thousands of children are diagnosed with cancer. These newly diagnosed children are faced with a variety of challenging and stressful experiences. Some may not understand the magnitude of their diagnosis and the rigors of their treatment. Repeated hospital visits, chemotherapy treatments, and prolonged absences from school affirm the fact that these children are experiencing something that most children or adults do not have to face. Through it all, their parents are by their side, helping them to cope in this difficult time.

As children struggle with their illness, parents grapple with how to communicate with their children about cancer, its treatment, and the possible effects of the cancer and treatment. The National Cancer Institute (2001) suggests that parents be open and honest in discussion with pediatric cancer patients. It is assumed that this form of communication makes the child feel less worried and anxious. However, these guidelines are very general and provide insufficient information to guide parents in their discussions with their children. Also, parents need to know that their communication methods are actually effective (i.e., that their communication helps their child to understand their illness and is making their child feel less anxious). To achieve these goals, parents need more specific guidelines on how to communicate with their children. Effective communication could reduce anxiety levels in pediatric cancer patients, allowing patients to more effectively cope with their cancer. This study is one of the first steps in developing more specific guidelines on how parents should communicate with their children about cancer.

*Childhood Cancer*

In 1998, approximately 12,400 children in the United States were diagnosed with cancer and 2,500 died from the disease. Cancer is the fourth leading cause of death among children between the ages of one and nineteen. Among children and adolescents, the highest cancer rates are in the youngest (less than 5 year old) age group and the oldest (from 15 to 19 years old) group. The majority of pediatric cancer belongs to three different groups: leukemias, malignant central nervous system (CNS) tumors, and lymphomas. Children 14 years and younger are diagnosed with leukemia more often, but children between the ages of 15 and 19 are diagnosed with lymphoma more frequently. In the past decade, survival of childhood cancer has improved, especially with leukemia, due to the improvement in chemotherapy agents. Because of this increase in survival, the focus of research should not only be on further improvements to treatment methods but should also include improving the quality of life of children during cancer treatment and remission (National Cancer Institute 1999).

Variables such as diagnosis and prognosis could influence communication between the parents and children and the ability of children to cope with their cancer. The child's diagnosis could influence how parents and children communicate about cancer and cope with the stressor of cancer. Different diagnoses require different treatment regimens. Parents may talk about different topics if their children are experiencing radiation therapy as opposed to chemotherapy. Parents and children may view the level of stress resulting from chemotherapy different from the stress caused by radiation or surgery. Also, different diagnoses may carry different prognoses because of the varied levels of effectiveness in treating different types of cancer. If a child receives a good prognosis, parents may be more positive about the effectiveness of the treatment and the likelihood of survival. If there is a poor prognosis, a parent is faced with the possibility of the death of their child. In the latter situation, parents may experience significantly higher

levels of anxiety and depression as a result of the news of a poor prognosis; as a result, parents may not be able to cope well. Children are responsive to their parents' behavior and emotions, and they may react to changes in their parents' demeanor. Even if children are not being told the intimate details of all that is going on, they pick up on the distress of the parent (Claflin & Barbarin, 1991).

### *Parental Involvement*

Parents are integral participants in the care of their children throughout the time they have cancer and recovery from the disease. Mothers and fathers have to take off work to accompany their children to the many doctors' appointments. Parents may also have to stay with their children during the course of treatment or surgery. It is little wonder that parents are considered to be the primary manager of information for their children (Young, Dixon-Woods, Windridge & Heney, 2003). Parents are bombarded with all sorts of new information—the diagnosis, the options for treatment, the treatment itself, its side effects, and the possibility of death of their child. Their task is to manage the information and decide what is appropriate to share with their child. Parents have to consider many different factors such as the maturity, age of their child and the child's prognosis while dealing with their own anxiety over this new information (Young et al.). At times the information that is imparted or shielded from the child is due more to the anxiety of the parent rather than the child's age or maturity.

Parents perform various roles in the transmission of information to their children. They may facilitate communication between children and doctors. Children may request that their parents ask questions on their behalf. Parents may also choose to shield their children from information they feel the child is not ready to receive. They may also be present during the patient-doctor discussion to add their own comments so the child better understands the

information that is given. In the midst of all these roles that they play, parents are also trying to assimilate and remember of all the information that they receive from the doctor even if this information never reaches the child (Young et al., 2003).

Clarke, Davies, Jenney, Glaser, and Eiser (2005) also recognized that parents manage the information during their child's experience with cancer. It is also known that children pick up information about their illness on their own and come to their own conclusions about what is happening. Regardless of whether the parent communicates the information directly to the child or the child discovers this information on their own, it would be best if the proper information were imparted to children in a way that they understand the information. If children understand what they are up against, perhaps they can cope better with their cancer. A cancer diagnosis and its treatment are extremely complex. As previously stated, even if children are not being informed about the diagnosis and treatment, it may be inevitable that they discover or speculate to a degree about their illness and treatment. They may also come to incorrect conclusions about the nature of their disease, why they have been diagnosed with cancer, and their prognosis. For example, children may think they have been diagnosed with cancer because they are in trouble for doing something wrong (Rushforth, 1999). Rushforth also suggests that parents be pragmatists in the way they dispense information to their children—balancing their tendencies to protect their children with their tendencies to liberate them. Children need to be informed about and involved in their health care; their perspectives, as well as the perspectives of their parents, on dealing with the stress of pediatric cancer diagnosis would be helpful.

### *Coping*

Coping may be an important factor in relation to children's distress during the diagnosis and treatment of cancer. Stress is defined as "environmental events or chronic conditions that

objectively threaten the physical and/or psychological health or well-being of individuals of a particular age in a particular society” (Grant, Behling, Gipson, & Ford, 2005). Cancer is a significant stressor for patients and their families. This chronic condition demands that families learn to cope with it; also, the families may be left coping with the effects of treatment regimens even after the cancer has gone into remission. Stressors may lead to psychopathology such as anxiety and depression. However, the presence of stressors does not directly result in these problems. Some children exposed to significant stress become anxious and depressed while others maintain their normal, anxiety-free and depression-free lives. Perhaps the difference between these two outcomes occurs because of factors that mediate or moderate the relation between stress and psychopathology (Compas, Champion, & Reeslund, 2005). Possible mediators or moderators could involve the type of communication that is present between the parent and child or the coping style that is used by the child. Through positive communication experiences, the anxiety and depression may be reduced, helping the child to be better able to cope with their cancer.

Parents and children must learn to cope effectively with stressors. As with most stressors, certain coping styles in response to the stress of cancer may be more effective than others, resulting in less anxiety and depression. The context of the stressor must be taken into account. For example, situations that are not controllable for a child, such as parental conflict, are coped with best by using secondary control engagement coping, including acceptance, distraction and cognitive restructuring (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001).

### *Communication*

The NCI (2001) has suggested that communication is important in children’s emotional responses to cancer diagnosis. A number of factors may affect parent-child communication,

including gender differences. From an early age, people treat girls and boys differently. Parents have a large role in producing this difference in treatment which, in turn, produces a difference in the way boys and girls act. Adult males and females communicate differently. For example, women use language to make and keep social connections, but men use language to assert independence and achieve goals (Leaper, Anderson, & Sanders, 1998). Perhaps because of the ways they have observed their parents use language, girls' communication is mainly cooperative but boys display a more controlling type of speech. It is plausible that mothers and fathers treat their sons and daughters differently, as this may be part of the socialization process. As a result, boys' and girls' styles of communication may differ, and this could lead to differences in the way boys and girls cope as well. For example, if fathers are evading discussion of emotional topics with their sons, their sons may develop a coping strategy of ignoring the stressor (Fivush, Brotman, Buckner, & Goodman, 2000). In fact, Fivush et al. found that mothers and fathers talk more about emotional experiences, especially events provoking sadness, with their daughters than with their sons.

Communication may also differ based on socioeconomic status (SES). SES provides a general index of the level of parental education and economic attainment. Parents with college degrees communicate differently with their children in comparison to parents who did not complete high school, and children of lower SES families do not have the same language experience as children of higher SES (Hoff, 2003). Children of parents with higher levels of educational attainment typically have more developed language skills than parents with less formal education. Parents with higher SES (including more education) express themselves with a richer vocabulary and more complex sentence structures; as a result, their children hear more different types of words. Hoff and Tian (2005) also found similar differences associated with

SES cross-culturally. Chinese and American mothers of higher SES speak in ways that foster more advanced language development in their children.

### *Coping and Communication*

Coping and communication may be interrelated when dealing with the diagnosis of a serious illness. Hardy, Armstrong, Routh, Albrecht, and Davis (1994) examined the relationships between coping style and communication style in respect to families dealing with human immunodeficiency virus (HIV) and cancer diagnosis in children; the relationship between these variables was examined by looking at parent reports of coping and communication. Just like the general guidelines from the National Cancer Institute (2001), it is suggested that open communication about HIV enhances the coping of parents and children (Hardy et al.).

Although much progress has been made in our understanding of coping and communication, there are significant gaps in the literature surrounding the relationship of coping and communication to emotional distress in pediatric cancer patients. The actual relationship of open communication to emotional distress in these children needs exploration. Also, research must not rely on the reports of parents alone; research needs to include the perspective of the children. Adolescents should be allowed to provide information regarding their emotional distress, coping responses to the stress of pediatric cancer, and their communication with their parents. Researchers in the past have relied on questionnaires (Hardy et al., 1994) or interviews (Clarke et al., 2005); these methods have also focused on the parents. Direct observations of parents and children communicating about cancer should now be included in this area of research especially since coding system such as the Iowa Family Interaction Rating Scales (IFIRS; Melby, et al., 1998) have been developed. This methodology also allows the perspective of children younger than adolescents to be considered.

### *Research Questions*

In a situation where families are dealing with the stress of the diagnosis and treatment of cancer in children, the children could experience emotional distress in the form of anxious/depressed symptoms. In the current study, I will examine the relationship between coping, communication, and emotional distress. The goal of my analyses is to answer four questions: (a) what is the association between children's different methods of coping and their emotional distress? (b) What is the association between parent-child communication quality and emotional distress? (c) How are coping methods and communication quality related? (d) What is the relative association of coping methods and parent-child communication with emotional distress?

### Methods

#### *Participants*

Seventy families have volunteered to complete the pilot portion of the current study. Of these families, 66 included at least a mother and a pediatric cancer patient; only 4 families collected data from only the father and the child so these families have been excluded from the following analyses. Of the pediatric cancer patients, 33 (50 %) were female and 33 (50 %) were male. Participants were recruited from two sites: 10 families (15 %) treated at Vanderbilt Children's Hospital/Vanderbilt University (VU) and 56 families (85 %) treated at Columbus Children's Hospital/Ohio State University (OSU). The average age of this sample was 10.92 years old, ranging from 5 to 18 ( $SD = 3.96$ ). Of this sample, 7 (11 %) are racial/ethnic minorities; 5 (8 %) are Black/African-American, and 2 (3 %) are Hispanic/Latino. Data concerning parental education and family socioeconomic status (SES) was also collected. The largest percentage (42 %;  $N = 28$ ) of mothers had attended at least some college, and 35 % ( $N = 23$ ) had graduated from

high school. The smallest percentage of mother (5 %; N = 3) had attended some high school but not graduated. Six mothers (9 %) had attended a trade/technical school, and 5 mothers had attended graduate school (8%). The majority (55%; N = 36) of mothers reported their income as being \$50,000 or less; the rest (45 %; N = 30) reported their income as being greater than \$50,000.

### *Measures*

Demographic information was obtained concerning background family characteristics such as marital status, education, occupation, religious and spiritual beliefs and practices, income, and number and age of children. The family's SES was computed using the Revised Duncan Socioeconomic Index (Nakao & Treas, 1992) which is sensitive to occupational attainment changes.

To assess the child's emotional or behavioral problems and distress, questionnaires concerning his/her problems were by the adolescent and the parent. The Youth Self-Report (YSR; Achenbach & Rescorla, 2002) requires the adolescent to report on his/her symptoms of internalizing and externalizing problems and the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2002) is a report of the parent on the same problems. Both have excellent internal consistency, test-retest reliability (all greater than .75), and construct validity. These corresponding questionnaires allow direct comparisons to be made between the reports of adolescents about their emotional distress with their parent's report on their emotional distress. The Anxious/Depressed subscale will be the measure of emotional distress in the pediatric cancer patients in this study.

The coping and stress responses of the parent and child will also be examined. Each has completed the Pediatric Cancer Version of the Response to Stress Questionnaire (RSQ); the RSQ

refers to the specific stressor in asking the questions but the item structure remains consistent across stressors. This 57-item measure will be completed by both the parent and child in reference to the child's responses to the stress of cancer over the past six months. It is also completed by the parent in reference to their personal responses to the stress of cancer over the past six months. Through factor analyses of the RSQ, five primary factors have been identified (Connor-Smith, et al., 2000): primary control engagement coping (problem solving, emotional expression, emotional modulation), secondary control engagement coping (cognitive restructuring, positive thinking, acceptance, distraction), disengagement coping (avoidance, denial, wishful thinking), involuntary engagement (emotional arousal, physiological arousal, rumination, intrusive thoughts, impulsive action), and involuntary disengagement (cognitive interference, emotional numbing, inaction, escape). A distinction is made between voluntary coping responses (primary control engagement coping, secondary control engagement coping, and disengagement coping) and involuntary stress responses (involuntary engagement and disengagement). Connor-Smith, et al. has evidenced good internal consistency, test-retest reliability, and convergent and discriminant validity. In this study, the focus will be on the voluntary coping responses of the children as reported by adolescents and the children's mothers.

To assess communication style and quality, the Family Communication Questionnaire (FCQ; Vannatta, 2005) and the Parent-Adolescent Communication Scale (PACS; Barnes & Olson, 1985) was used. The FCQ requires the parent to rate on a four-point Likert scale the importance the parent places on communication with their children about various aspects of the disease and treatment of cancer, the frequency that this subject is approached, and the satisfaction with overall communication of the family. Internal consistency with families affected by breast cancer has been established and has been proved to be associated with child and

parental adjustment (Vannatta). I will mainly examine the attitudes and practices subscales on this measure. The Attitudes scale looks at how important the parent considers certain topics pertaining to cancer (e.g. diagnosis, treatments, and side effects) in communicating with their child. The Practices scale looks at how often the parent and child actually discuss these topics together. The PACS is a 20-item measure that assesses the general communication experiences between the parent and the child. Its internal consistency ( $\alpha$ 's range from .80 to .92) and test-retest reliability ( $r$ 's range from .64 to .78) have been established (Barnes & Olson).

#### *Observation of Parent-Child Communication*

During the task, parents and children will be given instructions about the task. The observation will last 15 minutes; the participants are encouraged to talk to one another about various questions. These questions are intended to provoke thoughtful and interesting communication about cancers. The four questions are as follows: (a) When and where have we talked about your illness? (b) What kinds of things have we already talked about regarding your illness? (c) How does it go when we talk about your illness? What has made it easier to talk about it? What has made it harder to talk about it? (d) What do we think might happen next? The family will then be debriefed by a psychologist who is a member of the clinical staff in the Pediatric Hematology/Oncology unit and an oncology nurse. The psychologist and nurse will ask the following questions of the family: (a) What was it liking doing this today? (b) What was hard about talking like this? (c) What was good about this experience? (d) What kinds of things did healthcare professionals do that helped or did not help you talk about (your child's) illness? (e) Would you like some help or support in talking more about (your child's) illness? (f) (If yes) Support services are available to you through the medical center-would you like us to ask someone to contact you or ask someone to get in touch with you? (g) What advice would you

give to other families in similar situations? Additional information will be provided if the family requests it. The debriefing session will ensure that the family's questions are answered and emotional concerns are addressed.

The 15-minute observations of parent-child communication about cancer were coded according to the Iowa Family Interaction Rating Scales (IFIRS; Melby, et al., 1998). This global coding system is created to measure the quality of behavioral exchanges between parents and children, including both verbal and non-verbal behaviors and affective and contextual dimensions of interactions. The different aspects of behavior will be rated by frequency, intensity, and proportion. The scale ranges from one to nine (one representing the absence of the behavior and nine representing a behavior that is mainly characteristic of the interaction). The inter-rater reliability, internal consistency, and test-retest reliabilities have been established by past studies (Ge, Best, Conger & Simons, 1996; Melby & Conger, 2001; Melby, Ge, Conger & Warner, 1995).

Interactions are coded by two judges. During the coding of interactions, the coder focuses on one focal (the parent or the child). The actions of the focal are coded in respect to their individual characteristics and their characteristics in their dyadic interaction. In my analyses, I will focus on codes for distress in children and codes positive and negative communication in the parents. Codes for emotional distress are sadness (SD) and anxiety (AX). Codes particularly relevant to judging communication would be the communication (CO) and the listener responsiveness (LR) codes; another code that may be relevant to positive communication would be warmth and support (WM). Negative behavior as seen in the hostility (HO) code may also be an important predictor as well. SD measures how much the person's words and actions convey sadness, unhappiness, despondency, depression, and regret. AX measures how much the

person's words and actions convey anxiety, nervousness, fear, stress, and worry. CO measures how well the person communicates his/her point of view and considers the other person's point of view at the same time in a positive or neutral manner. A person who scores high on communication would be a good communicator who encourages the exchange of information. LR measures the degree to which a person validates and is attentive to the other interactor. WM measures how caring, concerned, supportive, or encouraging a person is to the other interactor. HO measures the extent to which the focal is hostile, angry, critical or rejecting toward the other interactor.

### *Procedure*

This study has received approval from the Vanderbilt University Institutional Review Board. The pediatric cancer families were initially recruited for a coping and adjustment study about children with cancer and their families within 3-4 weeks of the child's initial diagnosis or diagnosis of recurrent malignancy. When they agreed to participate, informed consent was obtained concerning the completion of questionnaires and the examination of medical records. During this phase, mothers and children complete a standardized battery of questionnaires. Mothers completed questionnaires about emotional distress, coping, and communication in their children who were 5 to 17 years old; only children who were 10 years old or older completed self-report questionnaires on their emotional distress, coping, and communication.

The following inclusion criteria were used in the recruitment of Phase I: (a) Each child will have received a primary diagnosis of cancer including acute lymphocytic or nonlymphocytic leukemia, lymphoma, central nervous system (CNS) tumor, neuroblastoma, soft tissue sarcoma, bone cancer, or other solid tumors. (b) Each child's disease will be either a new diagnosis where the child does not have any prior history of cancer or a new recurrence of a cancer for which they

had attained a previous period of remission. (c) Children must be 5- to 17-years old inclusive at the time of recruitment (only those who are 10-17 will be asked to complete the self-report measures of Phases I and III). (d) All participants (children and parents) must be fluent in English. (e) All participants must live within 100 miles of the medical center from which they are recruited.

The following exclusion criteria were used in Phase I: (a) The child does not have other chronic illnesses which we will define as a disease process lasting 6 or more months that requires treatment by pediatric subspecialist (e.g., diabetes, cystic fibrosis, sickle cell disease). Children with chronic asthma or allergies will be allergies. (b) The child does not suffer from a pre-existing neurodevelopmental disorder or disability (e.g., mental retardation) or pervasive development disorder (e.g., autism). (c) The child who is diagnosed with a recurrence will not be re-recruited for the study if the family had enrolled in the study at the time of the child's initial diagnosis.

After the questionnaire phase, the families were re-contacted about participating in a parent-child observational session. If they agreed to participate, the observations between the child and the mother were scheduled around eight weeks post-phase I. Informed consent was also obtained for this phase, allowing us to film them as they talked about their cancer experience.

## *Results*

### *Descriptive Analyses*

Means and standard deviations for the emotional distress, coping, and communication variables are displayed in Table 1. According to the reports of adolescents on their emotional distress on the YSR, they experienced slightly above average symptoms of anxiety/depression

( $M T$  score = 53.22,  $SD = 5.25$ ). When the mothers reported on the child's emotional distress on the CBCL were examined, mothers reported somewhat more symptoms of anxiety/depression on average ( $M T$  score = 54.49,  $SD = 6.67$ ).

Adolescents reported using secondary control engagement coping the most ( $M = .31$ ,  $SD = .06$ ); this type of coping was favored over primary control engagement coping ( $M = .17$ ,  $SD = .03$ ) and disengagement coping ( $M = .14$ ,  $SD = .03$ ). Their mothers also reported that their children used secondary control engagement coping the most ( $M = .26$ ,  $SD = .05$ ), followed by primary control engagement coping ( $M = .20$ ,  $SD = .05$ ) and disengagement coping ( $M = .14$ ,  $SD = .04$ ).

In reference to the quality of the communication between them and their mothers, adolescents reported greater openness ( $M = 42.74$ ,  $SD = 6.60$ ) as compared to problems ( $M = 22.29$ ,  $SD = 7.24$ ). The mothers' reports on the quality of the communication between them and their children followed the same pattern—greater openness ( $M = 39.67$ ,  $SD = 4.69$ ) and less problems ( $M = 22.05$ ,  $SD = 5.95$ ). Mothers also reported thinking of many of the topics surrounding cancer diagnosis, treatment, and side effects as important ( $M = 40.89$ ,  $SD = 4.97$ ), but there was a discrepancy with how much they actually communicating these topics to their children ( $M = 33.99$ ,  $SD = 5.97$ ). This reveals that mothers communicate less information to their children even if they think it is important.

### *Correlational Analyses*

Correlations between parent- and child- reports of emotional distress, coping, and communication variables are shown in Table 2. Adolescents' reports and mothers' reports on children's anxious/depressed were significantly associated ( $r = .75$ ,  $p < .001$ ).

*Research Question 1: Coping and Psychological Symptoms.* When adolescents reported using more primary control coping, they reported using significantly less disengagement coping ( $r = -.39, p < .05$ ). When they reported using more secondary control coping, they reported using significantly less disengagement coping as well ( $r = -.53, p < .001$ ). When they reported using more secondary control coping, their mothers reported that their children used significantly more disengagement coping ( $r = .44, p < .01$ ). A relationship approaching significance was also found between adolescent-reports of use of secondary control engagement coping and mothers' reports of children's use of primary control engagement coping ( $r = .31, p = .07$ ). When mothers reported that their children used more primary control coping, they also reported that their children used significantly more secondary control coping ( $r = .45, p < .001$ ).

Each of these reports was examined in respect to different types of coping. When adolescents reported less distress, they reported using significantly more primary control engagement coping ( $r = -.36, p < .05$ ) and more secondary control engagement coping ( $r = -.37, p < .05$ ). When adolescents reported less distress, their mothers reported that they used significantly more secondary control engagement coping ( $r = -.35, p < .05$ ). An association approaching significance was found between reduced adolescent-reported distress and mothers' reports of using primary control coping ( $r = -.29, p = .09$ ). When mothers reported less distress in their children, they also reported that their children used significantly more primary control engagement coping ( $r = -.37, p < .001$ ) and more secondary control engagement coping ( $r = -.37, p < .001$ ). When mothers reported less distress in their children, their adolescents also reported using more secondary control engagement coping ( $r = -.35, p < .05$ ). A trend approaching significance was observed between increased distress in children and increased used of disengagement coping as reported by the mother ( $r = .27, p = .10$ ). In summary, using more

primary control coping is significantly associated with less anxious/depressed symptoms when compared within informants. Using more secondary control coping is significantly associated with less anxious depressed symptoms when compared within informants and across informants.

*Research Question 2: Communication and Psychological Symptoms.* When adolescents reported more open communication with their mothers, they reported significantly less problematic communication with their mothers ( $r = -.68, p < .001$ ). When adolescents reported more open communication with their mothers, their mothers also reported significantly more open communication ( $r = .43, p < .05$ ) and significantly less problematic communication ( $r = -.53, p < .001$ ) with their children. When adolescents reported more problems in their communication with their mothers, their mothers reported significantly more problems in their communication with their children ( $r = .42, p < .05$ ). When mothers reported more open communication with their children in general, they also reported thinking that communicating about cancer topics to their children was significantly more important ( $r = .26, p < .05$ ). When mothers thought communicating about cancer topics with their children was important, they were more likely to actually communicate with their children on these topics ( $r = .46, p < .001$ ). An association approaching significance was found mothers' attitudes on communication about cancer topics and adolescents' reports of increasingly open communication ( $r = .22, p = .08$ ).

Reports of emotional distress were also examined in relation to communication quality and style. When adolescents reported more distress, they reported significantly more problems in communicating with their mothers ( $r = .39, p < .05$ ), and their mothers also reported significantly more problems in communicating with their children ( $r = .42, p < .05$ ). A trend toward significance was found as well; adolescents' reporting less distress had mothers' reporting more open communication ( $r = 0.32, p = .07$ ). When mothers reported less distress in

their children, they reported significantly more open communication with their children ( $r = -.35$ ,  $p < .001$ ) and less problematic communication with their children ( $r = .42$ ,  $p < .001$ ). Mothers' reports on their children's distress did not correlate with the reports of their children on communicating with their mother. Reports of children's distress from the adolescents or mothers did not significantly correlate with their specific attitudes on communicating about cancer or with their specific practices on communicating about cancer. An association approaching significance was found between mothers' reports of children's distress and mothers' attitudes on communication about cancer; the more important mothers felt communication about cancer was, the less distress their children experienced ( $r = 0.21$ ,  $p = .10$ ).

*Research Question 3: Coping and Communication.* The relationships between coping and communication variables were examined as well. When adolescents reported using more primary control coping, they also reported having a significantly more open communication relationship with their mothers ( $r = .55$ ,  $p < .001$ ) and a significantly less problematic communication relationship with them as well ( $r = -.40$ ,  $p < .05$ ). When adolescents reported using more disengagement coping, their mothers reported that they talked about cancer topics significantly less with their children ( $r = -.35$ ,  $p < .05$ ). When parents reported that their children used more primary control coping, they also reported having a significantly more open communication relationship with them ( $r = .26$ ,  $p < .05$ ) and a significantly less problematic communication relationship with them as well ( $r = -.26$ ,  $p < .05$ ). There was a trend toward significance between adolescents' reports of more open communication and mothers' reports of their decreased use of disengagement coping ( $r = 0.32$ ,  $p = .054$ ). A relationship that approached significance was also found between mothers' reports of increased importance of communicating about cancer topics and their reports' of children's decreased use of

disengagement coping ( $r = -.23, p = .06$ ). The reports from adolescents and parents reveal the same pattern—that primary control coping is related to more open communication and less problems with communication.

### *Regression Analyses*

#### *Research Question 4: Relative Associations of Coping and Communication to Distress.*

Four regression equations were examined. Coping and communication variables were used as predictors of emotional distress in children as reported by parents and adolescents. All four equations entered the variables in the same order; the only difference was the specific mother and adolescent report combinations. Secondary control coping, open communication, and problematic communication were used as predictors because each of these variables had yielded significant correlations with emotional distress in the children.

*Equation 1.* The first equation used adolescents' reports of coping and communication to predict adolescent-reported anxious/depressed symptoms. In the first step, adolescent-reported use of secondary control coping was entered and found to be a significant predictor of adolescent-reported anxious/depressed symptoms from the YSR ( $\beta = -.37, p < .05$ ); as adolescents reported using more secondary control coping, their reports anxious/depressed symptoms decreased as well. In the second step, adolescents' reports on open communication with their mothers were added. Secondary control coping remained a significant predictor ( $\beta = -.40, p < .05$ ), and openness approached significance as a predictor ( $\beta = -.26, p = .10$ ). In the final step, adolescents' reports on problematic communication with their mothers were added. Secondary control coping remained a significant predictor ( $\beta = -.34$ ) in this step; neither openness nor problems in communication was a significant predictor.

*Equation 2.* The second equation used parents' reports of coping and communication to predict parents' reports of anxious/depressed symptoms in children. In the first step, the mothers' reports of children's secondary control coping was entered and found to be a significant predictor of mothers' reports of children's anxious/depressed symptoms ( $\beta = -.36$ ). In the second step, mothers' reports of open communication were added. Both secondary control coping ( $\beta = -.32$ ,  $p < .05$ ) and open communication ( $\beta = -.30$ ,  $p < .05$ ) were significant predictors of anxious/depressed symptoms. In the final step, mothers' reports of problematic communication were added. Both secondary control coping ( $\beta = -.30$ ,  $p < .05$ ) and communication problems ( $\beta = .35$ ,  $p < .05$ ) were significant predictors of anxious/depressed symptoms. Open communication was no longer a significant predictors of anxious/depressed symptoms.

*Equation 3.* The third equation used parents' reports of coping and communication to predict adolescent-reported anxious/depressed symptoms. In the first step, mothers' reports of secondary control coping was entered and found to be non-significant in predicting adolescents' reports of anxious/depressed symptoms; this report of coping did approaching significance as a predictor ( $\beta = -.29$ ,  $p = .10$ ). In the second step, mothers' reports on open communication were added; neither of the variables was found to be significant in predicting emotional distress in adolescents. Both variables approached significance as predictors (coping,  $\beta = -.29$ ,  $p = .11$ ; open communication,  $\beta = -.31$ ,  $p = .08$ ). In the final step, mothers' reports on problematic communication were added. None of the three variables were found to be significant in predicting anxious/depressed symptoms in adolescents.

*Equation 4.* The fourth equation used adolescents' reports of coping and communication to predict parents' reports of anxious/depressed symptoms in children. In the first step, adolescents' reports of secondary control coping was entered and found to be non-significant in

predicting mothers' reports of anxious/depressed symptoms. In the second step, adolescents' reports on open communication were added; neither of the variables was found to be significant in predicting emotional distress in the children as reported by mothers. In the final step, adolescents' reports on problematic communication were added. None of the three variables were found to be significant in predicting anxious/depressed symptoms in adolescents.

#### *Exploratory Analyses with Observational Data*

Means and standard deviations for the observed maternal and child communication as coded using the IFIRS are reported in Table 4. The observational portion of this study is conducted three months after the first part. As of April, 2007, 33 families have reached this point and agreed to participate in this portion of the study. A team of coders and I have been trained to code these interactions and 13 interactions have been independently coded by two coders; these two raters have also met and resolved all the discrepancies of two points or more. On all 34 of the codes, the two raters have agreed within one point 75% of the time. The following are the preliminary analyses of six codes. Children's SD and AX ratings were examined, and parents WM, LR, CO, and HO ratings were examined. When observed, this sample of children exhibits about the same levels of SD ( $M = 4.23$ ,  $SD = 1.36$ ) and AX ( $M = 4.31$ ,  $SD = 1.25$ ). Their parents show medium levels of WM ( $M = 5.46$ ,  $SD = 1.56$ ) and more LR ( $M = 6.46$ ,  $SD = 1.27$ ) and CO ( $M = 6.46$ ,  $SD = 1.13$ ). These parents do not show much HO ( $M = 2.23$ ,  $SD = 1.42$ ).

Children's AX ratings tend to decrease as parent's LR ( $r = -.46$ ,  $p = .11$ ) and CO ( $r = -.52$ ,  $p = .07$ ) increase, but these associations do not reach significance. When parents are rated as being higher on WM, they are also rated as being significantly higher on LR ( $r = .85$ ,  $p < .001$ ) and on CO ( $r = .67$ ,  $p < .05$ ). When parents are rated as higher on WM, they also tend to be rated

lower on HO ( $r = -.47, p = .11$ ). When parents are rated higher on LR, they are also rated significantly higher on CO ( $r = .89, p < .001$ ) and significantly lower on HO ( $r = -.67, p < .01$ ). When parents are rated higher on CO, they are also rated significantly lower on HO ( $r = -.75, p < .01$ ).

### Discussion

In this study, I examined the relationships among emotional distress, coping, and parent-child communication in a sample of children with cancer and their parents. Through correlation and regression analyses, I examined the association of children's coping and communication with their parents with children's emotional distress near the time of their diagnosis. Through these analyses I attempted to elucidate the relationship between coping and pediatric cancer patients' anxious/depressed symptoms, the relationship between communication and pediatric cancer patients' emotional distress, the relationships between communication and coping, and the relative contributions of each in predicting emotional distress. Information on all these variables was obtained from mothers on children and adolescents.

Mothers and adolescents reported anxious/depressed symptoms that were somewhat elevated when compared to norms for children in this age range. Further, according to both mothers and adolescents in the sample, the pediatric cancer patients used secondary control coping when specifically coping with the stress of their cancer; patients used primary control coping the second most. Pediatric cancer patients seem to be using the appropriate types of coping for the type of stressor with which they are dealing. Like the previously mentioned parental conflict example (Compas et al., 2001), cancer is uncontrollable by the patient so it is appropriate that they are using secondary control coping (cognitive restructuring, positive thinking, acceptance, or distraction).

Their use of primary control coping (problem solving, emotional expression, or emotional modulations) is expected as well because there are still certain aspects of dealing with cancer that are controllable. For example, if a pediatric cancer patient is concerned about changes in his/her appearance like losing his/her hair, he/she can come up with ways to compensate for this change like wearing a hat, a scarf, or a wig.

The pediatric cancer patients in this sample and their mothers reported more open and less problematic communication. This may indicate that mothers and their children already have a good basis for communicating about cancer since they are generally open anyway. These mothers and children are still experiencing problems though. Mothers also report a discrepancy between what they think is important to communicate with their children and what they actually communicate to their children; they communicate less about cancer topics than their importance ratings would indicate. Rushforth (1999) has suggested that parents must balance their protectionist tendencies with their liberationist tendencies. These reports from the mother suggest that they err on the side of caution in communicating to their children about their children's cancer diagnoses and treatment; they choose to protect their children which is a naturally expected reaction of most parents.

*Research Question 1: Coping and Psychological Symptoms*

Adolescents reporting more primary and secondary control engagement coping used less disengagement coping. Adolescents reporting more secondary control coping were viewed by their mothers as using more disengagement coping (avoidance, denial, or wishful thinking), but mothers reporting that their children used more primary control coping also reported that their children used more secondary control engagement coping. Overall, it seems that pediatric cancer patients favor the two most effective forms of coping with their cancer; also, if they use one form

of effective coping, they are more likely to use the other form. Mothers may have interpreted their adolescents' use of secondary control engagement coping, a form of coping that at times is more introspective, as disengagement from the stressor.

The use of secondary control engagement coping seems to be associated with reduced emotional distress in pediatric cancer patients; this finding is corroborated by adolescents' reports and mothers' reports, across and within informants. This points to a strong finding that supports the benefit of using secondary control coping with the stress of pediatric cancer diagnosis and treatment. The use of primary control engagement coping also is associated with reduced emotional distress in pediatric cancer patients; this finding is corroborated by adolescents' reports and mothers' reports, within informants. This finding also approached significance across informants with adolescents' reports of distress and mothers' reports of their children's coping. These findings support the benefit of using primary control coping with this stressor. Mothers' reports suggest an association between more distress in children and the use of disengagement coping. Using disengagement coping strategies may be to the detriment of pediatric cancer patients. In summary, these findings suggest that the best strategy for coping for pediatric cancer patients may be secondary control coping; primary control coping has its benefits as well, but there may be a cost to using disengagement coping with this stressor.

#### *Research Question 2: Communication and Psychological Symptoms*

Mothers' reports of open and problematic communication agreed with adolescents' reports on these types of communication; more open communication is associated with fewer problems in communicating. Mothers that placed value on communicating about cancer topics were more likely to actually communicate about these topics. These findings suggest that if parents are taught that certain topics are important in communicating with their children about

cancer, they will communicate about these topics with their children. These findings also suggest that placing value on communicating about cancer topics also translates into adolescents feeling that their communication with their mothers is more open. This may be because these parents are actually communicating with their children about cancer and other topics as well.

Less emotional distress in pediatric cancer patients was associated with fewer problems in communication and more open communication overall. The strongest finding was the one dealing with problematic communication; it was corroborated by adolescents and mothers within informants and adolescents' reports of distress combined with mothers' reports on communication. These findings suggest that problematic communication in general, not just about cancer topics), between mothers and their children could already be in place, causing the distress in children and adolescents. Mothers' reports on open communication are associated with less distress in children; our data suggest that these reports of open communication are also associated with more open communication as reported by the adolescent. These findings suggest that if open communication is already in place between the mothers and children, the children do not experience more anxious/depressed symptoms when they are diagnosed with cancer. Also, mothers who value who think communicating about cancer with their children is important report less distress in their children. These findings may appear because as reported before parents who value communicating about cancer actually communicate about cancer with their children.

*Research Question 3: Coping and Communication.*

Both mothers and adolescents reported more open communication and less problematic communication when they both reported the use of primary control engagement coping. Adolescents' reports on communication and mothers' reports on coping suggest a relationship

between open communication and using disengagement coping less. Adolescents reported using more disengagement coping when their parents reported talking less about cancer with them. The findings also suggest that mothers reporting that their children used more disengagement coping also reported feeling that cancer topics were less important in communicating to their children. Primary control coping seems to be associated the most with overall communication quality. This may be because certain forms of primary control coping involve talking with others, perhaps mothers, about the stressor. These findings also suggest that adolescents do not experience open communication with their mothers because of their disengagement coping strategies.

*Research Question 4: Relative Associations of Coping and Communication to Distress*

Four models were tested comparing within informants and across informants on emotional distress, coping, and communication. The third and fourth models tested across informant comparisons. The third model suggests that coping and open communication as reported by mothers will tend to predict anxious/depressed symptoms as reported by adolescents. In the fourth model, no predictors were found. The first model was significant and this model tested within informant comparisons in adolescents. Secondary control coping remained a predictor of emotional distress throughout. Secondary control coping and open communication predicted distress when they were entered at the same time. Problematic communication and open communication did not predict distress in the presence of secondary control coping. These models may have not reached significance because of the decreased sample size of adolescents so there were fewer cases included in these analyses.

The second model explained the greatest portion of variance in symptoms. This model tested within informant comparisons in mothers. By itself, secondary control coping predicted

emotional distress in children. Secondary control coping and open communication predicted emotional distress when they are considered together. Secondary control coping and problematic communication predicted emotional distress when they were considered with open communication, open communication no longer predicted distress. This suggests the following: (a) secondary control coping is helpful in dealing with the stress of pediatric cancer; (b) overall open communication is important as well when dealing with the stress of pediatric cancer; (c) in the presence of problems with communication, it does not matter that parents are being open in their overall communication with their children.

#### *Observations of parent-child interactions*

Warmth and support, listener responsiveness, and communication are highly related. Our data suggest that effective listening and communicating on the part of the parent may be important in reducing anxiety in pediatric cancer patients. Hostility is negatively related to warmth and support, listener responsiveness, and communication. More observations need to be coded to examine other patterns that may exist in this data.

#### *Implications*

These findings have implications in the medical setting, in the parent-child relationships, and psychological research. To improve emotional health near of the time of diagnosis, several things could be done. When families first find out about their children's cancer diagnosis, parents and children could be provided with information regarding the benefits of primary and secondary control engagement coping; these information sessions or pamphlets could also provide practical applications of these types of coping for the specific stressor of pediatric cancer diagnosis and treatment. Doctors and clinical psychologists may also need to be there to facilitate open communication between parents and children; clinical psychologists may also

want to focus more of their energies on helping parents and children who already have problems communicating since this is more detrimental to pediatric cancer patients' mental health. Also, parents know more than they communicate, and this study suggests that if they consider it to be important, they will be talk about it more with their children. If parents were made aware of the important topics to discuss with their children, they would be more likely to talk to their children about it. Multiple reporters were essential to the success of this study; this allowed for comparisons within informants and across informants. Whenever research is conducted on pediatric cancer patients, it should always include the perspective of the pediatric cancer patients as much as possible.

### *Limitations*

Even with all the benefits to this study, there are limitations to its scope. Some of the data analyses were limited in statistical power because of the small sample size. The most powerful analyses included mothers' reports, and mothers were the largest part of the data. Our power was limited in some of the analyses involving adolescents' reports because patients younger than 10 were recruited to participate in the study as well but could not fill out questionnaires. Our power was significantly limited in the analyses of observational data because the small amount of coded data. To detect smaller differences, we need to increase the size of the family sample and the size of the adolescent sample. Also, neither parents nor adolescents reported on the quality of communication surrounding the topic of cancer diagnosis and treatment, and adolescents were never asked what they thought that they should be told when talking with their parents.

### *Future Research*

The observational data needs to be examined in more detail when the sample size has increased. The possible impact of age, gender, diagnosis, and prognosis needs to be assessed as well in this population. Also, the perspective of fathers needs to be examined; it was not examined in this sample because of low sample size, but it is still important. Parents and adolescents need to be given the opportunity to report on the quality of communication surrounding their cancer diagnosis and treatment. The perspective of the pediatric cancer patient needs to be further examined by looking at topics concerning cancer that they value and the extent these topics have been communicated to them.

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Table 1

*Means and Standard Deviations for Emotional Distress, Coping, and Communication Variables*

<b>Variable</b>	<b>M</b>	<b>SD</b>
Child	1. Anxiety/depression ( <i>T</i> Score)	53.22 5.25
	2. Primary control engagement coping	0.17 0.03
	3. Secondary control engagement coping	0.31 0.06
	4. Disengagement coping	0.14 0.03
	5. PACS openness score	42.74 6.60
	6. PACS problems score	22.29 7.24
Mother	7. Anxiety/depression ( <i>T</i> Score)	54.49 6.67
	8. Primary control engagement coping	0.20 0.05
	9. Secondary control engagement coping	0.26 0.05
	10. Disengagement coping	0.14 0.04
	11. PACS openness score	39.67 4.69
	12. PACS problems score	22.05 5.95
	13. FCQ attitudes score	40.89 4.97
	14. FCQ practices score	33.88 5.97

Note: M = mean, SD = standard deviation, PACS = Parent-Adolescent Communication Survey, FCQ = Family Communication Questionnaire

Table 2

*Correlations between Distress, Coping, and Communication Variables*

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Child-AD	—													
2. Child-PCC	-.36*	—												
3. Child-SCC	-.37*	.27	—											
4. Child-DC	.21	-.39*	-.53‡	—										
5. Child-OC	-.23	.55‡	-.06	.01	—									
6. Child-PC	.39*	-.39*	-.13	.10	-.68‡	—								
7. Mother-AD	.75‡	-.18	-.35*	.27	.09	.07	—							
8. Mother-PCC	-.30^	.08	.31^	-.12	-.15	-.02	-.37†	—						
9. Mother-SCC	-.35*	-.19	.14	.17	-.21	.05	-.37†	.45‡	—					
10. Mother-DC	-.17	-.16	.44†	-.20	-.32^	.06	-.11	.01	-.09	—				
11. Mother-OC	-.32^	.21	.09	.11	.43*	-.53‡	-.35†	.26*	.13	-.11	—			
12. Mother-PC	.42*	-.23	-.22	-.01	-.26	.42*	.42‡	-.26*	-.13	.07	-.56‡	—		
13. Mother-CCA	-.25	.18	.13	.06	.16	-.14	-.21^	-.14	.12	-.23^	.22^	-.18	—	
14. Mother-CCP	-.08	-.01	-.01	-.35*	.08	-.01	-.11	.05	.04	-.17	.26*	.00	.46‡	—

Note: AD = Anxious/Depressed symptoms (Child, YSR; Mother, CBCL); PCC = Primary control coping (RSQ); SCC = Secondary Control Coping (RSQ); DC = Disengagement Coping (RSQ); OC = Open Communication (PACS); PC = Problematic Communication (PACS); CCA = Cancer Communication Attitudes (FCQ); CCP = Cancer Communication Practices (FCQ)

\*p<0.05 †p<.01 ‡p<.001 ^approaching significance, p-values reported in text

Table 3.  
*Regressions Equation Predicting Distress as Reported by Adolescents and Mothers*

Equation 1 – YSR Anxious/Depressed Symptoms	Final $R^2 = .26$	F (3, 32) = 3.74, p < .05
Step 1: $R^2$ change = .14	$\beta$	$sr$
Secondary control coping (adolescent report)	-.37*	-.37
Step 2: $R^2$ change = .07		
Secondary control coping (adolescent report)	-.40*	-.41
PACS Openness (adolescent report)	-.26	-.28
Step 3: $R^2$ change = .05		
Secondary control coping (adolescent report)	-.34*	-.35
PACS Openness (adolescent report)	-.03	-.03
PACS Problems (adolescent report)	.33	.25
Equation 2 – CBCL Anxious/Depressed Symptoms	Final $R^2 = .30$	F (3, 54) = 7.73, p < .001
Step 1: $R^2$ change = .13	$\beta$	$sr$
Secondary control coping (mother report)	-.36†	-.36
Step 2: $R^2$ change = .09		
Secondary control coping (mother report)	-.32*	-.33
PACS Openness (mother report)	-.30*	-.32
Step 3: $R^2$ change = .08		
Secondary control coping (mother report)	-.30*	-.34
PACS Openness (mother report)	-.11	-.11
PACS Problems (mother report)	.35*	.32
Equation 3 – YSR Anxious/Depressed Symptoms	Final $R^2 = .24$	F (3, 27) = 2.62, p = .07

Step 1: R <sup>2</sup> change = .10	$\beta$	sr
Secondary control coping (mother report)	-.31	-.31
Step 2: R <sup>2</sup> change = .09		
Secondary control coping (mother report)	-.29	-.30
PACS Openness (mother report)	-.31	-.32
Step 3: R <sup>2</sup> change = .04		
Secondary control coping (mother report)	-.26	-.28
PACS Openness (mother report)	-.19	-.18
PACS Problems (mother report)	.23	.21
<hr/>		
Equation 4 – CBCL Anxious/Depressed Symptoms	Final R <sup>2</sup> = .10	F (3, 34) = 1.14, p = .35
Step 1: R <sup>2</sup> change = .05	$\beta$	sr
Secondary control coping (adolescent report)	-.23	-.23
Step 2: R <sup>2</sup> change = .02		
Secondary control coping (adolescent report)	-.24	-.24
PACS Openness (adolescent report)	-.15	-.16
Step 3: R <sup>2</sup> change = .02		
Secondary control coping (adolescent report)	-.21	-.21
PACS Openness (adolescent report)	-.04	-.03
PACS Problems (adolescent report)	.17	.13

Note:  $\beta$  = standardized beta, sr = semi-partial correlation.

\*p<0.05 †p<.01

Table 4

*Exploratory Analyses of Observational Data According to the IFIRS Coding System*

Variable	1	2	3	4	5	6
1. Child SD	—					
2. Child AX	-.05	—				
3. Parent WM	.34	-.34	—			
4. Parent LR	.08	-.47 <sup>^</sup>	.85 <sup>‡</sup>	—		
5. Parent CO	-.13	-.52 <sup>^</sup>	.67 <sup>*</sup>	.89 <sup>‡</sup>	—	
6. Parent HO	-.12	.38	-.47 <sup>^</sup>	-.67 <sup>*</sup>	-.75 <sup>†</sup>	—
Mean	4.23	4.31	5.46	6.46	6.46	2.23
Standard deviation	1.36	1.25	1.56	1.27	1.13	1.42

\*p<0.05 †p<.01 ‡p<.001 <sup>^</sup>approaching significance, p-values reported in text