

EMOTIONAL DISTRESS AND LINGUISTIC COMPLEXITY
IN PARENTS OF CHILDREN WITH CANCER

By

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CHAPTER I

INTRODUCTION

Although rates of survival for pediatric cancer have increased in the last two decades, many children and their families are affected by the stress and associated emotional distress related to the diagnosis, treatment, and late effects of pediatric cancer. Little empirical research has examined how parents and children communicate about a child's cancer and how communication is related to psychological adjustment. In this study, we examined characteristics of parents and children that may be related to parental linguistic complexity when talking about a child's cancer in order to better understand what factors influence the complexity of parents' speech, and how, in turn, this complexity affects children's adjustment to cancer.

Incidence of Pediatric Cancer Diagnosis and Survival

One to 2 children per 10,000 are diagnosed with pediatric cancer annually, so that approximately 12,400 U.S. children under 20 years old are diagnosed each year (Ries et. al. 2004). The incidence of diagnosis has increased in the past three decades (Ross et al., 1996). Approximately 11 cases were diagnosed per 100,000 children in the mid 1970's, contrasted with approximately 15 cases per 100,000 diagnosed in the mid-1990's. Fortunately, treatment methods have also improved, allowing more children to enter remission and survive. Five-year

survival increased to 77% in 1992–97 from 56% in 1974–76 (NCI, 2002). In spite of advances in treatment, pediatric cancer is the most common cause of death for children in the U.S. (Ries et. al 2004). Although many more children are surviving cancer than in the past, treatment for the disease is often intensive and can include such varied treatments as chemotherapy, radiation, and surgery. Furthermore, the treatments themselves may cause side effects such as pain, nausea, changes in physical appearance, and disruptions in daily activities, as well as increased financial strain on families. For children with a poor prognosis, the possibility of dying from cancer may also be an especially difficult and frightening issue.

Although most pediatric cancer patients reach five-year post-diagnosis survival, there is also evidence that survivors suffer long-term health and psychological consequences of their cancer. Hudson and colleagues found that, in a comparison of childhood cancer survivors and their siblings, survivors were more likely to have problems with general health, mental health, functional impairment, and engaging in physical activities. In addition, 44% of survivors reported difficulties in at least one of those areas (Hudson et. al., 2003). Overall, a diagnosis of and treatment for cancer has significant health-related consequences for most children who survive the disease.

Pediatric Cancer and Emotional Distress

Child Distress

The stress of a cancer diagnosis, treatment, and prognosis may all contribute to increased levels of emotional distress among children with cancer and their parents. While some research has suggested that children with cancer do not show higher levels of emotional distress (e.g. Canning et. al., 1992; Noll et. al., 1999), there is also evidence that newly diagnosed children with cancer experience significant distress. Sawyer et. al. (2000) examined children diagnosed with cancer and their parents. Both children and parents had higher than average levels of psychological problems when assessed immediately after diagnosis, although adjustment was comparable with a general sample at 2, 3 and 4 year follow-ups. In contrast, other studies have also demonstrated long-term psychological consequences of pediatric cancer for survivors. For example, a study by Erickson and Steiner (2001) sampled 40 survivors of childhood cancer for symptoms and presence of post-traumatic stress disorder. The authors found that 10 percent of long-term survivors met criteria for PTSD (compared with a 7.8% lifetime prevalence in the general population; Kessler et. al., 1995). The authors also found that 88% of survivors had at least one trauma symptom. Self-reported intrusive thoughts and avoidance in this sample of survivors were also higher than average. In a review of the literature, Bruce (2006) noted that childhood cancer survivors were at risk for PTSD and related symptoms, as well as poorer social functioning.

In a recent meta-analysis, Aldridge and Roesch (2006) examined how different types of coping related to adjustment in children with cancer. Coping was defined along two dimensions: the focus of children's coping responses (emotion- vs. problem- focused), and whether the stressor was approached or avoided (approach vs. avoidance focused). Analyses of 1230 pediatric cancer patients showed that, overall, emotion-focused coping (trying to regulate one's emotions in response to a stressor) approach coping (attending to the stressor), and avoidance coping were unrelated to children's adjustment. A small negative correlation was found between problem-focused coping (i.e. trying to control the environment/external stressor) and adjustment (Aldridge & Roesch, 2006) While these overall results might indicate lack of a strong relationship between most types of coping and adjustment, when the authors examined several moderating variables, they found that time since diagnosis moderated the relationship between different types of coping and adjustment. For example, at 6 months to 1 year, approach coping was associated with poorer adjustment, but at 4-5 years was associated with better adjustment. At 6 months to a year, problem focused coping was associated with poorer adjustment, and emotion focused coping was associated with better adjustment at 2-3 years and 3-4 years. These results are surprising, given that approach- and problem- focused coping included forms of social support such as communication and information seeking, which have been shown to be beneficial in several studies (see Bruce 2006 for a review). Although these findings suggest that approach- and problem-focused coping may lead to worse adjustment, analyses of the relationship between coping and adjustment

may benefit from an empirically validated model of coping that has been shown to relate to adjustment for several types of stressors.

Children's levels of emotional distress and adjustment near diagnosis and during treatment remain unclear. Regardless of their overall levels, distress in children with cancer may be related to their coping responses and to their communication with their parents, who serve as primary sources of information and emotional support (Rodriguez et. al., 2007).

Parental Distress

There is more conclusive evidence for emotional distress in the parents of children with cancer. Several studies and reviews have documented the presence of elevated levels of distress in parents of pediatric cancer patients, and have also shown effects on family and marital functioning. A recent meta-analysis by Pai and colleagues (2007) examined 29 studies on parental distress and adjustment and found a small but significant effect for both mothers' and fathers' self-reported distress. When comparing mothers and fathers of children with cancer, mothers reported significantly more distress than fathers, and longitudinal data indicated that this difference persisted up to 12 months post-diagnosis. A study by Hoekstra-Weebers et. al. (1998) found that distress in parents of children with cancer was significantly higher than a control group. They also found that marital dissatisfaction increased with time since diagnosis, although it was not significantly higher than controls. At 6 and 12 months post-diagnosis (but not at diagnosis), emotional distress was related to marital

dissatisfaction in both mothers and fathers (Hoekstra-Weebers et. al., 1998). Wijnberg-Williams and colleagues (2006) found that parents were still significantly more distressed at five years after diagnosis, especially if their child had relapsed.

Numerous studies have also documented the presence of posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in parents of children with cancer. Kazak and colleagues (2004) used questionnaire and interview measures to examine the presence of PTSD and PTSS in families of survivors of childhood cancer. They found that both mothers and fathers had higher levels of PTSS than survivors, and that 29.5% of mothers and 11.5% of fathers had met criteria for PTSD at some point since their child's diagnosis. In another study, regression analyses showed that PTSS in parents of children with cancer were related to negative self-blame/affect and substance use. State anxiety in parents was negatively related to social support/advice seeking, as well as optimism and religious coping (Greening & Stoppelbein, 2007). In a review by Bruce (2006) of 24 studies on posttraumatic stress in survivors and their families, the lifetime prevalence of cancer-related PTSD in parents ranged from 27% to 54%, with current PTSD ranging from 6% to 25% in parents. Numerous variables were predictive of higher rates of cancer-related PTSD and PTSS, including demographics and physical late effects, as well as family functioning and coping styles. Specifically, higher rates of PTSS were found in mothers compared to fathers, and in parents of children with physical late effects and poorer functioning. In addition, high levels of family conflict were associated

with more PTSS in mothers, while better family communication and satisfaction were negatively associated with PTSS. Furthermore, some studies have shown positive associations between parental and child PTSD/PTSS, although other studies have not found significant relations between the two (Bruce 2006). These findings have confirmed the increased risk and prevalence for PTSD and PTSS in parents of children with cancer, as well as the importance of interventions and treatments that target parents of children with cancer.

Parent-Child Communication and Pediatric Cancer

One of the most significant challenges for parents of children with cancer is how to communicate with their child about the disease. However, little empirical research has been conducted to offer definitive advice for parents grappling with the question, “How do I talk to my child about his or her cancer?”

Communication about a Child's Illness

The National Cancer Institute (NCI) recommends that parents communicate openly and honestly with their child about his or her disease and prognosis (NCI, 2002). However, research examining the role of parent-child communication in adjustment to pediatric cancer, and illness in general, is limited. In one study by Miller and Drotar (2007), parent-adolescent communication during an observed conversation was related to treatment adherence in adolescents with Type 1 Diabetes. Negative communication by the parent (such as criticizing and ignoring) was associated with medical providers'

reports of lower adherence to treatment in adolescents, while higher positive parent communication (such as reflecting and praising) was associated with better treatment adherence (Miller & Drotar, 2007). In a study by Wysocki (1993) of adolescents with Type 1 Diabetes and their families, adolescent and parent self-reports of family communication were related to adolescents' adjustment to diabetes, as well as adolescents' diabetes control. Poorer communication, including more conflicts and less problem-solving, was negatively correlated with adolescents' adjustment to diabetes (e.g. diabetes self-efficacy, social adjustment to the disease, and treatment adherence). Poorer parent-adolescent communication was also negatively correlated with glycohemoglobin, a measure of diabetes control (Wysocki 1993). These studies of children with diabetes and their parents suggest that parent-child communication may play an important role in medical adherence and perhaps, in overall adjustment to chronic illness.

In a qualitative study about parent-child communication about illness, Gallo et al. (2005) asked parents about disclosure and communication regarding their child's genetic condition, such as sickle-cell disease. About half (49%) of parents were categorized as communicating openly about the disease, while 41% were described as selective in their information sharing. Ten percent of parents reported not sharing information or using parent-health provider conversations as the only means of sharing information with their child. When parents reported not sharing information, it was usually because they believed that their child was too young or immature to understand the information (Gallo et al., 2005). This study suggests that some parents do not choose to

communicate openly with their child about the child's illness, and may limit the information they share based on the child's ability to understand.

Communication about a Child's Cancer

Several qualitative studies have specifically examined parents' information-sharing when communication with their child about the child's cancer. Chesler et. al. (1986) examined communication in parents of pediatric cancer patients. Parents were asked about what they told and withheld from their child about the child's illness. The authors reported that only 36% of families offered "relatively full disclosure" about the child's illness, while the other 64% did not talk openly about the child's cancer. In addition, the authors examined several correlates of open communication and found that child age was highly correlated ($r = .63, p < .01$) with parents' openness and disclosure about cancer (Chesler et. al., 1986). Other variables that were positively correlated with openness included number of other children in the family, parent's age, and support received from other children.

More recently, two qualitative studies examined parent-child communication about cancer. Young et. al. (2003) interviewed 13 children with cancer and their parents about how they communicated about the child's cancer. Parents reported that they felt compelled to manage what and how their children were told about their illness and its treatment. Parents also reported trying to maintain a strong and optimistic stance, regardless of their expectations, in order to protect their child's emotional well-being. In contrast, children reported feeling

somewhat left out of discussions about their diagnosis and treatment (Young et al., 2003). Clarke et al. (2005) asked 55 parents of children with cancer about their views of what to disclose to their child about cancer. Parents reported providing more information to older children and that their perceptions of childhood cancer affected the ways that they communicated with their child. However, neither of these studies directly observed parent-child communication and neither study utilized quantitative analytic methods.

The limited research indicates that children with cancer want to be told about their disease. Ellis and Leventhal (1993) asked 50 children and adolescents with cancer about their communication preferences, and found that 95% wanted to be told if they were dying. Additionally, 63% of adolescents preferred to be involved in making decisions about their care.

While these studies provide qualitative information about how parents and children communicate about a child's cancer, there is a relative lack of quantitative studies that examine the role of parent-child communication in adjustment to pediatric cancer. One study by Cline et al. (2006) examined parent-child communication during painful medical treatments for the child's cancer, and found that parental communication during a procedure was related to child's pain and distress ratings. Parents and children were videotaped during a painful procedure and the experimenters observed the interaction and categorized the parent's communication as one of four styles: normalizing, supportive, invalidating, or distancing. Their results indicated that parents who used invalidating communication had children who reported more pain during the

procedure than parents who used normalizing, supportive, or distancing communication. (Cline et al., 2006). While this study provided more quantitative results than earlier studies of parent-child communication about cancer, the study was limited to communication during a specific aspect of cancer treatment, and focused on the emotional, but not the informational, content of the parents' communication. In addition, the observational coding scheme was designed by the investigators during the study, and had not been validated. However, this study is important in that it included observational data of actual parent-child communication and quantitative methods were used. No other quantitative research was found about parent-child communication about cancer.

Factors Affecting Parent-Child Communication

An important next step in contributing to quantitative research about parent-child communication about cancer is to examine the factors that affect differences in parent-child communication. Child age, or developmental level, is an important variable in how parents communicate with their child. Pediatric cancer affects children in every age range, and parents may have beliefs about the way in which they should communicate with someone their son or daughter's age. Thus, the age and developmental level of the child plays a key role in the choice of words, topics, and information that parents communicate to their children. For example, a 5-year-old child may be aware that he is "sick," but unable to understand the specifics of cancer and its treatment. In this case, a parent might decide not to use too much detail or technical vocabulary, and focus

on the child's emotions and providing emotional support. In contrast, a 17-year-old has the cognitive resources to understand the specific details and meaning of treatment and prognosis, and may feel confused or distressed if her parent does not discuss the information at a more detailed level. In this case, a parent might choose to provide more information as well as emotional support. No studies have examined whether or to what degree parents adjust their communication about cancer as a function of their child's age.

Another aspect of communication about cancer that may be affected by the child's developmental level is the language and syntactic complexity that the parent uses when speaking to the child about cancer. Research indicates that parents modify their speech to match their child's comprehension level by using syntax that is appropriately complex (e.g. Snow, 1972; Huttenlocher et. al., 2007). However, a topic such as cancer may be especially difficult to explain using simple language, because the treatment, nature, and emotional impact of the disease is relatively complex. Because of this, some parents may struggle to match their syntax with their child's ability to understand and benefit from information and emotional support. Furthermore, emotional distress may result in changes in parental speech characteristics and children's processing abilities. Research has shown that distress, in the form of anxiety or depression, affects numerous facets of speech. For example, Ragsdale (1976) found that self-reported trait anxiety and internalization were related to "non-ah" speech interruptions, such as repetitions, omissions, sentence incompletions, and incoherent sounds. Breznitz and Sherman (1987) examined speech patterns in

depressed and nondepressed mothers. Their findings suggested that, in a normal situation (i.e., having lunch), depressed mothers spoke less to their child, but in a stressful situation (i.e., a doctor's visit) depressed mothers increased their speech production while the nondepressed mothers slightly decreased their speech (Breznitz & Sherman, 1987). The authors suggest that the speech patterns of depressed mothers may convey anxiety to their children about a stressful situation, affirm their children's distress, and negatively affect how these children learn to respond to stressors. In turn, child anxiety about distressing, cancer-related topics during conversation may result in difficulty processing parental language. Elliman and colleagues (1997) found that individuals with high self-reported trait anxiety had longer reaction times on a sustained attention task, compared with individuals with lower anxiety. These results suggest that anxiety affects processing ability. In the case of a child diagnosed with cancer, the child might be able to process one level of information for a neutral or positive topic (e.g. playing a game), but have difficulty processing the same level of complexity for a distressing topic (e.g. talking about cancer).

These studies suggest that anxiety on the part of parents and children may affect the nature of parent-child communication about cancer. Given the elevated levels of anxiety, and particularly symptoms of PTSD, that have been reported in parents of children with cancer, the association of parental anxiety and parental communication may be of particular importance.

Current Study

In the present study, children with cancer and their parents were assessed on levels of emotional distress shortly after the child's diagnosis of cancer.

Several weeks later, the parent and child were observed having a conversation about how they talked about the child's cancer. The following hypotheses were tested:

Hypothesis 1: Higher parental emotional distress as measured by self-report on the Beck Anxiety Inventory (BAI) and parent Impact of Events Scale-Revised (IES-R) would be related to higher child emotional distress as reported on the Youth Self-Report (YSR), Child Behavior Checklist (CBCL), and the child IES-R.

Hypothesis 2: Higher self-reported parental distress on the Beck Anxiety Inventory, Beck Depression Inventory-II, and Impact of Events Scale-Revised would be related to more speech or a higher word count (i.e., words per turn) and more revisions in parental speech during parent-child interactions about cancer.

Hypothesis 3: Higher parental syntactic complexity and more revisions would be related to higher child emotional distress as reported on the Youth Self-Report, Child Behavior Checklist and the Impact of Events Scale.

Hypothesis 4: Higher parental word count and more revisions would be related to older child age and female compared to male children.

CHAPTER II

METHODS

Participants

Seventy-eight families were recruited to participate in a questionnaire study of parent and child coping with and communication about pediatric cancer. Twenty-two families were recruited at the Vanderbilt University Monroe Carell, Jr. Children's Hospital in Nashville, TN, and 56 families were recruited at Nationwide Children's Hospital (formerly Columbus Children's Hospital) in Columbus, OH. The diagnoses of the children included acute lymphocytic leukemia, osteosarcoma, and Hodgkin's lymphoma. Approximately 50% of the children were female, and the sample was approximately 85% Caucasian, 8% African-American, 1% Asian, 3% American Indian/Alaskan Native, and 2% Hispanic/Latino. The average age of children in the study was 11.0 (SD = 3.91), with a range of ages 5-18. The average income of the families was \$33,000, with a range of incomes from under \$25,000 to over \$100,000 represented in our study.

Families were eligible for the study if the child had been given a first-time or relapse diagnosis of pediatric cancer and was between the ages of 5 and 18 years old. Families of children with developmental delays (e.g. Down Syndrome) or other chronic illnesses (e.g., cystic fibrosis) were ineligible. Only children ages 10-18 were asked to complete self-report questionnaires, due to the reading level

of the self-report questionnaires for children; however, parent reports on the child were obtained for children ages 5-18. Across both sites, 44 children ages 10-18 and 78 mothers completed the questionnaires. 32 fathers also participated in the questionnaire study, but mother reports were used in these analyses in all but one case (in which the father was the primary caregiver and participated in the parent-child observation).

Of the families who participated in the questionnaire study, 34 families agreed to participate in an observation of parent-child communication about cancer, representing approximately 44% of families that participated in the questionnaire study. Families were eligible if they had completed and returned their questionnaires. The analyses reported in this paper include data from 26 of these families (20 from Nationwide Children's Hospital and 6 from Vanderbilt). Several observations were lost to equipment failure or to families misunderstanding the observation directions (e.g., talking straight to the camera instead of having a conversation with each other).

Procedure

Eligible families were identified through hospital records of new pediatric cancer diagnoses. All attempts were made to recruit families as close as possible to one month post-diagnosis of the child's cancer. Families with children ages 5-18 years old were approached by a member of the research team and the study was described to them. If they expressed interest in participating, the families were guided through the informed consent process and were provided

questionnaire packets to complete. Participants worked on their questionnaire packets in their free time either at the hospital or at home, and returned completed packets to a research team member.

Families that had completed and returned their questionnaires were contacted at around 3 months post-diagnosis about participating in the observation study.

Measures

Questionnaires. As part of the questionnaire study battery, parents completed the Beck Depression Inventory-II (BDI-II; Beck and Steer, 1990) and the Beck Anxiety Inventory (BAI; Beck, Steer, & Brown, 1996). These inventories are widely used self-report measure of depression and anxiety symptoms in non-psychiatric populations, and have been show to have the best discriminant validity for the self-report of depression and anxiety symptoms in adults (Steer et al., 1993). In addition, parents completed the Impact of Events Scale – Revised (IES-R; Weiss & Marmar, 1997) in regard to their cancer-specific distress. The IES-R measures self-reported intrusive thoughts and avoidance related to a specific stressor and parallels DSM-IV criteria for PTSD.

In addition to self-reports, parents were also asked to complete the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2002), as a measure of their child’s emotional distress. The CBCL measures emotional and behavioral problems and provides scores for an Anxious/Depressed Syndrome scales as well as Anxiety Problems and Total Internalizing Problems subscales, which

were used as the measures of parent report of child emotional distress.

As part of the child's questionnaire battery, children ages 10 and older were asked to complete the IES-R in regard to their cancer as a measure of cancer-related distress. They also completed the Youth Self-Report (YSR; Achenbach & Rescorla, 2002) as a measure of emotional distress. The YSR provided a comparison of the child's self-reported emotional distress with the parent's report of the child's distress on the CBCL.

Observation of parent-child communication. As noted above, families that consented to participate were videotaped having a 15-minute conversation about the child's cancer. They were provided with four prompts to answer during the conversation: 1. "When and where have we talked about [child's name]'s illness?" 2. What kinds of things have we already talked about regarding [child's name]'s illness? 3. How does it go when we talk about [child's name]'s illness? What has made it easier to talk about it? What has made it harder to talk about it? 4. What do we think might happen next?" The observation ended when the research assistant returned to the room after 15 minutes, or, in some cases, when the family left the room to tell the researcher that they were done with the conversation.

The parent-child interactions about cancer were transcribed to obtain measures of speech characteristics. Syntactic complexity of the parent's speech was measured with word count (average words per turn). Words that were part of revisions were not included; for example, in the utterance "(I went to) – we went to the doctor," the words "I went to" would be considered a false start and not

included in the word count. In addition, words such as cool, well, so, and okay were not included if they were filler and interjections. In addition, nonverbal utterances such as “huh,” “mm-hmm,” and unintelligible utterances were not counted. The number of words in every turn was counted for each of the parent’s turns during the observation, and then divided by the total number of turns, to obtain word count. The parent’s mean number of revisions was also calculated. Revisions were considered as changes in the direction or content of an utterance or as corrections of speech mistakes. An example of a revision would be, “then (we came) we went back home.” The total number of revisions was divided by the total number of turns to obtain a ratio of revisions per turn.

CHAPTER III

RESULTS

Descriptive Analyses

Child distress as reported on the YSR was slightly elevated in comparison with the norms for this scale. *T*-score means for the child participants were 53.5 (*SD* = 5.73) on the Anxious-Depressed index, 54.0 (*SD* = 6.00) on Anxiety Problems index. However, the mean for the broadband total Internalizing scale was at the normative mean (*M* = 50.0, *SD* = 10.8). On the IES-R, children endorsed an average of 2.3 (*SD* = 1.89) symptoms of cancer-related distress (see Table 1).

Parental reports of child distress on the CBCL are consistent with the child reports of slightly elevated distress. *T*-score means of parental reports were 54.3 (*SD* = 6.46) on the Anxious-Depressed index, 55.7 (*SD* = 7.48) on Anxiety Problems index, and 52.6 (*SD* = 11.3) on the Internalizing Problems index (see Table 1).

Parental self-reports of distress were also elevated compared with normative samples. On the BAI, parents scored a mean of 11.8 (*SD* = 10.05). On the BDI-II, parents scored a mean of 14.2 (*SD* = 9.84). On the IES-R, parents endorsed 4.5 (*SD* = 2.14) symptoms of distress related to their child's cancer (see Table 2).

Table 1: Child and Parent Reports of Child Distress on CBCL YSR, and IES-R

	Mean	S.D.
YSR Anxious-Depressed	53.5	5.74
YSR Anxiety Problems	54.0	6.00
YSR Internalizing Problems	50.0	10.8
CBCL Anxious-Depressed	54.3	6.47
CBCL Anxiety Problems	55.7	7.48
CBCL Internalizing Problems	52.6	11.3
Child IES-R	2.34	1.89

Table 2: Parent Self-reported distress on BAI and IES

	Mean	S.D.
BAI	11.8	10.1
BDI	14.2	9.84
IES-R	4.47	2.15

Parental linguistic complexity showed variability in measures of word count (words per turn) and revisions. Parents spoke an average of 14.0 (SD = 5.18) words per turn, with a range of 7.0—29.1 words per turn. Revisions averaged at .25 (SD = .24) per turn, with a range of .02—1.08 revisions per turn (see Table 3). An independent samples t-test examined differences in mean word count and revisions ratio for the child’s gender (see Table 4). While no significant differences were found for boys compared to girls in word count ($t =$

0.96, $p = .35$) differences in revisions approached significance ($t = 1.59$, $p = .12$), with parents using more revisions with boys than with girls.

Table 3: Parent word count and revisions

	Mean	S.D.
Words per turn	14.0	5.18
Revisions per turn	.25	.24

Table 4: Parent Word count and Revisions by Gender of Child

	N	Mean	S.D.
Word count – Boys	14	14.8	6.5
Word count – Girls	12	13.0	3.1
Revisions – Boys	14	.31	.29
Revisions – Girls	12	.17	.14

Correlational Analyses

For the sample of parents and children participating in the questionnaire study, all measures of child self-reported distress and parent report of child distress were significantly and highly correlated with each other (see Table 5). In addition, all measures of parental distress were significantly highly correlated with each other (see Table 6). Significant associations were also found in parental reports of child and parent self-reports of emotional distress (see Table

7). While child self-reports of distress on the YSR were not significantly correlated with parent self-reports of distress on the BAI, BDI-II and IES-R, correlations were in the expected direction and one correlation (YSR Anxious-Depressed with Parent IES-R) approached significance ($r = .27, p = .10$).

Table 5: Correlations between parent and child report *T*-scores of child distress

	YSR Anx-Dep	YSR Anx Problems	YSR Intl Problems	CBCL Anx-Dep	CBCL Anx Problems	CBCL Intl Problems
YSR Anx- Dep	1	--	--	--	--	--
YSR Anx Problems	.93**	1	--	--	--	--
YSR Intl Problems	.95**	.89**	1	--	--	--
CBCL Anx- Dep	.68**	.61**	.58**	1	--	--
CBCL Anx Problems	.48**	.47**	.40**	.83**	1	--
CBCL Intl Problems	.75**	.72**	.62**	.75**	.71**	1

* Indicates that $p < .05$

** Indicates that $p < .01$

Table 6: Correlations between parent self-reports of distress

	Parent IES	Parent BAI	Parent BDI
Parent IES	1	--	--
Parent BAI	.73**	1	--
Parent BDI	.72**	.66**	1

* Indicates that $p < .05$

** Indicates that $p < .01$

Table 7: Correlations between parent self-reports and reports of child distress

	Parent IES	Parent BAI	Parent BDI
CBCL Anx-Dep	.42**	.48**	.39**
CBCL Anx Problems	.39**	.44**	.31**
CBCL Intl Problems	.36**	.34**	.23

* Indicates that $p < .05$

** Indicates that $p < .01$

For the families that participated in the observation, measures of parental linguistic complexity (word count and revisions per turn) were positively correlated with one another ($r = .89, p < .001$). Both word count and revisions were significantly negatively correlated with child age (for word count, $r = .42, p < .05$; for revisions, $r = .46, p < .05$; see Table 8).

Table 8: Correlations between parent linguistic complexity and child age and gender

	Parent Word Count	Parent Revisions	Child Age	Child Gender
Parent Word count	1	--	--	--
Parent Revisions	.89**	1	--	--
Child Age	.42*	.46*	1	--

* Indicates that $p < .05$

** Indicates that $p < .01$

Word count and revisions were not significantly related to any measures of parental distress. However, non-significant but positive associations occurred between word count and revisions and measures of parental anxiety symptoms (BAI and IES-R), while non-significant but negative associations were found with the measure of parental depressive symptoms (BDI-II). Neither measure of parental linguistic complexity was significantly associated with child distress as measured by parent-report or child-report.

Examples of Parents' Communication

The following is an excerpt of an interaction by a mother and her 9-year-old daughter. This mother had an average word count (12.4) and below-average revisions per turn ratio (.07) in comparison to the study sample.

*M: What kinds of things have we already talked about regarding your illness?
What kind of things have we already talked about?*

D: {shrugs shoulders}

M: School.

D: School. (yes).

M: What about school? Talk clear.

D: School. How I am not allowed to go to because of all the germs.

M: (Yep). Do we go sometimes though?

D: Yes, for (like) parties and stuff.

M: And when are we allowed to go?

D: When my counts are up.

M: {Mm-hmm}. What other kinds of things have we talked about with you being sick?

D: That sometimes I'll have to go to the hospital for a little bit.

M: {Mm-hmm}, like this time. What else have we talked about regarding your illness? What about, {um}, some of the medicines you have to take?

D: Some of them might be yucky, but you need to take them.

M: What is some of the yucky stuff about your medicine?

D: The weekends.

M: The weekends? What don't you like about the weekends?

D: That stuff that

M: Oh, you take an antibiotic on the weekends and you don't like it? What else? What about {um} your medicines?

D: {shrugs shoulders} That's it.

M: What about what medicine has done to your hair and, does any of that stuff bother you anymore?

D: (No).

M: (No.) You forget don't you?

D: {smiles}

M: *You forget that your hair's not even there. And it's growin' back already, {huh}?*

The following is an excerpt of an interaction by a mother and her 6-year-old son. In contrast with the previous example, this mother had a higher-than-average word count (18.7) and revisions ratio (.35), relative to the sample mean and distribution.

M: *What other kinds of things have we talked about regarding the leukemia? (Some of the) {um}, (like) some of the side effects of, {uh}, the chemo and stuff, (like) maybe if you have sore legs, or, {um}, if your tummy feels funny, we talked about all the side effects, {huh}?*

S: {Nods head}

M: {um}, what other kinds of things have we talked about regarding your leukemia? Can you think of one?

S: {Hmm}

M: {Hmm} : How 'bout. What kinds of things have we talked about regarding leukemia? Have we talked about, {um}, (like) how long you'll have it and how long you'll be on treatment and all that stuff? : {Hmm?} : Yep? (yeah)?

S: {Nods head}

M: (okay), we'll move on, maybe come back to that. How does it go when we talk about leukemia?

S: Good.

M: Good! (okay). What has made it easier to talk about it? (So) is there something you can think about that has made it easier to talk about the leukemia? We never really had any problems talking about it, did we?

S: <{Uh-huh}> {shakes head}

M: <(It was all)> it's usually pretty easy, and {um}, has there been anything that's made it harder to talk about leukemia? (like) {um}, I know sometimes, {um}, well : it's a hard question.

S: {uh huh}.

M: So, what has made it harder to talk about? What has made it harder to talk about it? Well I guess the hardest thing about talking about it is just that, (you know), it's (like) pretty serious, right? (We) we found out that it's not just (you know), a cold, or (you know)

M: It's not just a fever : It's pretty serious, so we understand that now, (so that's) sometimes it's harder to talk about it, 'cause sometimes it's hard to deal with, having leukemia, it's a pretty tough job, {huh}?

S: {uh huh}

M: So (sometimes) sometimes it's hard to talk about, just because it's so serious. (you know) that it's a really serious disease, {huh}? So sometimes that makes it hard to talk about. And we wish we didn't have it sometimes, {huh}?

S: (yeah).

The following excerpt is from an interaction between a mother and her 14-year-old daughter. This mother's word count (16.1) and revision ratio (.32) are comparable with the previous example.

D: Okay (when where) We talk about it at night. <Sometimes when I'm> upset about it.

M: <sometimes when you're sad>

D: I mean, it's a whole lot easier just to sit down and, cry sometimes.

M: {nods in agreement}

D: And just kinda get it out.

M: And sometimes at night when you're trying to go to sleep is the time that stuff floods your brain. (Do you think, for you) it does for me. {<D> nods in agreement}

D: Kind of makes it a little harder : {<M> nods in agreement}

M: But (I think) I think that you've been better about that kind of stuff since you've been reading at night. Do you think that reading at night : <kind of>

D: <Pick your> favorite book and just have something to look forward to. {<M> nods in agreement.} Kind of gets stuff X. {umm} : We've talked about a bunch of different things regarding my illness, I mean,

M: What you can eat

D: what you <should>

M: <how much> you should eat, and

D: Yeah.

M: How hard it is to eat, and {both laugh}

D: (And) : Times when I can go fun places, times when there're too many people. {Umm} :

M: I think yeah just the basic stuff : (You know how to) when we're gonna be in the hospital, when we think we're gonna be out of the hospital and

D: {Um Hmm in agreement} and how you're always gonna be there.

M: {Hmm} That's right. Siamese twins {M laughs}

D: That makes it so much easier having someone (with ya) with me 24/7, who knows what I'm going through.*

In contrast, the following interaction was between a mother and her 16-year-old son. The mother's word count was 21 and her revision ration was .48, which were both approximately 1 standard deviation above the sample means.

M: What kinds of things have we already talked about regarding your illness? : What if the cancer comes back now that you're in remission?

S: {uhhuh} what happens if it does come back :

M: The options that we might have and : If you would wanna go on with treatment or?

S: (Yeah).

M: (Yeah)? But don't give up : How sick you might get with the chemo and?

S: If the chemo don't work and it comes back then X bone marrow transplant

M: Yeah that would be your next <> option regarding : How does it go when we talk about your illness? What (ha) has made it easier to talk about it and what has made it harder to talk about it? :*

S: <X>

S: *Read that again?*

M: *How does it go when we talk about your illness?*

S: *It goes fine. X*

M: *We talk awhile about it and: <> then just let it go and whatever questions come up we deal with it when it comes up : What has made it easier to talk about it? :*

S: <X>

S: *Just the fact that I'm on remission.*

M: *(Yeah). What's made it harder to talk about it? When you was first diagnosed I couldn't talk about it with you because every time I did I'd cry : That was always hard : And every little fever and everything, I just: was worried and still am. And I guess what's made it harder to talk about it is knowing that so many of my family have had leukemia, been diagnosed with leukemia, and died from (leu*) leukemia :*

Near the end of the of the interaction, this mother directly expressed her feelings of helplessness and continued distress about her son's cancer:

M: X : *I know as a parent you're feeling helpless. Can't help you. Can't do nothing to make you better and: that's always scary : Can't fix what's happening and can't control what's happening and> :*

S X : *You really been getting going about it and I really don't think you have much to worry about. : I mean if it's gone, it's gone. There's always a chance of its coming back, but if you worry about (it) it always coming back then you won't get anywhere in life :*

M: *But for me, I'm always going to worry about it.*

S: *Don't worry X*

M: *Cause I'm Mom : I'm always going to be worried about what if :*

CHAPTER IV

DISCUSSION

The findings of the current study supported our hypothesis that parental emotional distress would be associated with child emotional distress. Specifically, parental self-reported distress on the BDI-II, BAI and IES-R were positively correlated with parental reports of child distress on the CBCL. While child self-reports of distress on the YSR were not correlated with parental distress, this may be due to the smaller child sample ($n = 44$) compared with the parent sample ($n=78$), and the limited statistical power as a consequence.

There was a significant relationship between parental word count/revisions and child age. Both higher word count and revisions were associated with older age child. These findings suggest that, despite other factors such as parental distress, most parents do adjust some aspects of their speech to their child's age or developmental level. Parents used more words in their communication with older children, possibly because they were explaining or disclosing more information about cancer. Future analyses should examine the content of the communication in relation to the word count, to examine how the number of words used may vary with the topic of discussion. Parents also used more revisions with older children. Revisions in speech could signify several things. In some cases, revisions might indicate that parents are adjusting their language to get it "just right" or in response to feedback from their child (e.g. a false start),

which would be helpful strategies in communicating with their child. In contrast, revisions might also signify a parent who is talking fast, perhaps due to anxiety, and making speech mistakes (e.g. syllable repetitions) or who is unsure of what to say and leaves a topic of conversation abruptly (e.g. abandoned utterances); both would suggest poorer communication. Future analyses should differentiate between the multiple types of revisions, such as false starts, repetitions, and abandoned utterances, all of which may have different implications for parent-child communication and emotional distress.

We hypothesized that parental distress would be related to a higher parental word count and more revisions in speech during parent-child interactions about cancer. While none of the parental distress measures were significantly correlated with word count or revisions, we did find interesting differences in directionality between correlations of anxiety (on the BAI and IES-R) and speech and depression (on the BDI) and speech. Although nonsignificant, positive correlations were found between word count/revisions and anxiety, and negative associations were found between word count/revisions and depression. These findings hint at how different types of emotional distress may affect parental speech in different ways. Anxious parents may speak rapidly and with many speech errors, which would lead to higher word count and revisions. Depressed parents may speak more slowly and say less, because of decreased energy and feelings of worthlessness about what they say. Notably, however, anxiety and depression are highly co-morbid, and co-occurrence in our sample

may have resulted a “cancellation” effect on linguistic complexity and may partly explain the lack of findings.

Our hypothesis that higher parental syntactic complexity and more revisions would be related to higher child emotional distress was not supported by the current study. This is likely because we did not find a significant relationship between parental linguistic complexity and parental distress, and linguistic complexity is a potential mediator of the relationship between parental distress and child distress.

The transcribed examples of parent-child communication illustrate the various ways in which parents communicated with their child about the child's cancer. They also suggest that measures of word count and ratio of revisions provide a starting point, but not a complete picture, of the relationship between parental linguistic complexity and parent and child distress and adjustment. For example, in the second and third examples, the parents' word count and revisions are comparable; however, the quality of these interactions is different. In the second interaction, the mother is speaking to her 6-year-old son. She appears uncertain about how to talk to him, and avoidant of certain topics. Her word count and revisions are slightly higher than the sample mean. In this case, the higher word count and revisions appear consistent with the idea that anxiety or uncertainty elevates word count and revisions. In the third interaction, between a mother and her 14-year-old daughter, there is an apparent “give-and-take” in the conversation. The mother appears to revise her language in response to something her daughter has just said, such as her daughter expressing her

cancer-related fears. In this case, word count and revisions appear to result from the mother's adjustment of her language to her daughter's needs. These two examples illustrate the differences in communication despite similar linguistic complexity, and the importance of other factors, such as child age and the content of the conversation, that likely interact with parental linguistic complexity to affect child adjustment.

The current study examined the relationship between parent and child distress and parental linguistic complexity. Our findings indicated that both recently diagnosed children and their parents have higher levels of cancer related distress, supporting the growing literature showing poorer than normal adjustment in these children and parents. Our findings also added quantitative results to the qualitative findings about parental openness in communication about cancer, with our finding that parents use more words and revisions with older children during cancer-related conversations. Age, or developmental level, is a key factor in the linguistic complexity that parents use when talking with their child about cancer.

We hypothesized that parental and child distress would be related to parental linguistic complexity. While findings were nonsignificant for the current study, this was likely due to the small sample size to detect small effects as well as the potentially opposing effects that different types of distress (i.e., anxiety and depression) have on speech patterns. In addition, the current results are somewhat limited by the measures of linguistic complexity used. The first measure, word count, gives an overall but rather simple measure of linguistic

complexity. The other linguistic measure used in this study, revisions per turn, was a somewhat imprecise measure of complexity. Revisions may occur for several reasons; parents may have many revisions because they are anxious or unsure how to communicate with their child, or because they are searching for the right words and making an effort to tailor their communication to their child. Thus, revisions may indicate better communication in some cases, and poorer communication in others. Future analyses of complexity should differentiate between types of revisions. An additional measure of complexity, clause type (e.g. embedded and non-embedded) may also provide more information. For example, embedded clauses in parental speech may be a more sensitive measure of complexity, and therefore relate more closely to the child's ability to process information and benefit from communication.

In addition to addressing the above limitations, future studies should address the relationship between observed distress during parent-child interactions (measured by a validated coding scheme) and linguistic complexity. Future research should also examine the possible results of an intervention that targets parent-child communication about cancer. Parent-child communication when a child is diagnosed with cancer may be a deciding factor in how children and their parents adjust to the diagnosis and treatment, not only immediately after diagnosis, but when faced with the long-term stressors that affect many survivors and their families.

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