Parent-Child Communication and Child Distress

In Response to a Child's Diagnosis of Cancer

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Introduction

Childhood cancer is a disease that affects a relatively small number of children and families in the US each year, but those families who are affected are often devastated. The stress and heartbreak of childhood cancer affects not only the patient's emotions but also deeply affects the parents and other family members. Unfortunately, the problem does not end with the family having higher stress levels, but these higher stress levels can lead to an entirely new set of problems for the child and the family in the form of significant emotional distress, psychopathology or psychopathological symptoms, developmental problems, and social deficiencies. Despite the good news that childhood cancer is becoming increasingly more curable, there are lasting negative effects from the cancer called "late effects" that continue to adversely effect the patients for decades to come (Gloeker, Percy & Bunin, 1995). So, not only are childhood cancer victims prone to developing problems during treatment, but these problems are not quickly resolved once the child has completed treatment and gone into remission.

Incidence and Prevalence

The incidence of childhood cancer in the US is 14.8 per 100,000 for children under the age of 14 and 16.4 per 100,000 for children under the age of 19 years (Ries, Harkins, Krapcho, Mariotto, Miller, Feuer, Clegg, Eisner, Horner, Howlader, Hayat, Hankey, & Edwards, 2003). These numbers may seem quite small, but it is important to remember that the incidence merely tells us the number of newly diagnosed cases for any given period of time, in this case, one year. Because childhood cancer is a chronic disease that can last much of a person's childhood, it is perhaps more pertinent to consider the

fact that approximately 1 in 300 children will receive a diagnosis of cancer by the time they are 20 (Gloeker Ries, Percy, & Bunin, 1995).

Mortality

Despite theses seemingly low numbers of the incidence and prevalence of the disease, cancer is the leading cause of death by disease among US children under age 15 years old today (http://www.cancer.gov/cancertopics/factsheet/NCI-childhood-cancers-research). For children under the age of 19 years, the mortality rate for those diagnosed with any form of cancer is 2.8 per 100, 000. Though the incidence has been increasing slightly, the good news is that the mortality rate has been steadily decreasing since 1975. The most deadly of all childhood cancers is Leukemia but fortunately, the death rate of this disease is down from 2.1 per 100,000 in 1975 to only .9 per 100,000 in 2003 (Ries et. al., 2003).

There are 11 major types of childhood cancer, but Leukemias, brain tumors and cancers in the central nervous system account for over half of all cancers diagnosed in children each year (http://www.cancer.gov/cancertopics/factsheet/NCI-childhood-cancers-research). The best news about the prognosis for a child diagnosed with cancer is that, due to the constantly improving treatments for the disease, the 5-year survival rate is now 79% (Ries et al., 2003).

Cancer as a source of stress

There are a number of challenges in the life of a child with cancer that add up to significant amounts of stress in the young person’s life. Among theses stressors are the grueling physical trauma involved in how the cancer adversely affects the body and the

painful and uncomfortable procedures involved in the treatment of the disease. For a young child who has not had much experience in the world, it may seem as though this pain has been a constant in their lives, and they may not be able to see any end in sight. Beyond the obvious physical stress of having cancer, children have to deal with the adverse emotional effects of the disease. For example, the majority of children diagnosed with cancer are too sick to continue going to school during their treatment, which can contribute to both scholastic and social developmental problems.

With all of these stressors taking a toll, not only on the child, but also causing high levels of anxiety for the entire family, it is somewhat surprising that many studies report that children with cancer do not score significantly differently on levels of anxiety and depression than control groups (e.g., Noll, Gartstein, Vannatta, Correll, Bukowski, & Davies, 1999). Because of studies such as the one done by Noll et al. (1999), many people have assumed that significant emotional distress in childhood cancer victims is not an issue that should concern the scientific community. However, it is important that such studies are analyzed critically and conclusions from the experimenters are not just taken at face value. For example, the study done by Noll et al. (1999) excluded all children with cancers of the nervous system that, as stated earlier, is one of the most prevalent types of childhood cancer. Also, all of the participants in this study had recently gone into remission and we no longer undergoing treatment for the disease, which clearly could have an effect on their emotional well-being. It is unfortunate that so many researchers have assumed that psychopathology in children with cancer is an unimportant thing to study, and more research should be done to determine whether this is actually true, and whether children's emotional well-being is related to the type of cancer they have.

Communication

Often the people most acutely aware of the stressors associated with a child's cancer diagnosis are the child's parents. For any parent, one of the greatest tools they have at their disposal for helping their child through a difficult time is that of good communication and listening skills, so that their child better understands their diagnosis and treatment and does not feel that he or she is going through it alone. Being able to communicate and listen well are especially important skills for a parent of a child with cancer because there is often little else that they can do to alleviate their child's suffering.

One part of being a good communicator that these parents must consider when talking to their child about cancer is being able to articulate their thoughts and feelings about the situation in a neutral or positive way and in a way that is age-appropriate for the child. However, the expressiveness of a parent is with a child may not be as important as how receptive parents are to their children's communication. A parent may need skills such as rephrasing things that a child says to indicate that they have heard them, giving positive feedback on things that the child discloses to their parent about their feelings, and even things as simple as nodding and saying "mm-hmm" to let the child know that the parent is being attentive to what the child is saying. An important feature of communication with another person is the style with which they speak and listen—how warm and supportive they are with the things they say and do.

Previous studies on parental communication about cancer

Degree of openness in parent-child communication

The National Cancer Institute's Handbook for Parents (2002) encourages parents

of children diagnosed with cancer to "speak openly and honestly" to their child about their diagnosis. Several studies have focused on the degree of openness and measure the amount of factual information that parents provide their children with cancer, however, these studies did not examine child outcomes in relation to amount of information divulged (e.g., Clarke, Davies, Jenney, Glaser, & Eiser, 2005; Young, Dixon-Woods, Windridge, & Heney, 2003; Claflin & Barbarin, 1990). The limitation of these studies is that they define parental communication simply in terms of how much the parent divulges to the child about their particular disease and the projected prognosis. The majority of these studies described the openness, sophistication, and detail of the factual information parents gave their children, when they provided the information, and what factors lead them to make these decisions and few of them actually discussed the effect of parental communication on child outcomes (Clarke et. al. 2005).

Communication about death

Other than talking to a child about their diagnosis, another area concerning parent communication and childhood cancer that has been studied is how parents talk to their child about the possibility or inevitability of death (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004). Again, these studies are focused on the amount of factual information given to the child, namely whether or not they are ever told that there is a possibility or likelihood of them dying.

Psychologists in Sweden conducted a study to determine the extent to which bereaved parents had talked to their child about the possibility of dying of cancer (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004). They were interested in the factors that affected the parents' decision about whether or not to disclose the

information and the parental reactions to this decision following the child's death. They found that in this sample (n = 429), 34% of the parents had talked to their child about death and 66 % of them had not talked to their child about death at all. None of the parents who talked to their child about the possibility regretted it when interviewed after the child's death. Of the parents who elected not to tell their child about the possibility of death, 27% later regretted it. Interestingly, the parents who sensed that the child was aware of his or her imminent death were the ones most likely to feel a sense of regret.

This information is useful for parents to make the decision about whether or not to talk to their child about dying, but only as far as it will affect their own reaction later. It is likely that many parents make the decision about what to tell their child based on what they believe is best for the child, not what is best for themselves, so it would be more useful to have data on child outcomes concerning parental communication about death. Additionally, if a parent chooses to talk to their child about their imminent death, it would be useful if there was evidence about the best way to go about doing it, not simply whether or not to touch on the issue at all.

What is lacking in the literature

Emotional distress in childhood cancer patients

In a review of the literature on the association between life stressors and symptoms of psychopathology, researchers found that in 88% of more than 60 studies they examined, there was a positive association between significant life stressors and symptoms of emotional and behavioral problems in children and adolescents (Grant, Compas, Thurm, McMahon & Gipson, 2004). Because it is clear that cancer causes significant stress for these children, the notion that they exhibit the same and sometimes

fewer symptoms of anxiety and depression than the general population is paradoxical and clearly warrants further investigation. Additionally, the limitations on the types of cancer included in these studies and the fact that all of the data were collected once the children were in remission from cancer indicate that the samples used in this study may not have been representative of the population of childhood cancer victims. Scientists must be careful not to dismiss that this special population is indeed under high levels of stress and might benefit from research done to determine how best to alleviate this stress and the negative psychological effects that come from it.

Parental Communication

The bulk of research done on parental communication with children with cancer has been focused on the content of the information that parents divulge to their sick child. Most healthcare providers suggest that being open and honest with your child at an age appropriate level is the best way to go about talking to your child about cancer, and this is what the evidence seems to support (National Cancer Institute, 2002). However, other than indicating to parents that they should tell the child about their diagnosis and prognosis of their disease, the research gives parents very little advice on the best way to go about doing this.

One of the most striking things about the research done thus far on communication in pediatric oncology is that it is "adult-centered." There have been studies done that explain what factors contribute to a parent's likelihood of telling their child more or less factual information about their illness, such as marital status, income, knowledge of the disease (e.g., Kreicbergs et al., 2004; Clarke et al., 2005). However, there is a dearth of evidence indicating child outcomes based on parental communication

in the literature, which likely would be the most important information for a parent deciding how to speak with their child about cancer.

Research Questions

Based on these gaps and discrepancies in the literature on parental communication and child outcomes in pediatric oncology, there are several areas that are in need of further examination by researchers wishing to understand and help families with children with cancer. First, basic research on the true incidence and prevalence of symptoms of emotional and behavioral problems, specifically anxiety and depression, needs to be done on this population to better understand their needs in this arena and to gain an understanding of the factors that may mask psychopathological symptoms in these children. Second, in the field of parental communication with children with cancer, although research has explored the amount of information that parents give their child about the child's diagnosis and treatment, there has been very little research done to find out about the manner in which parents should give this information, or the effect of the information given on child outcomes. Eventually, parents may benefit from instruction on the best way to talk to their children about cancer and "best" should be based on child outcomes. So ideally, research on parent communication should be focused on finding details on how a parent should communicate with their child about the illness that results in the lowest levels of anxiety and depression in the child.

The purpose of this study is to take a first step toward understanding whether parents' communication and listening skills, coupled with a warm and supportive approach on the part of the parents, is associated with better psychological adjustment in children with a diagnosis of cancer. It is hypothesized that high scores on communication

skills on the part of the parents will result in fewer psychopathological symptoms in their children, namely lower levels of anxiety and depression.

Method

Participants

This is a two-site study, with participants being drawn from both the Monroe Carell Jr. Children's Hospital at Vanderbilt University, in Nashville, TN and from Nationwide Children's Hospital at Ohio State University in Columbus, Ohio. Currently, data are available from 76 families in the pilot sample (recruitment in the current study is ongoing; however, only data from the pilot sample will be used for the current study).

The sample includes 40 boys and 37 girls ranging in age from 5 to 18, with a mean age of 10.524 with a standard deviation of 3.684 years. There were sixty-nine Caucasians, five African-Americans, 1 Asian, and 2 Hispanic children.

Procedure

Data collection for this study was done in three phases. In phase one the families are recruited to participate in a battery of questionnaires assessing coping and adjustment. Three months later, these families are offered the opportunity to participate in another study, phase two, on parent-child communication in pediatric oncology that includes a taped fifteen minute interaction that is coded for various behaviors. Regardless of whether the family decides to participate in phase two, a year after phase one is completed, the families fill out another set of questionnaires—many of them identical to those in phase one. The current study focuses only on the data collected at the first data collection phase.

Measures

Phase I

At least one parent filled out a packet of questionnaires for each child recruited to the study, regardless of age. Self-report questionnaires from the children were obtained from all children age 10-17.

Demographic Data: Parents completed a questionnaire to determine marital status, education, occupation, religious and spiritual beliefs and practices, income, and number and age of children. Additionally, permission was granted to obtain medical data for each child, including type of diagnosis, date of diagnosis, types of treatment (e.g., chemotherapy, surgery, radiation), date of relapse, type of relapse (e.g., local recurrence or metastatic disease), illness or treatment-related complications, and prognosis.

Youth Self-Report (YSR; Achenbach & Rescorla, 2002): A self-report questionnaire completed by adolescents to determine symptoms of internalizing and externalizing emotional or behavioral problems.

Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2002) is completed by the parents to determine symptoms of internalizing and externalizing emotional or behavioral problems in their children.

Parent-Adolescent Communication Scale (PACS; Barnes & Olson, 1985): Parents and children age 10 years and older, will fill out this questionnaire to assesses their general communication experiences. Each participating parent fills it out once and the child fills one out for each parent in the home. This questionnaire is reasonably reliable, with high internal consistency (α = .80 to .92) and moderate 4-week test-retest reliability (r = .64 to .78). The subscales of interest for this particular study are *Open*

Family Communication and *Problems in Family Communication.*

Phase II

Three months after each family fills out the battery of questionnaires in Phase I, they are invited to participate in the interaction portion of the study, Phase II. In this phase, the child and his or her primary caregiver is videotaped during a 15 minute interaction in which they are asked to discuss the child's illness and how they communicate about it. The caregiver is given four cards with prompts on them and is instructed to read them aloud to help guide the interaction. The four cards read as follows, (1) When and where have we talked about your illness? (2) What kinds of things have we already talked about regarding your illness? (3) 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? (4) What do we think might happen next?

Iowa Family Interaction Rating Scales (IFIRS; Melby et al., 2001)

This scale will be used to code the behavior of the child and their parent in the taped 15 minute interaction. It is designed to measure both verbal and nonverbal behaviors of each individual as well as determine the quality of the interaction between them. Inter-rater reliability is assessed for each interaction by each tape being coded by two research assistants. The codes relevant to this particular study are *Communication, Listener Responsiveness* and *Warmth/Support* for the parent and *Sadness* and *Anxiety* for the child.

Results

It was hypothesized that high scores on communication skills on the part of the

parents would result in fewer psychopathological symptoms in their children, namely lower levels of anxiety and depression.

Descriptive statistics from the various questionnaires administered in Phase I are given in Table I. T scores are given for both the YSR and the CBCL, as compared to normative data as given by the author of the measures. The T score for the YSR (M = 54.54, SD = 6.65), though not significantly higher than the national average, was indeed elevated to a degree. It is also important to note that the distribution of this sample was tighter than the national average, given that the standard deviation was much smaller than the normative data. The same held true with the T scores for the CBCL (M = 54.05, SD = 5.86) where the mean for this sample was slightly elevated, with a smaller than normal standard deviation.

Correlations Between Variables Measuring the Same Construct

The relationships between these variables are illuminated by the analysis of the correlation coefficients (*r),* as seen in Table II. The child report of distress (anxiety and depression) as given by the score on the YSR (A/D) and the parent report of their child's anxiety and depression as given by the CBCL (A/D) score indicate that there is a significant relationship ($r = .63$, $p < .01$) between child and parent reports of the child's state of distress. Other correlations that demonstrate the validity of the following relationships are those that show the child and the parent having similar reports of their communication patterns. For example, the correlation between the PACM Openness and the MPAC Openness is significant ($r = .45$, $p < .01$), supporting the agreement between mother and child on the nature of their communication. In further evidence of this point, is the relationship between the PACM problems score and MPAC problems score, which

has are also significantly correlated ($r = .45$, $p < .01$).

Communication With Mother and Child Distress

With this confidence that the variables that make up our two constructs (parent communication and child distress) report similar findings, across the two sources of information, the following correlations can be analyzed with more confidence. The correlation between PACM Problems scores and YSR (A/D) scores was significant ($r = .37$, $p < .05$), while the PACM Openness score was not correlated with the child report of distress. Of note is the fact that the other report of child distress—the CBCL—did not correlate with either the PACM Openness or Problems scales.

The MPAC scores report the Mothers' reports of communication with their children and are another way to measure this construct. The correlation between the MPAC Openness score and the CBCL was significant ($r = -.29$, $p < .05$), while the correlation between the MPAC Openness score and the YSR, though also negative, was not significant. The relationship between the MPAC Problems and each of the two measures of child distress, on the other hand, were both statistically significant ($r = .43$, $p < .01$, for the YSR, and $r = .37$, $p < .01$, for the CBCL). These comparisons are consistent with the earlier correlations, serving as a sign that better communication on the part of the mother, leads to better child outcomes.

Communication with Father and Distress

The findings from the child reports of the communication with their fathers were similar, yet more consistent, than the reports of communication with the mothers. For example, the correlation between the PACF Problems score and the YSR were significant

($r = .37$, $p < .05$), as well as the PACF Openness score and the YSR ($r = -.43$, $p < .05$). Not only were both of these significant, but the correlation with the CBCL and the PACF Problems score was also significant ($r = .55$, $p < .01$). This is especially important in light of the fact that this correlation reflects the relationship between the child's report of communication with their father and the *mother's* report of child distress. This might shed light on the fact that the role of the father when it comes to parent-child communication might be of more importance than initially suspected.

Discussion

The findings of this study indicate that there is indeed a relationship between the quality of communication between parents and the distress of the child in this population of pediatric oncology patients. Those children who had better communication patterns with their parents tended to also have lower symptoms of distress, namely anxiety and depression. Though these correlations do not imply causation, the direction of the relationship was in accordance with the hypothesized association. There were a few instances, however, where two correlations were aimed to measure the same construct relationship but only one came out as statistically significant. Though not all of these correlations resulted in a p value less than .05, there were some strong associations and significant correlations might be found with a larger sample and greater statistical power.

It was also of note that these children did indeed have levels of distress that were higher than their healthy peers, as indicated by the T scores of a nationally representative sample. Not only were the means for these measures higher than normal, but the distribution was also tighter, indicating that many of these children hover around this slightly elevated score of distress. It seems as though these children do indeed suffer from

higher levels of anxious and depressed symptoms and thus, it is important to determine whether there is a relationship between the child's communication with his or her parent and their levels of distress.

One finding that was of particular interest to this researcher was the findings on the fathers in the study. Throughout the study we were focused on the child's communication with the "primary caregiver" and the effect the quality of this communication had on the child's distress. In nearly all of the cases, the primary caregiver was the mother, which may have made the role of communication with the father seem to be of less importance. However, upon analyses of the correlations between these children's communication patterns with their fathers and their levels of anxiety and depression, there were very strong correlations between the two, indicating that children's communication with their fathers is of more import than previously expected.

Because of the slight discrepancies between the findings of the various correlations, depending on the source of the information, it will be important in further research to analyze the different methods of measurement and see how well they really measure the same thing. It will be of great assistance to see how the data from the observation period falls into these findings. Currently, there is only information on how the children and the mothers *say* they communicate, but data from the actual interaction might tell the story a bit better.

Overall, this study has filled in several missing pieces in the literature on the psychology of pediatric oncology patients, particularly in the importance of parent-child communication in this population. This study gives researchers confidence that, not only do these patients suffer from higher than normal levels of anxiety and depressive

symptoms as compared with normative samples, but that these symptoms are tied to the quality of their communication patterns with their parents—both mom and dad. This area of research warrants further study to determine the detailed facets of communication that are most closely related to child outcomes. The most important thing to keep in mind as research in this field develops is the overall goal of helping parents to understand how best talk with their child about this life-threatening disease. All of this research should be conducted with the end-goal of an empirically supported intervention program to teach parents the clinically tested *best* ways of communicating with their children about this illness.

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Table I: Descriptive Statistics

	M	*S*	N
YSR			
A/D raw score	3.93	3.93	44
A/D T score	54.55	6.65	
CBCL (A/D)			
A/D raw score	2.96	2.93	76
A/D T score	54.05	5.86	
PACM Openness	42.86	6.84	36
PACM Problems	21.88	7.08	35
PACF Openness	38.23	9.03	34
PACF Problems	23.59	7.47	32
MPAC Openness	39.75	4.71	60
MPAC Problems	21.46	5.64	60
M BDI	15.96	10.06	57

Note. YSR (A/D): Youth Self Report (Anxious-Depressed subscale), CBCL (A/D): Child Behavior Checklist (Anxious-Depressed subscale), PACM Open: child's report of mother on Parent-Adolescent Communication Scale (Openness subscale), PACM Prob: child's report of mother on Parent-Adolescent Communication Scale (Problems subscale), PACF Open: child's report of father on Parent-Adolescent Communication Scale (Openness subscale), PACF Prob: child's report of father on Parent-Adolescent Communication Scale (Problems) subscale, MPAC Open: mother's report of child on Parent-Adolescent Communication Scale (Openness subscale), MPAC Prob: mother's report of child on Parent-Adolescent Communication Scale (Problems subscale)
M: Mean
S: Standard Deviation

Table II. Correlations for Parent-Child Communication Patterns and Child Distress Levels[r]

	YSR (A/D)	CBCL (A/D)	PACM Open	PACM Prob	PACF Oben	PACF Prob	MPAC Open	MPAC Prob	M BDI Total
YSR (A/D)	--								
CBCL (A/D)	.632**	--							
PACM Open	-.209	.051	--						
PACM Prob	.367*	.077	-.688**	--					
PACF Open	-.428*	-.189	.424*	-.313	--				
PACF Prob	.674**	.548**	-.215	.346	-.681**	--			
MPAC Open	-.143	-.294*	.446*	-.493**	.199	-.202	--		
MPAC Prob	.434*	.374**	-.332	.464**	-.148	.300	-.485**	--	
M BDI Total	.154	.332*	.160	-.077	-.025	.162	-.113	.237	--

Note. YSR (A/D): Youth Self Report (Anxious-Depressed subscale), CBCL (A/D): Child Behavior Checklist (Anxious-Depressed subscale), PACM Open: child's report of mother on Parent-Adolescent Communication Scale (Openness subscale), PACM Prob: child's report of mother on Parent-Adolescent Communication Scale (Problems subscale), PACF Open: child's report of father on Parent-Adolescent Communication Scale (Openness subscale), PACF Prob: child's report of father on Parent-Adolescent Communication Scale (Problems) subscale, MPAC Open: mother's report of child on Parent-Adolescent Communication Scale (Openness subscale), MPAC Prob: mother's report of child on Parent-Adolescent Communication Scale (Problems subscale)

[r] As determined by Pearson's Correlation Coefficient

* $p < .05$, ** $p < .01$