

# Posttraumatic Stress Disorder (PTSD) and Posttraumatic Stress Symptoms (PTSS) in Families of Adolescent Childhood Cancer Survivors

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**Objective** To describe rates and concordance of posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in adolescent childhood cancer survivors and their mothers and fathers. **Method** Participants were 150 adolescent survivors of childhood cancer, 146 mothers, and 103 fathers who completed the Impact of Events Scale–Revised, the Posttraumatic Stress Disorder Reaction Index, and the PTSD module of the Structured Clinical Interview for the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition. **Results** PTSS are common in families of childhood cancer survivors. Parents reported more symptomatology than former patients. Mothers and fathers had relatively equal rates of current PTSD and levels of PTSS. Nearly 30% of mothers met diagnostic criteria since their child's diagnosis, with 13.7% currently experiencing PTSD. Nearly 20% of families had at least one parent with current PTSD. Ninety-nine percent of the sample had at least one family member reexperiencing symptoms. **Conclusions** Both PTSD and PTSS help in understanding the experience of adolescent cancer survivors and their families. Within families of childhood cancer survivors, it is likely that some member may be experiencing treatable bothersome memories, arousal, or avoidance specific to the cancer experience.

**Key words** pediatric oncology; cancer survivors; adolescents; families; posttraumatic stress symptoms; PTSD.

Most survivors of childhood cancer and their families adjust well after cancer diagnosis and treatment, although a subset experience continuing distress that may interfere with functioning (Kazak, 1994). The posttraumatic stress model is helpful for understanding the long-term psychological sequelae for survivors of childhood cancer and their family members (Stuber, Kazak, Meeske, & Barakat, 1998). Posttraumatic stress acknowledges the life threat inherent in the diagnosis and treatment of childhood cancer while also providing a framework in which ongoing distress such as intrusive thoughts, arousal, and avoidance may be conceptualized and treated. Most research in this field has looked at

posttraumatic stress in individuals, rather than examining the impact on the family system.

Nir (1985) and Pot-Mees (1989) first described posttraumatic stress disorder (PTSD) in childhood cancer survivors, and Stuber and colleagues published the first quantitative pilot report (Stuber, Nader, Yasuda, Pynoos, & Cohen, 1991) laying the groundwork for subsequent field trials for the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) (American Psychiatric Association, 1994). These field trials documented PTSD in childhood cancer survivors and their parents (Alter et al., 1996; Pelcovitz et al., 1996), and the DSM-IV reflects these findings:

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“[E]xperiencing, witnessing or confronting events that involve actual or threatened death or serious injury, or a threat to the physical integrity of self or others” was added as a potentially traumatic event. Subsequent empirical research consistently demonstrates low rates of PTSD in the cancer-survivor population but substantial rates of subclinical posttraumatic stress symptoms (PTSS), particularly for parents and for young adults who had cancer during childhood.

In a study of 320 families of childhood cancer survivors 8–16 years old and their parents, the survivors did not differ from controls on level of PTSS (Kazak et al., 1997). Additionally, the incidence of PTSD was not remarkable; structured psychiatric interviews completed with a subset of participants revealed that 5% of survivors met criteria for a diagnosis of PTSD. These data were substantiated by Butler, Rizzi, and Handwerker (1996), who found that 7% of adolescent cancer survivors qualified for a diagnosis of PTSD, and Erickson and Steiner (2001), who reported that 10% of their sample of survivors 12–35 years old qualified for the diagnosis of PTSD. The most impressive data arose from examining the number of respondents fulfilling PTSD symptom clusters. Kazak et al. (2001) found that 50% of survivors fulfilled criteria for the B symptom (reexperiencing) cluster and 29% fulfilled criteria for the D (arousal) cluster. Additionally, Erickson and Steiner (2001) reported that 78% of their sample met at least one symptom of reexperiencing, arousal, or avoidance at a functionally significant level.

Higher rates of PTSD and PTSS have been found in young adult survivors of childhood cancer than in younger cohorts, suggesting that the traumatic impact of serious childhood illness may be more evident at a later developmental stage. Hobbie et al. (2000) reported that 21.0% of survivors at a long-term follow-up clinic had experienced PTSD since their diagnosis. In a larger and higher-functioning sample of young adult survivors recruited from the community, 15.9% had PTSD since the end of their cancer treatment. Most (75.3%) met criteria of cluster B (reexperiencing), with nearly half (47.3%) meeting criteria of cluster D (arousal) (Rourke, Hobbie, & Kazak, 2002).

Rates of PTSD and PTSS tend to be somewhat higher in parents of adolescent cancer survivors than in the survivors themselves. Kazak et al. (2001) found that 11% of their sample of mothers met criteria for a diagnosis of PTSD based upon clinical interviews. Manne, DuHamel, Gallelli, Sorgen, and Redd (1998) report similar rates. In one study, 6% of mothers of pediatric cancer survivors

had current PTSD. In a subsequent multisite study, 8% of mothers qualified for the diagnosis (Manne et al., 2002). Again, despite these low rates of diagnosis, subclinical PTSS rates were elevated. Manne et al. (1998) found that 20% of their sample of mothers reported partial PTSD, defined as meeting criteria on two of the three symptom clusters. Kazak et al. (2001) found that 95% of mothers fulfilled criteria for reexperiencing and 53% of mothers fulfilled criteria for hyperarousal. Furthermore, data from self-report inventories indicate that mothers and fathers of childhood cancer survivors have levels of PTSS that are elevated relative to control subjects (Kazak et al., 1997).

Given that PTSD is conceptualized at the individual level yet affects multiple members of the family (particularly parents), understanding PTSS from a family systems perspective is important. If individuals with PTSS cluster within families, that is, if symptoms are concordant within families, a relatively smaller overall number of survivor families would be affected. Alternatively, if only one person within a family tends to have PTSS, then more families would be affected. Examining concordance of PTSS among family members is one approach to begin to understand the impact of childhood cancer on families.

The current study examines how PTSD and PTSS cluster within families of survivors of childhood cancer. Prior discrepancies in rates of PTSD and PTSS indicate the importance of assessing both. We used two approaches—well-validated and frequently used questionnaire measures of posttraumatic stress and a structured psychiatric interview. Data from adolescent survivors, mothers, and fathers provide the opportunity to identify and compare symptoms reported by family members with different roles and to describe concordance within families.

## Method

### *Sample Recruitment and Procedure*

Names and contact information of childhood cancer survivors between 11 and 19 years of age and 1–10 years posttreatment were gathered from our hospital's tumor registry. Exclusion criteria were: relapse, severe cognitive impairment, lack of fluency in English, and current residence greater than 150 miles from the hospital. After medical record review, eligible families were sent letters inviting participation. Follow-up phone calls were made to ensure eligibility, describe the research program, answer questions, and secure enrollment. Of 530 families, 437 (82.5%) were reached by phone. Of these, 107 (24.5%) were found to be ineligible (i.e., out of the

limits for age, time since treatment, or geographic range). Of the 330 contacted families whose eligibility was confirmed, 150 (45.5%) enrolled in the study. Those declining participation were asked their reasons for refusal: 45.8% indicated that they did not want to revisit the cancer experience; 61.4% cited time and scheduling difficulties.

Across the 150 families, data were collected from 150 teen survivors, 146 mothers, and 106 fathers. The teen survivors ranged in age from 11.1 to 19.3 years ( $M = 14.7$ ,  $SD = 2.4$ ) and had completed treatment, on average, for 5.3 years ( $SD = 2.9$ ) prior to participation. Roughly half of the teens were female (52.0%). Diagnoses included: leukemias (30.5%), solid tumors (35.1%), lymphomas (21.2%), and other (13.2%). The mean age at diagnosis was 7.9 years ( $SD = 4.3$ ; range = 3 months to 16.4 years). Most of the survivors were white (84.7%) with 9.3% black, 4.7% Hispanic, and 1.3% Asian. This distribution is characteristic of our survivorship clinic population and of national samples of cancer survivors (Robison et al., 2002). Mean parental age was in the early to mid-forties (mothers,  $M = 43.2$ ,  $SD = 5.6$ ; fathers,  $M = 45.7$ ,  $SD = 6.0$ ). Median household income was in the \$50,000 to \$75,000 range, consistent with census tract data for the hospital's catchment area (U.S. Census Bureau, 2002). Educational attainment of the parents completing the study was as follows: 22.6% of mothers and 17.0% of fathers completed grades 9–12; 24.0% of mothers and 17.9% of fathers completed some college and/or vocational school; 48.0% of mothers and 52% of fathers received at least a degree from a 4-year college.

### Procedure

The data presented within this paper are culled from preintervention home visits, collected as part of a randomized clinical trial of an integrated cognitive-behavioral and family therapy intervention, the Surviving Cancer Competently Intervention Program (SCCIP) (Kazak et al., 1999). Research assistants secured written informed consent or assent from all participants and guided the family members through the structured clinical interviews and questionnaires. To promote disclosure, the interviews were conducted privately with individual family members. They were also audiotaped and reviewed to ensure accuracy.

### Measures

#### Impact of Events Scale–Revised (IES-R)

All participants completed the 22-item IES-R (Weiss & Marmar, 1997). The items reflect the DSM-IV cluster

criteria for PTSD: intrusive thoughts (e.g., “I thought about it when I didn’t mean to”), avoidance (“I stayed away from reminders about it”), and hyperarousal (“I was jumpy and easily startled”). Respondents were asked to focus on the child’s cancer experience as the stressful event. Each item was rated for frequency of occurrence in the past 7 days on a weighted 4-point scale (0 = not at all, 1 = rarely, 3 = sometimes, 5 = often). A total score and the three subscale scores were calculated. In our samples, internal consistency for the IES-R total score ranged from .91 to .95.

#### Posttraumatic Stress Disorder Reaction Index (PTSD-RI)

All participants completed the PTSD-RI (Pynoos, Frederick, Nader, & Arroyo, 1987), a 20-item self-report measure with items paralleling the diagnostic criteria for PTSD. Each item was worded with the child’s cancer as the potentially traumatic event and was rated by participants for frequency of occurrence on a 5-point scale. Total scores were calculated and categorized into severity of posttraumatic stress reaction based upon the following scores: 12 to 24 = mild reaction; 25 to 39 = moderate reaction; above 40 = severe reaction. Two reversed coded items were estimated from the adolescent’s other responses to create a total score, as our past research has indicated that these items are difficult for younger participants to comprehend. Across mothers, fathers, and survivors, internal consistency was .89.

#### Structured Clinical Interview for DSM-IV (SCID)

Mothers, fathers, and teen survivors were administered the PTSD section of the nonpatient edition of the SCID (First, Spitzer, Gibbon, & Williams, 1995). This interview includes items assessing each of the DSM-IV diagnostic criteria for PTSD, plus current and lifetime (here defined as *since cancer diagnosis*) PTSD. Interviews were conducted by graduate students and postdoctoral fellows trained in the administration of the SCID. Each interview was audiotaped and rated by a second interviewer to ascertain and ensure accuracy and consistency across raters and time. Kappas for the full-scale PTSD items ranged from .58 for mothers to .71 for fathers and adolescent survivors.

### Results

Three sets of analyses were conducted. First, using descriptive statistics, the rates and prevalence of PTSD and PTSS for individuals in this sample are reported.

**Table I.** Posttraumatic Stress Symptoms in Survivors of Childhood Cancer and Their Mothers and Fathers

	Survivors (N = 150)	Mothers (N = 146)	Fathers (N = 106)
Measure, <i>M</i> ( <i>SD</i> )			
IES-R: intrusion	7.38 (7.55)	12.08 (9.73)	9.88 (8.43)
IES-R: avoidance	10.54 (8.55)	9.40 (9.41)	9.11 (8.58)
IES-R: arousal	5.90 (6.35)	6.73 (7.29)	5.16 (5.72)
IES-R: total	23.63 (19.49)	28.20 (24.49)	24.15 (19.96)
PTSD-RI	15.67 (12.51)	23.89 (12.83)	20.87 (12.77)
Measure, %			
SCID cluster B: reexperiencing	73.3	97.3	86.5
SCID cluster C: avoidance	16.1	34.2	16.3
SCID cluster D: arousal	41.3	63.7	44.2
SCID PTSD since diagnosis	8.0	29.5	11.5
SCID PTSD current	4.7	13.7	9.6

IES-RI = Impact of Events Scale-Revised; PTSD-RI = Posttraumatic Stress Disorder Reaction Index; SCID = Structured Clinical Interview for the *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed.; PTSD = posttraumatic stress disorder. These data represent the full sample.

Second, planned comparisons on rates of PTSD and PTSS between mothers and fathers and parents and survivors are presented. For the PTSD-RI and IES-R total scores, paired *t*-tests were used, nesting participants within their families. Given that the average intercorrelation of family members' PTSS scores in this sample was approximately equal to .2, and using an  $\alpha$  of .05, our smallest paired sample ( $n = 94$ ) afforded a power greater than .95 to find a medium size difference (Cohen, 1988). To examine similarities and differences between family members on rates of PTSD on the SCID, we conducted a series of McNemar analyses with continuity correction (Siegel & Castellan, 1988). Finally, the concordance of post-traumatic stress symptomatology of family members within families and the total number of families with PTSD and PTSS in at least one family member have been calculated. Chi-square analyses were used to determine whether family members shared PTSS at a rate greater than chance. In these analyses, at  $\alpha = .05$ , our sample sizes afforded us power greater than .85 to find a medium size effect (Cohen, 1988).

### **Rates and Prevalence of PTSD and PTSS**

Scores on the IES-R and the PTSD-RI indicate substantial endorsement of PTSS for all members of the family (see Table I). Moderate to severe levels of PTSS were seen on

the PTSD-RI for mothers (43.7%), fathers (35.3%), and teen survivors (17.6%).

Current PTSD diagnosis was noteworthy, with 13.7% of mothers and 9.6% of fathers qualifying for the diagnosis based on the SCID. Previously reported rates of current PTSD for adults exposed to violent crimes or tragic deaths fall in the 7% to 11% range (Breslau, 2001). More strikingly, 29.5% of mothers had met criteria for a PTSD diagnosis at some point since their child's diagnosis with cancer; 11.5% of fathers fulfilled the same criteria. Data from the National Comorbidity Survey (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995) suggest that the lifetime prevalence rates of PTSD, given a history of at least one traumatic event, are 20.4% for females and 8.1% for males. Rates for survivors were 4.7% for current PTSD and 8.0% for PTSD since cancer diagnosis. Although well-developed norms are currently unavailable for PTSD in children, these rates are similar to the 5.4% of children who qualified for a diagnosis of PTSD 3 months after Hurricane Hugo (Shannon, Lonigan, Finch, & Taylor, 1994).

Responses to the SCID revealed that the majority of survivors of childhood cancer and their mothers and fathers met criteria for PTSD diagnostic criteria cluster B (reexperiencing). A total of 63.7% of mothers, 44.2% of fathers, and 41.3% of survivors endorsed enough symptoms of arousal to meet criteria for PTSD cluster D. It was less common for family members to fulfill criteria for cluster C (avoidance), yet more than one third of mothers did meet the criteria, reporting three or more avoidance symptoms.

### **Comparing Family Members on Rates of PTSD and PTSS**

Mothers and fathers had relatively equal rates of current PTSD and levels of PTSS (see Table II), though mothers were more likely than fathers to endorse a history of PTSD at some time since their child's cancer diagnosis,  $\chi^2(1, N = 100) = 8.26, p < .005$ . Parents' PTSS scores tended to be higher than those of their children: mothers vs. survivors, PTSD-RI,  $t(135) = 5.59, p < .001$ ; IES-R,  $t(136) = 2.26, p < .03$ ; fathers vs. survivors, PTSD-RI,  $t(95) = 4.03, p < .001$ ; IES-R,  $t(94) = 1.27, p = .21$ . SCID data revealed that mothers' rates of PTSD were significantly higher than those in their children: current PTSD,  $\chi^2(1, N = 146) = 7.35, p = .01$ ; PTSD since diagnosis,  $\chi^2(1, N = 146) = 20.00, p < .005$ . Fathers' rates tended in the same direction: current PTSD,  $\chi^2(1, N = 103) = 3.77, p = .09$ ; PTSD since diagnosis,  $\chi^2(1, N = 103) = 3.77, p = .09$ .

**Table II.** Comparisons Between Family Members Within Families on PTSS Scores and Rates of PTSD

	Mothers <i>M (SD), %</i>	Fathers <i>M (SD), %</i>	<i>N</i>	Mothers <i>M (SD), %</i>	Survivors <i>M (SD), %</i>	<i>N</i>	Fathers <i>M (SD), %</i>	Survivors <i>M (SD), %</i>	<i>N</i>
PTSD-RI	22.9 (12.2)	20.5 (12.6)	97	23.9 (13.0)	15.8 (12.7)***	136	20.8 (12.7)	14.4 (11.3)***	96
IES-R	27.8 (23.9)	24.1 (19.6)	94	28.9 (24.6)	23.4 (19.7)**	137	23.4 (19.7)	20.4 (16.9)	95
Current PTSD	12.0	10.0	100	13.7	4.8**	146	9.7	2.9*	103
PTSD since diagnosis	29.0	12.0***	100	29.5	8.2***	146	11.7	4.9%*	103

PTSS = posttraumatic stress symptoms; PTSD = posttraumatic stress disorder; PTSD-RI = Posttraumatic Stress Disorder Reaction Index; IES-R = Impact of Events Scale-Revised. \*  $p < .10$ ; \*\*  $p < .05$ ; \*\*\*  $p < .005$ . Values in this table are slightly different from those of Table I, as the use of paired analyses curtailed the sample.

**Concordance of PTSD Among Family Members**

In general, concordance among survivors, mothers, and fathers for PTSD current and since diagnosis was infrequent, ranging from 0% to 5 % (Table III). However, one third of two-parent families had both parents fulfill criteria for the arousal symptom cluster and 84% of families had both parents endorse symptoms of reexperiencing. Only arousal symptoms were shared at a rate greater than that expected by chance,  $\chi^2(1, N = 101) = 7.7, p < .006$ ; odds ratio = 3.47 (confidence interval = 1.4 to 8.5). It was uncommon for both parents to fulfill criteria for avoidance. It was also uncharacteristic for teenage survivors to share symptomatology with their parents. Only 2 families had both a parent and the teen survivor currently experiencing PTSD and only 6 families had both a parent and the teen survivor report PTSD at some time since the cancer diagnosis. Although only 15 (10%) parents and survivors shared symptoms of avoidance, this had a level of concordance that exceeded chance,  $\chi^2(1, N = 149) = 5.36, p < .02$ . This effect was driven by concordance between mothers and survivors,  $\chi^2(1, N = 146) = 5.88, p < .02$ ; odds ratio = 2.9 (confidence interval = 1.17 to 7.22).

With elevated rates of occurrence and low rates of concordance of PTSD across family members, the overall number of families in which PTSD was seen in at least one member since diagnosis was noteworthy, ranging from 34% to 38% (Table IV). Nearly 20% of the families had at least one parent qualify for a current diagnosis of PTSD and over one third had at least one parent qualify at some time since the cancer diagnosis. At least one parent met cluster criteria for reexperiencing in 98.7% of families, for arousal in 69.1% of families, and for avoidance in 40.9% of families.

When including survivors, 37.6% of the families had at least one member with PTSD at some time since the cancer diagnosis, and 22.1% currently had a family member who qualified for a diagnosis of PTSD. The sample found 99.3% of families with at least one member who met cluster B (reexperiencing). Over 80% had at

least one member who had two or more symptoms of arousal, and nearly half had at least one member with three or more symptoms of avoidance.

**Discussion**

The diagnosis of childhood cancer and the demands of treatment are unquestionably among the most distressing of experiences for families. The conceptualization of PTSD and PTSS provide a framework for understanding the ongoing psychological sequelae of survival and offer opportunities for intervention and prevention. The data in this study provide additional support for the relevance of the posttraumatic stress framework in serious childhood illness and highlight how trauma responses affect families more broadly. Posttraumatic distress is common across families but tends to affect particularly one member, rather than multiple people, within a single family.

The substantial rates of endorsement of PTSS in this sample of adolescent survivors and their parents are not surprising. Reexperiencing, avoidance, and arousal are all understandable reactions to particular events during treatment (e.g., knowing that your child could die, invasive medical procedures, pain, emergency department and intensive care admissions, knowing other children who died). Even when cancer treatment has concluded, ongoing medical surveillance is essential, given known and emerging late effects of treatment and the risk for second malignancies (Friedman & Meadows, 2002). Exposure to potentially traumatic events therefore continues.

These data suggest that both PTSD and PTSS are important in understanding the psychological sequelae of childhood cancer survivors and their families. Particularly for mothers of survivors, the likelihood of PTSD at some point since the child’s illness was 30% in this sample. Perhaps reflecting gender patterns, differences in exposure, or family patterns, fathers did not report such elevated levels of PTSD. However, a focus on

**Table III.** Concordance, *n* (%), of PTSD for Mothers, Fathers, and Adolescent Cancer Survivors Within Families

	Mother and Father ( <i>N</i> = 100)	One Parent and Survivor ( <i>N</i> = 49)	Mother and Survivor ( <i>N</i> = 146)	Father and Survivor ( <i>N</i> = 103)
SCID cluster B:				
reexperiencing	84 (84)	109 (73)	105 (72)	64 (62)
SCID cluster C:				
avoidance	6 (6)	15 (10)	13 (9)	3 (3)
SCID				
cluster D: arousal	36 (36)	44 (30)	38 (26)	18 (17)
SCID PTSD				
since diagnosis	5 (5)	6 (4)	5 (3)	2 (2)
SCID PTSD				
current	2 (2)	2 (1)	2 (1)	0 (0)

PTSD = posttraumatic stress disorder; SCID = Structured Clinical Interview for the *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed.

diagnosing PTSD would limit understanding of the full traumatic impact of cancer on families given the prevalence of subsyndromal symptoms of reexperiencing, avoidance, and arousal.

This study provides data on fathers and draws particular attention to the relevance of posttraumatic stress for multiple family members. Both mothers and fathers remember many cancer-related events, recall their psychological reactions vividly, and are likely to have a clear and somber understanding of the circumstances (including the potential for the child to die), perhaps more so than their children. Fathers, who are sometimes seen as more peripherally involved in the care of their child, were similar to mothers in current PTSS, showing that the experience has long-lasting effects for them. Although fathers tend to participate in research studies like ours at lower rates than mothers, they were active participants and their data are important. Home-based data collection procedures (such as those in this study) may facilitate the involvement of fathers and other family members. We view the study results as strongly supportive of the recommendations of Seagull (2000) regarding the importance of fathers in pediatric psychology research and practice. Additionally, the potentially traumatic effect of childhood cancer is seen in adolescent siblings, reported in another paper originating from this project (Alderfer, Labay, & Kazak, 2003).

The finding that PTSS tend to be reported by only one member of a given family is new. This suggests the importance of evaluating all family members for PTSS. Indeed, if only mothers had been researched, 40% (8 of 20) of the two-parent families with a parent with PTSD

**Table IV.** Posttraumatic Stress Disorder (PTSD) in Families, *n* (%)

	Mother or Father ( <i>N</i> = 149)	Parent or Teen Survivor ( <i>N</i> = 149)
SCID B: reexperiencing	147 (98.7)	148 (99.3)
SCID C: avoidance	61 (40.9)	70 (47.3)
SCID D: arousal	103 (69.1)	121 (80.7)
SCID PTSD since diagnosis	50 (33.6)	56 (37.6)
SCID PTSD current	28 (18.8)	33 (22.1)

SCID = Structured Clinical Interview for the *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed.

would have been overlooked. In working with families of children with cancer, it is important to assess PTSD and PTSS across members of the family, as the patient or parent present may not be the symptomatic person in the family. It seems from our data that one person tends to hold the symptoms for the family and that PTSD and PTSS are not “contagious.” Speculatively, it might be that differences between family members in PTSS may reflect differences in exposure, preexisting psychological resilience or vulnerability, and/or cancer-related beliefs. Neither the impact on other family members of the PTSD/PTSS of one member nor the differential effect of parental or child symptoms on individual and family functioning is known. However, PTSS in one family member may affect parenting style, parent-child interactions, and ongoing attention to medical concerns for the survivor in ways that have yet to be explored.

These data provide additional documentation of the relevance of PTSS in pediatric health care more broadly. PTSS have been documented in pediatric liver transplantation (Walker, Harris, Baker, Kelly, & Houghton, 1999). Avoidance related to PTSS has also been associated with nonadherence to pediatric liver transplantation regimens (Shemesh et al., 2000). A series of studies on child PTSS supports the importance of the concept in pediatric injury (Aaron, Zaglul, & Emery, 1999; Fein et al., 2002; Stallard, Velleman, & Baldwin, 1998) and subsequent to traumatic brain injury (Levi, Drotar, Yeates, & Taylor, 1999; Max et al., 1998). Expanding the appreciation of PTSD and PTSS responses at the family level for these groups may facilitate a broader understanding of the morbidity of pediatric illness and help to identify interventions to reduce long-term distress.

The participants in this study were part of an intervention study and therefore could reflect a biased sample. However, rates of PTSS on the PTSD-RI for survivors, mothers, and fathers in this sample are similar to those in a previous (nonintervention) study of cancer

survivors (Kazak et al., 1997), indicating that this sample was not more distressed than a nonintervention sample. If more symptomatic families agreed to participate in studies, compared with those who are less affected by psychological sequelae, this would result in an overestimation of PTSD and PTSS. However, refusal to participate in studies is linked closely to explicit concerns about not wanting to revisit the cancer experience (Streisand, Rourke, Katz, Stein, & Kazak, 1999). It is therefore also possible that this study underestimates the prevalence of PTSD and PTSS because the most avoidant families do not participate.

Methodologically, reliance on retrospective report of symptoms since diagnosis is a limitation. With respect to appreciating the impact at the family level, the data would be enriched by consideration of how symptoms are expressed, recognized, and addressed within the family, and over time. It is not known, for example, the extent to which exposure to traumatic events during treatment (e.g., a parent in a direct caregiver role) is predictive of PTSS, or what components of family structure and process might contribute to PTSS. Although there are data that illustrate commonalities and differences between mothers of survivors and young adult survivors in terms of what contributes to PTSS (Kazak et al., 2001), the interpersonal impact of PTSD or PTSS on close family members is not known. In the cancer survivor literature, symptoms that do not meet diagnostic criteria for PTSD are generally accepted as important and clinically meaningful. However, further exploration of the implications of subdiagnostic PTSS for intervention structure and delivery are necessary and important.

These data have several implications with respect to intervention. First, parents of children who have survived cancer may experience PTSD and, if so, should be considered for treatment. Second, it is likely that any member of a family with a childhood cancer survivor may be experiencing treatable bothersome intrusive memories, arousal, or avoidance specific to the cancer treatment for themselves or another family member. We have reported on a pilot study that indicates that a brief, integrated cognitive-behavioral/family therapy intervention may be effective in reducing PTSS and enhancing family functioning (Kazak et al., 1999). Within this treatment model, ongoing cancer-related adversities (e.g., symptoms of intrusion, avoidance) are identified, with the goal of reframing beliefs about the experience to achieve a more adaptive outcome. Importantly, this process is conducted within the context of the family, with an emphasis on using family

communication about PTSS to help family members recognize and respond in ways that reduce distress and promote adaptive development for individuals and the family. Given the presence of the diagnosis of PTSS in the majority of families in this sample and its distribution across family member roles, family intervention models seem well suited for this population (regardless of which family member[s] may be affected). By intervening contextually, the strengths of the family can be identified to promote both understanding of the legacy of cancer and the growth of the family system.

Even one or two symptoms of posttraumatic stress may have repercussions for this medically vulnerable population. If a long-term survivor (or parent who oversees medical care) has reexperiencing or arousal symptoms when reminded of cancer treatment, that distress may impede the ability to understand medical guidelines or to relay important information to the health care team. Individuals with PTSS may refuse medical care to avoid the distress that is triggered by exposure to medical treatments, leading to potentially suboptimal medical care for survivors who are at risk for long-term medical complications. Alternatively, hypervigilance may be another response to PTSS and could contribute to higher health care utilization and cost.

Although some of the exposure to traumatic events that occurs during treatment is inevitable and actually likely to increase with more intensive cancer treatment protocols, there are implications for prevention. Interventions that decrease the traumatic impact of treatment may help to reduce the development of PTSD in childhood cancer survivors and other groups. These include effective strategies for child pain and distress, attention to the impact of treatment-related events on all members of the family (e.g., admissions to the intensive care unit, death of a patient known to the family), and helping families to anticipate the likelihood of PTSS after treatment ends.

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