

# Cancer-Related Sources of Stress for Children With Cancer and Their Parents

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**Objectives** The current study examines reports and correlates of cancer-specific stressors in children with cancer and their parents. **Measures** Mothers ( $n = 191$ ) and fathers ( $n = 95$ ) reported on their own and their child's stressors, general perceived stress, and posttraumatic stress symptoms. Children ( $n = 106$ ) completed self-reports of their own stressors and posttraumatic stress symptoms. **Results** Mother and father self-reports were positively correlated, but mothers reported higher levels of stressors than fathers. Child and parent reports of children's stressors were positively correlated, but parents rated physical effects as more stressful while children rated role-functioning stressors as more stressful. Parents' and children's reports of stressors were also positively associated with general perceived stress and posttraumatic stress symptoms. **Conclusions** The findings extend research on stress in children with cancer and their parents, and may help inform research on risk and intervention in pediatric cancer populations.

**Key words** adjustment; cancer and oncology; children; stress.

The diagnosis and treatment of childhood cancer present numerous challenges and sources of stress for children and their parents (Kupst & Bingen, 2006). Despite general agreement that cancer and its treatment can be stressful for families, more information is needed on the cancer-specific stressors that affect mothers, fathers, and children, how stressful they report these stressors to be, and how these stressors are associated with their adjustment to the disease and its treatment, particularly in children. Research on the nature, frequency, and correlates of cancer-related stressors experienced by children with cancer and their parents may provide important information regarding individual differences in risk for psychological distress and psychosocial interventions to help manage these stressors.

Several studies have examined sources of stress for parents of children with cancer. For example, Kazak and Barakat (1997) administered a general measure of

parenting stress and found that higher levels of parenting stress were related to higher levels of posttraumatic stress symptoms (PTSS). Other studies have examined sources of stress directly associated with having a child with an illness using the Pediatric Inventory for Parents (PIP; Streisand, Braniecki, Tercyak, & Kazak, 2001). The PIP includes four domains of stressors related to caring for a child with a chronic illness, including communication, emotional functioning, medical care, and role function. In a sample of parents of children with cancer, Streisand et al. (2001) found that levels of stress on the PIP did not differ as a function of parental gender, marital status, education, employment status, or household income; however, the level of stress reported by parents was inversely correlated with child age. Another study with a pediatric cancer sample in the Netherlands found that higher PIP scores were correlated with younger child age, and mothers reported higher levels of stress than fathers (Vrijmoet-Wiersma et al., 2010).

The finding that mothers may have higher levels of stressors is also consistent with research indicating that mothers have higher rates of cancer-related PTSS than fathers (Bruce, 2006). Several studies have also found that higher levels of parental stressors on the PIP were related to higher levels of psychological distress in parents of children with cancer (Streisand et al., 2001; Streisand, Kazak, & Tercyak, 2003; Vrijmoet-Wiersma et al., 2010). Additional research has also examined cancer-specific perceived stressors and psychological distress in childhood cancer survivors and their mothers using the Impact of Traumatic Stressors Interview Schedule (ITSIS), a semi-structured interview that measures cancer-related stressors relevant to childhood survivors of cancer and their parents in several domains, including distress, changes in perception of self, communication, and vigilance (Kazak et al., 2001; Kazak, Stuber, Barakat, & Meeske, 1996). Reports and perceptions of cancer- and treatment-related events as traumatic stressors on the ITSIS were positively associated with reports of PTSS and internalizing problems (Kazak et al., 1996, 2001).

Fewer studies have focused on stressors faced by children with cancer, and most of these studies have used general measures of life stress. For example, Currier, Jobe-Shields, and Phipps (2009) examined stressful life events that were not directly related to the child's cancer, and found that they predicted PTSS in these children. Brown, Madan-Swain, and Lambert (2003) examined stressful life events unrelated to cancer in childhood cancer survivors and found that they reported more recent and past stressful events than healthy controls. In contrast, some studies have focused directly on cancer-related stressors for children undergoing treatment (e.g., Hockenberry-Eaton, Kemp, & Dilorio 1994; Varni & Katz, 1997) or off-treatment (e.g., Kazak et al., 1996, 2001). Findings from these studies have been mixed, as some studies suggested that cancer-related stressors were not associated with children's physiological distress (Hockenberry-Eaton et al., 1994), while others found that perceived stressors were associated with higher levels of negative affect (Varni & Katz, 1997) and PTSS (Kazak et al., 2001; Kazak et al., 1996). Further, no studies with a pediatric cancer sample have measured cross-informant (e.g., parents and children) correlations of reports of children's stressors. Research and theory in developmental psychopathology and pediatric psychology has highlighted the importance of obtaining reports from the self and others for both children and adults (e.g., Achenbach, 2006, 2010; Felder-Puig, Topf, Gadner, & Formann, 2008). Significant cross-informant correlations have been found for emotional and behavioral symptoms in children,

with small effects for parent-child cross-informant reports and larger effects for mother-father reports of children (Achenbach, McConaughy, & Howell, 1987). Therefore, we expected that parent-child reports of children's stressors would be moderately associated and mother-father reports of children's stressors would be more strongly associated.

In general, there is relatively little research that describes which types or domains stressors are most salient and what types of stressors are most stressful to children with cancer and their parents. To address this gap and guided by research and theory on the importance of considering specific domains and sources of stress in children and adolescents (e.g., Grant et al., 2003; McMahan, Grant, Compas, Thurm, & Ey, 2003), the current study examined cancer-related stressors in a sample of children with first diagnoses of cancer or relapsed disease and their parents. Similar to the domains of stress included on the PIP (Streisand et al., 2001), we examined stressors faced by mothers and fathers of children with cancer in several domains: daily role functioning, cancer communication, and cancer caregiving. Recent theory and research on stress has highlighted the role of the "tend-and-befriend" response that engages caretaking behaviors in parents and is heightened in women as compared with men (e.g., Han-Holbrook, Holbrook, & Haleston, 2011; Taylor & Master, 2011). We also extended this work by examining child self-reports and parents' reports of children's stressors in the domains of daily role functioning, physical effects of treatment, and uncertainty about cancer. Further, we examined how cancer-related stressors in these families were related to general perceived stress and PTSS, as previous research specifically indicates that PTSS may be elevated in these parents (e.g., Bruce, 2006; Kazak, Boevig, Alderfer, Hwang, & Reilly, 2005) and that higher levels of stressors may be related to higher levels of PTSS (e.g., Kazak & Barakat, 1997).

With regard to stressors faced by parents, we hypothesized: (a) mean levels of cancer-related stressors would be higher for mothers than fathers; (b) mothers' and fathers' levels of stressors would be positively correlated; and (c) higher levels of cancer-related stressors experienced by mothers and fathers would be positively correlated with levels of general perceived stress, younger child age, and higher levels of PTSS. We also conducted exploratory analyses comparing the different subdomains of stress (role functioning, communication, and caregiving) for mothers and fathers.

We hypothesized that with regard to stressors faced by children with cancer: (a) cross-informant reports

(children's, mothers', and fathers' reports) of children's stressors would be positively correlated, and (b) higher levels of children's cancer-related stressors would be positively correlated with higher levels of PTSS. In addition, we explored the question of whether the mean levels of cancer-related stressors for children differed across informants (i.e., children, mothers, and fathers), and whether higher levels of stress for children were associated with family income and child age. We also conducted exploratory analyses comparing subdomains of stressors (role functioning, physical effects, and cancer uncertainty) for children.

## Methods

### Participants

Parents and children were recruited from cancer registries at two pediatric oncology centers in the midwestern and southern United States. Eligible families had children who: (a) were ages 5–17 years, (b) had a first diagnosis or relapse of cancer, (c) were receiving treatment through the oncology division, and (d) had no pre-existing developmental disability. Families of children who were at least 1-week post first diagnosis or post relapse were eligible for recruitment. Parents provided self-reports and completed measures about their children, and children ages 10–17 years provided self-report data on age-appropriate measures.

Two hundred and thirty-seven families were approached about the study, and at least one parent consented to participate in 90.7% ( $n=214$ ) of these families. Ninety-three percent ( $n=199$ ) of families who consented to the study (84% of all eligible families) had at least one parent or child who completed the questionnaires. This resulted in a sample of 290 parents of children with cancer (193 mothers and 97 fathers of 199 patients ages 5–17 years) and 106 children (ages 10–17 years) with cancer who completed the measures. Four of these parents (two mothers and two fathers) completed the measures >200 days after their child's first diagnosis or relapse and were excluded as outliers. Thus, the final sample included 286 parents of children (ages 5–17 years) with cancer (191 mothers and 95 fathers of 195 children with cancer) and 106 children (ages 10–17 years) who completed self-report measures. Approximately 60% of eligible fathers in two-parent homes completed questionnaires.

For all the families included in the study, children were on average 10.6 years old ( $SD=3.9$ ), 56.5% ( $n=108$ ) male, 86% ( $n=164$ ) White/Caucasian, 9% ( $n=17$ ) Black/African-American, 5% ( $n=9$ ) Hispanic/Latino, 1% ( $n=2$ ) Asian-American, and 4% ( $n=7$ )

Other. Children had diagnoses of leukemia (38%;  $n=75$ ), lymphoma (25%;  $n=49$ ), brain tumor (11%  $n=21$ ), and other solid tumor (e.g., osteosarcoma, Wilm's tumor; 26%;  $n=50$ ). Twenty-eight children (14%) were recruited into the study following a relapse of their original cancer. For the subgroup of children who provided self-report data, children were on average 13.4 years old ( $SD=2.4$ ), 54% ( $n=55$ ) male, 88% ( $n=90$ ) White/Caucasian, 8% ( $n=8$ ) Black/African-American, 3% ( $n=3$ ) Hispanic/Latino, 1% ( $n=1$ ) Asian-American, and 3% ( $n=3$ ) Other. They had diagnoses of leukemia (34%  $n=36$ ), lymphoma (36%;  $n=38$ ), brain tumor (7%;  $n=7$ ), and other solid tumor (24%;  $n=25$ ). Sixteen (15%) were children with relapsed disease.

Mothers were on average 37.9 years old ( $SD=8.4$ ) and fathers were 39.5 years old ( $SD=7.6$ ). Duncan scores of SES for families based on reports of currently held jobs and responsibilities within those jobs (Total Socio-Economic Index 2; Nakao & Treas, 1992) indicated that, on average, mothers held positions equivalent to administrative assistants and clerks ( $M=34.1$ ,  $SD=22.9$ ) and fathers held positions equivalent to supervisors and managers ( $M=51.9$ ,  $SD=21.0$ ). The families represented a variety of annual income levels: 25% ( $n=47$ ) earned \$25,000 or under, 31% ( $n=58$ ) earned between \$25,001 and \$50,000, 14% ( $n=26$ ) earned between \$50,001 and \$75,000, 13% ( $n=25$ ) earned between \$75,001 and \$100,000, and 17% ( $n=33$ ) earned over \$100,000.

### Measures

#### Demographic and Medical Data

Parents provided demographic information including age, race, ethnicity, marital status, family income, education level, and employment. Participants gave permission for the research staff to access medical data, where the child's diagnosis/relapse status was extracted.

#### Cancer-Related Stressors

Participants completed the stressor items from the Responses to Stress Questionnaire-Pediatric Cancer Version (RSQ; Miller et al., 2009) concerning cancer-related stressors. Mothers and fathers provided self-report and parent-report of children, and children ages 10–17 years provided self-report data. The stressor items from the RSQ-Pediatric Cancer Version include a list of cancer-related stressors (11 for parents' self-reports, 10 for parent report of child and child self-report) and participants rate how stressful each item has been recently on a scale from 1 (Not at all) to 4 (Very). Stressor items were

generated to reflect previous research and the research team's clinical experience with children on treatment and their parents. Stressors were then grouped into subdomains similar to the domains of stress on the PIP (Streisand et al., 2001). For mothers and fathers of children with cancer, the subdomains of stressors were: (a) daily/role functioning (paying bills and family expenses, concerns about my job or my spouse/partner's job, having less time and energy for my other children and/or spouse); (b) cancer communication (talking with my child about cancer, talking to my other children, family, and friends about cancer, understanding information about cancer and medical treatment, arguing with my child about taking medicines and other treatment); and (c) cancer caregiving (not being able to help my child feel better, the effects of my child's treatment, not knowing if my child's cancer will get better). Internal consistencies for each domain on the parent self-report RSQ ranged from .68 to .75 (mean = 0.72).

Stressors on the child self-reports and parents' reports of children's stressors were grouped into three subdomains: (a) daily/role functioning (missing school days or falling behind in school work, not being able to do the things I used to do, having to go to the hospital or clinic so often, concerns about my family and friends); (b) physical effects of treatment (feeling sick or nauseous from treatments, concerns about changes in the way I look, pain and soreness from medical procedures); and (c) uncertainty about cancer (not understanding what doctors tell me about cancer, feeling confused about what cancer is and how I got it; concerns about the future). Internal consistencies for the child RSQ subdomains ranged from .71 to .76 (mean = 0.74) on the child self-report version, and .57 to .73 (mean = 0.64) on the parent report of child version.

### Perceived Stress

Mothers and fathers completed the Perceived Stress Scale (PSS; Cohen & Williamson, 1988). The PSS is a widely used instrument that assesses subjective experiences of psychological stress in the past month (e.g., how often have you felt difficulties were piling up so high that you could not overcome them). It consists of 10 items that ask respondents to rate how often each item was true for them on a scale from 0 (Never) to 4 (Very Often). Internal consistency for the total PSS score with the current sample was  $\alpha = .87$  for mothers and  $\alpha = .82$  for fathers.

### PTSS

Participants who provided self-report data (i.e., mothers, fathers, children age 10–17 years) completed the Impact of Event Scale-Revised (IES-R; Weiss & Marmar, 1997) as an

index of PTSS, including intrusive thoughts, avoidance, and physiological hyperarousal related to the child's cancer. The 22 items are rated for the distress caused by each symptom over the past 7 days from 0 (not at all) to 4 (extremely) specifically in reference to the child's first or relapsed cancer diagnosis and treatment. The total summary score was used in the current study. The IES-R has been used with pediatric cancer samples (e.g., Kazak et al., 2004; Phipps, Long, Hudson, & Rai, 2005) and demonstrates good reliability and validity (Weiss & Marmar, 1997). Internal consistency was  $\alpha = .93$  for mothers,  $\alpha = .95$  for fathers, and  $\alpha = .91$  for children.

### Procedure

The Institutional Review Boards at the two respective sites approved the study protocol. Families were identified from cancer registries at two hospitals in the Southern and Midwestern United States. Parents were approached in the clinic or hospital by a member of the research team to introduce the study and determine interest in participating. If interested, parents completed an informed consent form, and children (ages 10–17 years) completed an assent form. Questionnaire packets were given to participants to complete at the hospital or in the home. In the case that only one parent was present, consent forms and questionnaires were sent home for the other parent to consider. Families were approached between 0.25 and 5.10 months after the child's first diagnosis or relapse ( $M = 1.26$  months,  $SD = 0.80$ ). Parents and children completed the questionnaires between 0.40 and 5.50 months after the child's first diagnosis or relapse ( $M = 1.75$ ,  $SD = 1.13$ ). Families received compensation when at least one parent or child completed the measures.

### Statistical Analyses

Means and standard deviations for cancer-related stressor scores and PTSS were calculated. Pearson correlations were calculated for hypothesized associations except for those involving rank ordered data (i.e., annual family income), for which Spearman correlations were calculated.<sup>1</sup> Differences in mothers' and fathers' levels of stressors, as well as cross-informant differences about children's stressors, were calculated using paired *t*-tests. Relations between the domains of stress and PTSS for mothers,

<sup>1</sup> Intraclass correlations (ICCs) were also examined to adjust for the possible lack of independence between mother, father, and child reports. All ICCs between mother–child, father–child, and mother–father reports of children were significant and ranged from .32 to .57. These findings were consistent with the results using Pearson correlations to calculate the associations between mother, father, and child reports of children.



fathers, and children were examined using correlations and linear multiple regression. Power analyses using  $R^2$  (Steiger & Fouladi, 1992) indicated that the current sample of 190 mothers, 95 fathers, and 106 children all produced adequate power (.80–.99) to detect small correlations ( $r < .20$  and small effect sizes, Cohen's  $d = .20$ –.35) for within and between group comparisons (Cohen, 1992).<sup>2</sup>

## Results

### *Preliminary Analyses of Medical Variables*

Participants from both sites were compared and no significant differences were found due to site. Time since first diagnosis or relapse, diagnosis type (i.e., leukemia, lymphoma, brain tumor, and other solid tumor), and relapse status (i.e., first diagnosis or relapsed disease) were examined for associations and group differences on cancer-related stressors. Time in days since first diagnosis or relapse was not significantly correlated with level of stressors for parents or children ( $r$ 's ranged from  $-.09$  to  $.15$ ; all  $p$ 's  $> .12$ ). Time since first diagnosis or relapse was also examined as a categorical variable ( $\leq 1$  month vs.  $> 4$  months post first diagnosis or relapse), although the

<sup>2</sup> All analyses were also conducted using the sample of families for which mothers, fathers, and children all participated ( $n = 47$ ). This sample represented a decrease in power from the total sample ( $n = 102$  for mother–child comparisons,  $n = 52$  for father–child comparisons, and  $n = 90$  for mother–father comparisons). The pattern of results using this smaller sample was consistent with results from our full sample for child–mother–father comparisons of children's stressors, cross-informant correlations of children's stressors, and correlations between children's stressors and PTSS (significance decreased for some correlations but all  $p$ 's remained  $< .05$ ). However, in testing our first hypothesis that mean levels of cancer-related stressors would be higher for mothers than fathers, differences between mothers and fathers using the smaller paired sample were not statistically significant, in contrast to the findings using our full sample, which indicated that mothers reported higher levels of role functioning, communication, caregiver, and total stressors than fathers. Due to the possible confound of child age in the preceding analyses, the sample of mothers and fathers with children ages 10 and older ( $n = 51$ ), was also compared with the sample of mothers and fathers with children ages 5–9 years ( $n = 39$ ). The results indicated that, in families of children ages 10 years and older, there were no significant differences between mothers and fathers in any domains of stress for parent-report of child or for self-report. However, in families of children ages 5–9 years, significant differences emerged for mother and father self-reports of role-functioning ( $t = 2.65$ ,  $p = .01$ ), cancer communication ( $t = 2.09$ ,  $p = .04$ ), and total stressors ( $t = 2.41$ ,  $p = .02$ ). This finding suggests that mothers of younger children may experience more stressors in these domains compared to those fathers, but mothers' and fathers' stressor levels may not differ when they are the parents of older children.

sample was underpowered to compare reports at  $< 1$  month post first diagnosis or relapse to those at  $> 4$  months post first diagnosis or relapse, due to the extremely small sample for the  $> 4$  months group ( $n = 10$  mothers,  $n = 2$  fathers, and  $n = 6$  children). These analyses indicated that there was one group difference for mothers' levels of cancer communication stressors at  $< 1$  month (i.e., mothers of children first diagnosed or relapsed  $< 1$  month ago experienced higher levels of communication stressors). No other significant differences were found. Correlational analyses were also conducted for time since first diagnosis or relapse and parent and child IES-R scores. Analyses indicated that time since first diagnosis or relapse was significantly related to mothers' IES-R scores ( $r = -.18$ ,  $p = .01$ ), but not significantly related to children's or fathers' IES-R scores.

A series of one-way ANOVAs to examine group differences by diagnosis type did not find significant differences for parents' or children's self-reported stressors ( $F$ 's ranged from 0.09 to 2.53; all  $p$ 's  $> .05$ ). Analyses were also conducted to compare families of children with new diagnoses and families of children with relapses, although it should be noted that power was insufficient ( $\beta < .50$ ) to detect even large effects (.80) with the relapse group alone, due to the small  $n$ 's for relapsed patients ( $n = 27$  mothers,  $n = 11$  fathers, and  $n = 16$  children). No significant differences in the results were found for any comparisons between new diagnoses and relapses. The results from the full sample were also compared with those from the sample of children with new diagnoses only, and minimal differences were found in the results between the new diagnoses alone and the full sample. Although several correlations became marginally significant or nonsignificant ( $p$ 's ranged from .06 to .22), the magnitude and direction of the effect sizes did not change. Therefore, in order to maintain a representative sample of families of children with cancer, the following results include children with all types of cancer as well as children with first-time and relapsed disease.

### *Parents' Cancer-Related Stressors*

#### *Frequency and Mean Levels of Cancer-Related Stressors Reported by Mothers and Fathers*

Means and standard deviations of subscale scores and total scores for mothers and fathers are presented in Table I. For both mothers and fathers, the subdomain of cancer caregiving was rated as stressful for the largest percentage of parents, with 88% of mothers and 74.3% of fathers endorsing these stressors as somewhat or very stressful. Mothers reported significantly higher stressors in daily/role functioning,  $t(87) = 2.97$ ,  $p = .004$ ,  $d = .30$ ;

Table I. Percentage of Mothers and Fathers Who Endorsed Each Stressor

	How stressful have these things been for you lately?		
	Not at all/ A little (%)	Somewhat/ Very (%)	Mean (SD)
Daily/Role functioning			
Mother report	40.3	59.7	2.76 (0.80)
Father report	53.3	46.7	2.44 (0.78)
Cancer communication			
Mother report	64.7	35.3	2.11 (0.77)
Father report	74.5	24.5	1.95 (0.69)
Cancer caregiving			
Mother report	22	88	3.24 (0.72)
Father report	25.7	74.3	3.12 (0.72)
Total			
Mother report	42.3	57.7	2.65 (0.61)
Father report	51.2	48.8	2.44 (0.62)

Note. Total percentages may not equal 100% due to rounding. Response options for each item ranged from 1 to 4.

communication,  $t(87) = 2.22$ ,  $p = .029$ ,  $d = .27$ ; and caregiving,  $t(87) = 2.02$ ,  $p = .047$ ,  $d = .25$ , than fathers. Mothers also reported higher levels of total stressors,  $t(87) = 2.92$ ,  $p = .004$ ,  $d = .33$ , than fathers.

Mothers rated role functioning as significantly more stressful than cancer communication,  $t(187) = 11.13$ ,  $p < .001$ ,  $d = .82$ ; and cancer caregiving as significantly more stressful than role functioning,  $t(187) = 7.38$ ,  $p < .001$ ,  $d = .63$ , and cancer communication,  $t(187) = 21.00$ ,  $p < .001$ ,  $d = 1.5$ . Fathers demonstrated the same pattern as mothers, rating role functioning as significantly more stressful than cancer communication,  $t(92) = 6.93$ ,  $p < .001$ ,  $d = .65$ ; and cancer caregiving as significantly more stressful than role functioning,  $t(92) = 8.90$ ,  $p < .001$ ,  $d = .91$ , and cancer communication,  $t(92) = 18.42$ ,  $p < .001$ ,  $d = 1.7$ .

#### Correlations Between Mothers' and Fathers' Reports of Cancer-Related Stressors

Mothers' self-reported daily role functioning was significantly positively correlated with fathers' daily role functioning, cancer communication, and cancer caregiving ( $r$ 's from .27 to .56,  $p$ 's  $< .05$ ), and mothers' cancer communication was significantly correlated with fathers' daily role functioning ( $r = .27$ ,  $p = .01$ ) and cancer communication ( $r = .37$ ,  $p < .001$ ), but not fathers' cancer caregiving ( $r = .19$ ,  $p = .07$ ). Mothers' cancer caregiving was not significantly related to fathers' daily role functioning ( $r = .11$ ,  $n.s.$ ) or cancer communication ( $r = .15$ ,  $n.s.$ ), but was positively correlated with fathers' cancer caregiving ( $r = .25$ ,  $p = .02$ ). Mothers' and fathers' total scores were significantly positively correlated ( $r = .25$ ,  $p < .005$ ).

Table II. Correlations Among Mother and Father Self-Reports of Stressor Subdomain Scores with Self-Reports of Posttraumatic Stress on the IES-R and Demographic Variables

	Mother PSS	Mother IES-R	Child age	Family Income
Mother Daily/Role Fxn	.47**	.34**	-.08	-.27**
Mother CanCom	.48**	.54**	-.23*	-.02
Mother CanCare	.42**	.52**	-.07	.02
Mother total	.58**	.58**	-.17*	-.14
	Father PSS	Father IES-R		
Father Daily/Role Fxn	.57**	.39**	-.04	-.23*
Father CanCom	.55**	.59**	-.14	-.14
Father CanCare	.58**	.55**	.02	-.05
Father Total	.67**	.59**	-.06	-.18

\* $p < .05$ ; \*\* $p < .0015$ .

PSS, Perceived Stress Scale; IES-R, Impact of Event Scale-Revised; Daily/Role Fxn, Daily/Role Functioning; PhyEff, Physical Effects; CanUnc, Cancer Uncertainty; CanCom, Cancer Communication; CanCare, Cancer Caregiving; Total, Mean Total stressor score; Child age and annual family income based on mother report.

#### Group Comparisons by Psychological and Demographic Variables and Correlations with Mothers' and Fathers' Cancer-Related Stressors

Means for mothers and fathers on the IES-R were, respectively, 29.3 ( $SD = 16.6$ ), and 25.9 ( $SD = 17.0$ ), with scores ranging from 0 to 68. A substantial percentage of mothers (41%;  $n = 78$ ) and fathers (30%,  $n = 28$ ) had scores above 34, a clinical cutoff to predict cases of PTSD established by Rash, Coffey, Baschnagel, Drobos, and Saladin (2008). Comparisons of participants above and below this cutoff indicated that, for mother and father self-reports of stressors, those above the cutoff had significantly higher stressors in all domains (all  $p$ 's  $< .01$ ).

Correlations among subdomain and total stressors, perceived stress scores, PTSS, and demographic variables are presented in Table II. Due to multiple correlations, results are reported at the .05 level (not corrected for multiple correlations) and those at the .0015 level (Bonferroni correction for multiple correlations in the same family;  $p = .05/32 = .0015$ ). All correlations between self-report of cancer-related stressors and perceived stress, and cancer-related stressors and PTSS, were positive, significant, and medium to large in magnitude ( $r$ 's from .34 to .67,  $p < .0015$ ). Correlations between mothers' and fathers' stressors and demographic variables revealed that child age at first diagnosis or relapse was negatively correlated with mothers' cancer communication stressors ( $r = -.23$ ,  $p = .002$ ) and total stressors ( $r = -.17$ ,  $p = .02$ ). Family income was also negatively correlated with mothers' daily/role functioning stressors ( $r = -.27$ ,

Table III. Means, Standard Deviations, and Percentage of Sample Who Endorsed Each Stressor on the Child RSQ, Organized by Child, Mother, and Father Report

	How stressful have these things been for you lately?		
	Not At all/ A little (%)	Somewhat/ Very (%)	Mean (SD)
Daily/Role functioning			
Child report	46.5	53.5	2.57 (0.88)
Mother report	43.5	56.5	2.65 (0.70)
Father report	55.5	45.5	2.40 (0.63)
Physical Effects			
Child report	55.3	45.7	2.39 (0.91)
Mother report	42	58	2.74 (0.74)
Father report	45	55	2.62 (0.76)
Cancer Uncertainty			
Child report	68	32	2.20 (0.94)
Mother report	71.7	29.3	2.04 (0.72)
Father report	76	24	1.91 (0.71)
Total Stressors			
Child self-report	56.6	44.4	2.35 (0.77)
Mother report of child	52.4	47.6	2.49 (0.61)
Father report of child	58.8	41.2	2.30 (0.60)

Total percentages may not equal 100% due to rounding.

$p < .001$ ) and fathers' daily/role functioning stressors ( $r = -.23$ ,  $p = .03$ ).

### Children's Cancer-Related Stressors

#### Frequency and Mean Levels of Child Cancer-Related Stressors Reported by Children, Mothers, and Fathers

Means and standard deviations of subscale scores, individual item scores, and total scores for mothers and fathers are summarized in Table III. Over half of children and mothers rated daily/role functioning stressors as somewhat or very stressful, while over half of mothers and fathers also rated physical effects as somewhat or very stressful for children. Mothers' reports of children's stressors were significantly higher than children's self-reports for physical effects,  $t(101) = 5.07$ ,  $p < .001$ ,  $d = .47$ , and total stressors,  $t(101) = 2.90$ ,  $p = .005$ ,  $d = .26$ . Fathers' self-reports were significantly higher than children's self-reports for physical effects,  $t(51) = 3.37$ ,  $p = .001$ ,  $d = .54$ . No significant differences were found between mothers' and fathers' reports of their children.

#### Within-subject Comparisons of Child, Mother and Father Reports of Children's Cancer-Related Stressors

Children's rated their role functioning as significantly more stressful than physical effects,  $t(105) = 2.56$ ,  $p = .01$ ,  $d = .20$ , and cancer uncertainty,  $t(105) = 6.12$ ,  $p < .001$ ,

Table IV. Correlations Among Child, Mother and Father Reports of Children's Subdomain and Total Stressor Scores

	Mother Report-Child Report	Father Report-Child Report	Mother Report-Father Report
Daily/Role Functioning	.52**	.53**	.37**
Physical Effects	.58**	.33*	.44**
Cancer Uncertainty	.46**	.45**	.43**
Total Stressors	.61**	.53**	.45**

Note.  $n = 106$  for child-child correlations,  $n = 102$  for mother-child correlations,  $n = 52$  for father-child correlations, and  $n = 90$  for mother-father correlations.

\*\* $p < .004$

$d = .41$ . Mothers' reports of their children rated physical effects as significantly more stressful than role functioning,  $t(190) = 2.05$ ,  $p = .04$ ,  $d = .13$ , and cancer uncertainty,  $t(190) = 14.35$ ,  $p < .001$ ,  $d = .96$ ; and role functioning as more stressful than cancer uncertainty,  $t(190) = 14.34$ ,  $p < .001$ ,  $d = .87$ . Similar to mothers, fathers' reports of their children also rated physical effects as significantly more stressful than role functioning,  $t(92) = 3.23$ ,  $p = .002$ ,  $d = .30$ , and cancer uncertainty,  $t(92) = 8.76$ ,  $p < .001$ ,  $d = .97$ ; and role functioning as more stressful than cancer uncertainty,  $t(92) = 10.63$ ,  $p < .001$ ,  $d = .74$ .

### Correlations Among Child, Mother and Father Reports of Children's Cancer-Related Stressors

Correlations between child, mother, and father reports of children's stressors are presented in Table IV. Again, due to multiple correlations, results are differentiated by significance at the .05 level (not corrected for multiple correlations), and those at the .004 level (Bonferroni correction for multiple correlations;  $p = .05/12 = .004$ ). All correlations between child, mother and father reports of children's subdomain and total stressors were positive and significant even after correcting for multiple correlations ( $r$ 's from .37 to .61,  $p < .004$ ) except for the child-father correlation for physical effects ( $r = .33$ ,  $p < .05$ ).

#### Group Comparisons by Psychological and Demographic Variables and Correlations With Children's Cancer-Related Stressors

Children's mean score on the IES-R was 20.0 ( $SD = 15.1$ ), with scores ranging from 0 to 56. Twenty-five percent ( $n = 21$ ) of children scored above the clinical cutoff (Rash et al., 2008) for predicted cases of PTSD. Comparisons of children above and below this cutoff indicated that, on child self-reports, those above the cutoff had significantly

Table V. Correlations Among Child Self-Report, Mother Report of Child, and Father Report of Child Stressors and Child Self-Report of PTSS

	Children's IES-R	Child Age	Annual Family Income
Child	.53**	.18	-.14
Daily/Role functioning			
Physical effects	.56**	.19	.01
Cancer uncertainty	.61**	.24*	-.02
Total stressors	.62**	.20*	-.08
Mother report of child	.41**	.17*	-.02
Daily/Role functioning			
Physical effects	.35**	.08	-.01
Cancer uncertainty	.41**	.14	-.02
Total stressors	.46**	.15*	-.02
Father report of child	.30*	.12	-.21*
Daily/Role functioning			
Physical effects	.28*	.04	-.03
Cancer uncertainty	.38*	.20	-.17
Total stressors	.36*	.16	-.14

Note.  $n = 104$  for child-child correlations,  $n = 100$  for mother-child correlations,  $n = 51$  for father-child correlations,  $n = 191$  for mother-mother correlations,  $n = 90$  for mother-father correlations. Child age and annual family income based on mother report.

\* $p < .05$ ; \*\* $p < .001$ .

higher stressors in all domains ( $p$ 's  $< .01$ ). For mothers' reports of children's stressors, children above the IES-R cutoff only had higher levels of cancer uncertainty and total stressors ( $p$ 's  $< .05$ ); for fathers' reports of children's stressors, children above the IES-R cutoff were significantly higher only on physical effects, cancer uncertainty, and total stressors ( $p$ 's  $< .05$ ).

Correlations among mother, father, and self-reports of children's subdomain and total stressors, child self-reported PTSS, and demographic variables are presented in Table V. Due to multiple correlations, results are differentiated by significance at the .05 level (not corrected for multiple correlations), and those at the .001 level (Bonferroni correction for multiple correlations in the same family;  $p = .05/36 = .001$ ). After correcting for multiple comparisons, significant positive correlations emerged among child and mother reports of children's stressors with children's PTSS ( $r$ 's from .35 to .62,  $p$ 's  $< .001$ ). There was also a nonsignificant trend for father reports of children's stressors and children's PTSS to be related ( $r$ 's from .28 to .38,  $p$ 's  $< .05$ ). Correlations of stressors with child age and family income were nonsignificant after correcting for multiple comparisons. However, there were nonsignificant trends for a positive correlation between child age and child reports of cancer uncertainty ( $r = .24$ ,  $p = .02$ ) and total stressors ( $r = .20$ ,  $p = .046$ ),

child age and mother reports of child daily/role functioning ( $r = .17$ ,  $p = .02$ ) and total stressors ( $r = .15$ ,  $p = .04$ ), and annual family income and father reports of child daily/role functioning ( $r = -.21$ ,  $p = .048$ ).

### Linear Multiple Regression Analyses

A series of linear multiple regression analyses were conducted with IES-R scores for mothers, fathers, and children as the dependent variables. In each regression equation, child age and family income were entered first, followed by the scores for levels of stressors in each of the subdomains. For the model predicting mothers' total scores on the IES-R, the overall equation was significant,  $F(3, 178) = 34.38$ ,  $p < .001$ , adjusted  $R^2 = .38$ . Child age and family income were not significant predictors, but mothers' reports of cancer communication stress ( $\beta = .34$ ,  $p < .001$ ) and caregiver stress ( $\beta = .33$ ,  $p < .001$ ) were both significant independent predictors. For the model predicting fathers' total scores on the IES-R, the overall equation was significant,  $F(3, 83) = 17.88$ ,  $p < .001$ , adjusted  $R^2 = .37$ . As was found in the model predicting mothers' IES-R scores, for fathers, child age and family income were not significant predictors; however, fathers' reports of cancer communication stress ( $\beta = .42$ ,  $p < .001$ ) and caregiver stress ( $\beta = .29$ ,  $p < .001$ ) were both significant independent predictors.

Three regression models were tested for children using mother reports, father reports, and child self-reports of children's stressors separately to predict children's IES-R scores. The equation using children's self-reports was significant,  $F(3, 94) = 23.31$ ,  $p < .001$ , adjusted  $R^2 = .43$ . Child age and family income were not significant predictors; however, children's reports of physical effects stressors ( $\beta = .28$ ,  $p = .009$ ) and cancer uncertainty stressors ( $\beta = .44$ ,  $p < .001$ ) were both significant independent predictors. The equation using mothers' reports was significant,  $F(3, 94) = 8.18$ ,  $p < .001$ , adjusted  $R^2 = .21$ . However, neither child age, family income, nor any of the specific domains of stressors were unique significant predictors of children's IES-R scores. Finally, the equation using fathers' reports was significant,  $F(3, 42) = 4.58$ ,  $p = .007$ , adjusted  $R^2 = .21$ . Family income ( $\beta = .33$ ,  $p = .043$ ) and fathers' reports children's cancer uncertainty stressors ( $\beta = .46$ ,  $p = .031$ ) were unique significant predictors of children's IES-R scores.

### Discussion

This study examined the stressors of childhood cancer from both parents' and children's perspectives. The



results of this study extend previous research by providing some of the first information about cancer-related stressors in a sample of children with first diagnoses or relapses of cancer and their mothers and fathers, including information about the types of stressors parents and children perceive to be most stressful; how mother, father, and child experiences are related; and the relations between domains of stress and PTSS for mothers, fathers, and children. The current study's findings provide clinically relevant information regarding individual differences in risk for psychological distress in pediatric cancer populations, and ultimately may inform interventions designed to help these families adjust to and cope with these stressors.

The findings regarding parents' reports of stressors indicate that, as predicted, mothers reported higher levels of daily/role functioning, communication, caregiving, and total stressors compared with fathers. This is consistent with earlier findings that mothers experience more parental stressors (Vrijmoet-Wiersma et al., 2010) and cancer-related PTSS (Bruce, 2006) in pediatric cancer populations. This finding also reflects research on gender differences in stressors that involve caretaking responses (Taylor & Master, 2011). However, supplementary analyses indicated that, while this finding was true for the sample as a whole and for parents of children ages 5–9 years, these differences became nonsignificant in the sample of parents of children ages 10 years and older, suggesting that differences between mothers' and fathers' levels of stressors are more salient in families of younger children. Caregiving stressors were also the most frequently endorsed stressors at a high level by both mothers and fathers (i.e., 88% of mothers and 74% of fathers rated cancer caregiving stressors as "somewhat" or "very" stressful). Furthermore, caregiving stressors were rated by both mothers and fathers as more stressful than role functioning and communication stressors (with effect sizes ranging from .63 to 1.7). The findings suggest that the most stressful aspects of having a child with cancer for both mothers and fathers may be related to the uncontrollability of the experience in the context of caregiving, such as not being able to help their child feel better and having concerns about their child's survival.

As hypothesized, each subdomain of parents' stressors (daily/role functioning, communication, caregiving) was positively correlated between mothers and fathers, suggesting that mothers and fathers experience similar types and patterns of stressors, even though mothers' stress levels are higher than fathers. Mothers' higher reported stress levels may be due to their common role as the child's primary caregiver (Dunn et al., in press) and therefore their probability of spending more time

carrying for the child and encountering more cancer-related stressors. Correlations between cancer-related stressors, perceived stress, and PTSS were positive and medium to large in magnitude, suggesting that parents' experiences of cancer-related stressors are related to a more general subjective measure of stress (the Perceived Stress Scale) and symptoms such as intrusive thoughts, avoidance, and hyperarousal. This is consistent with previous findings that parental stressors are related to PTSS in parents of children with cancer (e.g., Kazak & Barakat, 1997) and higher levels of pediatric parental stressors are related to higher levels of anxiety in parents of children with cancer (e.g., Streisand et al., 2001).

Child age at first diagnosis or relapse was negatively correlated with mothers' cancer communication stressors and total stressors, which suggests that mothers experience more communication stress (e.g., talking with the child about cancer) with younger children, and which is consistent with literature suggesting that parents may struggle with disclosure about cancer to younger children (Chesler, Paris, & Barbarin, 1986; Clarke, Davies, Jenney, Glaser, & Eiser, 2005). Family income was negatively correlated with mothers' and fathers' daily/role functioning stressors. This finding diverges from earlier findings that income is not related to pediatric parenting stress (e.g., Streisand et al., 2001); however, the current finding is specific to daily/role functioning stressors, which include financial concerns (e.g., paying bills). This finding provides external validity for the items used in the current study and suggests that external factors may have relations to specific domains of perceived stress but not to more general reports of stress.

The findings regarding children's self-reports indicate that daily/role functioning stressors were the most frequently experienced stressors. Furthermore, all informants rated role functioning as more stressful than cancer uncertainty for children. These results suggest that children find their functional impairment (e.g., not being able to do the things they used to do) more stressful than uncertainty about their disease and chances for survival. Although within-informant analyses suggest that parents and children may disagree about what is most stressful for children (i.e., parents rate children's physical effects stressors as more stressful than role functioning stressors) between-informant analyses indicate that there are more similarities between informants, such that parents and children report similar patterns of how these stressors affect the child. Furthermore, although mother, father, and child reports of the child differed in regards to the levels of stressors in each subdomain (e.g., mothers and fathers reported higher levels of physical effect

stressors, and mothers reports more total stressors, than children), their reports of children's stressors were positively correlated, with small to medium effect sizes. These results suggest that, while mothers, fathers and children may disagree about the level of stressors being experienced by the child (with mothers reporting the highest levels), parents and children in the same family generally agree about which types of stressors the child has experienced. Finally, similar to parents' reports of stressors and PTSS, children's cancer-related stressors were positively correlated with children's PTSS. This result is consistent with findings that children with cancer who experience more stressful life experiences have higher levels of PTSS (Currier et al., 2009) and extends previous research by finding associations specifically with cancer-related stressors. Overall, the current results regarding cancer-related stressors and PTSS suggest the importance of monitoring stressors in both parents and children after a child is diagnosed because higher levels of cancer-related stressors may indicate greater risk for PTSS and adjustment difficulties.

The results of the linear multiple regression analyses in which all domains of stressors were included as predictors of PTSS for mothers, fathers, and children offers a relatively cohesive picture of which aspects of cancer-related stressors may be most challenging. It is noteworthy that communication stressors and caregiver stressors were significant and independent predictors of PTSS for both mothers and fathers, whereas daily role functioning stressors were not a predictor for either parent group. Thus, although mothers reported higher levels of communication and caregiver stressors than fathers, these types of stressors were equally important in accounting for PTSS for mothers and fathers. For children, stressors related to uncertainty about cancer was a predictor of children's PTSS based on children's and father's reports. In addition, children's reports of physical effects stressors were also significantly related to PTSS. Although mothers' reports of all three domains of stressors were correlated with children's PTSS, none of the domains were significant predictors in the regression analyses, perhaps due to the relatively high correlations among these domains of stressors. Taken together, these findings suggest targets of interventions to help parents and children cope with specific aspects of cancer-related stressors that are most strongly related to distress.

One limitation of this study is that, although our overall sample size was sufficient to test our hypotheses, we were underpowered to examine group differences related to diagnostic status (e.g., first diagnosis vs. relapse) and diagnosis type (e.g., leukemia vs. brain

tumor). Research suggests that children with relapsed disease and their parents may experience more PTSS than families of children with first diagnoses of cancer (e.g. Jurbergs, Long, Ticonia, & Phipps 2009; Phipps, Jurbergs & Long, 2009). Although the cancer-related stressor items on the RSQ were written to be relevant for families of children with all types of cancer and children with either first diagnoses or relapses, it is likely that disease-related variables affect the experience of certain types of stressors. For example, role functioning stressors may be different for a child who has a limb removed, while cancer uncertainty stressors may be different for children with relapsed disease. Families of children with relapsed disease may also experience additional stressors (e.g., physical and neurocognitive late effects of previous treatments, poorer prognosis) that were not captured with the current measure of cancer-related stressors. Furthermore, the additional stressors related to relapsed disease may explain why relapsed disease can be more traumatic than first diagnoses and may explain the increased risk of PTSS in children with relapsed disease and their parents.

Another limitation is that only children ages 10 years and older provided self-report data, due to the reading level required for the questionnaires. It is possible that the child data cannot be generalized to younger children. The generalizability of the results may also be affected by the limited racial and ethnic diversity in the sample, and the null findings with regards to family income may be due to asking families to report income as a categorical variable, rather than a continuous variable. It should also be noted that the internal consistency of mothers' and fathers' reports of child's stressors was below desirable levels (mean = 0.64), likely due to the small number of items used to calculate reliability for each of the subdomains, which limits the magnitude of correlations possible with other variables. It would be beneficial to include additional items on each subscale on the next revision of the RSQ-Pediatric Cancer Version. An additional limitation of the current study is that the design is cross-sectional, making it impossible to determine the true direction of experiencing stressors and having PTSS. Future studies would benefit from measuring children's and parents' stressors and PTSS at several timepoints during treatment. Only families of children with first diagnoses or relapses that occurred <200 days before completing the study were included here, but treatment for childhood cancer often lasts several years. Follow-up data on these families is necessary to examine changes related to time since first diagnosis or relapse on a larger scale, and to examine the directionality of perceived cancer-related stressors and symptoms of posttraumatic stress.

The strengths of the current study include the relatively large sample, which included children with cancer and their mothers and fathers. This study is one of the first to compare mothers' and fathers' levels of cancer-related stressors in several domains, and the inclusion of a child measure of cancer-related stressors with multiple informants provides some of the first data about children's perceptions of cancer-related stressors. Another strength was that families of children with cancer were recruited relatively soon after the child's first diagnosis or relapse, rather than years later. Most studies about children's adjustment to cancer have examined adjustment years after diagnosis, and before now, little data existed regarding children's reactions and experiences in the first few months after a first diagnosis or relapse.

The results of this study have implications for intervention for families of children with cancer. Specifically, the results suggest that, in addition to providing information and problem-solving techniques to parents, interventions should focus on helping parents cope with the uncontrollable aspects of childhood cancer, such as not being able to help their child feel better and feeling unsure about their child's survival. Coping strategies such as acceptance and cognitive reappraisal may be especially helpful for these families, as they have been shown to relate to better adjustment in children who experience uncontrollable stressors (Jaser et al., 2005, in press). For children, the results of this study indicate that most of the stressors children with cancer experience are related to disruptions in their role functioning, including interference with daily activities such as attending school and interacting with family and friends. These results suggest that interventions for children should include efforts to maintain their involvement in school and social activities as much as possible (Varni, Katz, Colgrove & Dolgin, 1993), while also providing interventions that support secondary coping strategies (e.g., acceptance, reappraisal) to deal with the uncontrollable changes in their role functioning.

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