Parental Distress During Pediatric Leukemia and Posttraumatic Stress Symptoms (PTSS) After Treatment Ends

Mary Best, PhD, *Randi Streisand,* PhD, *Lori Catania,* MEd, and *Anne E. Kazak,* PhD
The Children's Hospital of Philadelphia

Objective: To evaluate prospectively the association between parental anxiety during treatment for childhood leukemia and posttraumatic stress symptoms (PTSS) after treatment ends. A secondary goal is to explore concurrent variables associated with parental avoidance after treatment ends.
Methods: This is a longitudinal follow-up study of 113 parents of children treated for leukemia who previously participated in a study of procedural distress during treatment. Data included parental self-report questionnaires completed during treatment *and* after treatment.
Results: Using hierarchical multiple regression, we found anxiety during treatment to be a significant predictor of later PTSS for mothers, but not fathers. Anxiety, self-efficacy, posttraumatic growth and length of time since treatment ended were associated with parental avoidance.
Conclusions: Highly anxious parents are at risk for PTSS and may benefit from approaches that decrease anxiety during treatment and afterward. Enhancing self-efficacy related to follow-up care and identifying positive aspects of the traumatic experiences are suggested as treatment approaches for families after cancer treatment.

Key words: childhood cancer; posttraumatic stress; parental adjustment; self-efficacy.

Few would argue that parents experience intense and extreme distress when their children are being treated for cancer. Parents are present during upsetting procedures or treatments and struggle with their own anxiety and the disruption to their families. This psychological trauma that parents experience may lead to subsequent posttraumatic stress. That is, childhood cancer is life-threatening and elicits feelings of helplessness in parents. Subse-

quently, mothers and fathers report posttraumatic stress symptoms (PTSS), including intrusive memories, physiological arousal, and avoidance (Barakat et al., 1997; Butler, Rizzi, & Handwerger, 1996; Manne, Du Hamel, Gallelli, Sorgen, & Redd, 1998; Pelcovitz et al., 1996).

For most parents, symptoms are not sufficient to warrant a diagnosis of posttraumatic stress disorder (PTSD; American Psychiatric Association, 1994). In our earlier studies, we found that only 5% of survivors and 10% of their mothers met full diagnostic criteria. However, meeting criteria for PTSD symptom clusters was common. For example, 95.3% of mothers met the criteria for reexperiencing, 28.1%

for avoidance, and 53.1% for symptoms of arousal (Kazak et al., under review).

In the benchmark longitudinal study of psychological adjustment in childhood cancer, Kupst and colleagues verified previously anecdotal evidence; the families that had difficulty coping at diagnosis continued to be the least successful at coping 10 years later (Kupst et al., 1995; Kupst & Schulman, 1988). In a sample of 29 families, we also found that parenting stress and quality of life during treatment were significantly correlated with later PTSS (Kazak & Barakat, 1997). Additional data clarifying the relationship between distress during treatment and functioning after treatment may facilitate the prediction and prevention of PTSS.

Our previous research showed that subjective measures of coping were better predictors of parental PTSS than objective measures. In a path analytic model, trait anxiety was the best direct and indirect predictor of posttreatment PTSS (Kazak, Stuber, et al., 1998). Other subjective measures, including beliefs about treatment and perceived social support, were also significant predictors of PTSS. More objective measures (e.g., length of time off treatment) were not predictors of PTSS. These studies also showed that memories about specific procedures such as lumbar punctures and bone marrow aspirates remain bothersome over the long term for both parents and children (Kazak, Penati, et al., 1996). Previous studies have shown that alleviation of children's stress during the procedures does not always decrease PTSS in parents who often witness the procedures. Therefore, although the short-term efficacy of psychological interventions for reducing pain and distress in children is clear (Powers, 1999), the long-term distress of parents related to these procedures is less well understood.

Even though distressing memories may be the most prevalent manifestation of PTSS, the symptom of avoidance is also potentially critical both to survivors' long-term health and to health care providers delivering care. The extent to which parents think about avoiding, or actually avoid, reminders of cancer could have implications for adhering to follow-up recommendations, including awareness of symptoms that may indicate medical sequelae or second malignancies. Studies of the longitudinal course of PTSD have found that in some trauma groups avoidance symptoms actually increase over time (McFarlane, 2000). Preliminary studies with parents suggest that chronic avoidance symptoms are present in this population (Kazak et. al., under review).

Several factors may predict posttraumatic stress symptoms, including one's general level of distress (anxiety), parental resilience (beliefs and attributions about the experience), and social support. For example, studies have shown that self-efficacy, or an individual's belief in his or her own ability to cope with adversity, may be an important predictor of long-term distress associated with severe stress (Bandura, 1997). Similarly, beliefs that promote a balanced view of adversity, by including optimistic thoughts and perceived benefits of adversity, are associated with positive adaptation to illness (McMillen, Smith, & Fisher, 1997; Tedeshi & Calhoun, 1996). Last, in other studies of parents, perceived social support has been related to the level of PTSS (Kazak & Barakat, 1997).

The main objective in this study is to predict PTSS after treatment ends in mothers and fathers of survivors of childhood leukemia, using data from the same families collected approximately 4 years previously. The hypotheses are derived from our existing models (Kazak, Stuber, et al., 1998). That is, we hypothesize that parental anxiety and distress during procedures will be predictive of later PTSS. Consistent with our previous work, objective characteristics (length of time off treatment) will not be predictive of PTSS.

An ancillary objective is to explore variables related to parental anxiety and to a parental behavioral outcome associated with PTSS, avoidance. Our predictive model measured current levels of distress and resilience. Based on previous work, we hypothesized that high levels of distress would be positively related to avoidance, whereas resilience factors, such as high self- efficacy, perceived benefit, and social support, would be negatively associated with avoidance.

Method

Research Design

This is a follow-up study of families who participated in a prospective randomized clinical intervention trial for procedural pain and distress during spinal taps and lumbar punctures in pediatric leukemia, the Analgesia Protocol for Procedures in Oncology (APPO) (Kazak, Penati, Boyer, et al., 1996; Kazak, Penati, et al. 1998). Patients with leukemia were enrolled in APPO from 1991 to 1995. All surviving patients off treatment and free of current relapse from the APPO study and their families were

eligible for this (follow-up) study. Our interest was to predict current symptoms of posttraumatic stress off treatment (OFFTX) using data collected when the patients were in treatment, in the APPO study (INTX). We created a new measure of anxiety and avoidance of medical situations that parents still face with their children and a measure of parental self-efficacy in a variety of medical situations that they face with their children, such as follow-up appointments and routine physical examinations. We also investigated predictors related to anxiety and beliefs about treatment and its effects.

Participants

Participants were identified from a list of 144 families who completed the APPO study. Five children were deceased and one had a recurrence of cancer, leaving 138 families who were sent letters explaining the follow-up study and inviting participation. Despite multiple efforts to confirm addresses and phone numbers, using hospital records, and phone and Internet directories, we were unable to confirm contact with 47 families, who are therefore considered lost to follow-up. During phone calls made as part of the recruitment protocol, 24 families declined to participate in the study, with most frequent reasons for refusals (not wanting to revisit the cancer experience, lack of time) consistent with those in our other studies on PTSS (Streisand, Rourke, Katz, Stein, & Kazak, 1999). The final sample included 67 families (mothers = 66, fathers = 47), reflecting two families in which a father but not a mother completed the study, with a participation rate of 67/91, or 76%.

The mean age of the participants when they were in treatment (INTX) was 7.30 years (SD = 4.61). Off treatment (OFFTX) survivors were an average of 13.30 years (SD = 4.61). The current ages ranged from 7 to 24, with a median age of 13. Distributions by gender were INTX: 53% male, 47% female and OFFTX: 61% male, 39% female. Ninety-one percent were survivors of acute lymphocytic leukemia (ALL); the remaining 9% were diagnosed with acute mylogenic leukemia (AML). Ethnic background of the families was 88% Caucasian, 6% Asian, 3% African American, and 3% Hispanic. The average number of years that families had been off treatment was 3.70 years; the median was 3.40 years, with a range of 7 months to 8.60 years. The majority (74%) of the sample reported total annual household income levels between $25,000 and $100,000, with 85% educated beyond high school.

There were no significant differences between participants and nonparticipants in child's age at diagnosis, child's age during the APPO study, or on the dependent variables from APPO.

Procedure

Packets of self-report questionnaires were mailed to parents who agreed to participate in the follow-up study. The study was approved by the institutional review board and consent forms were sent. The participation of two parents (when present) was encouraged. Phone calls were made to track progress of the return of questionnaires. Data on patients while they were in treatment were retrieved from a database developed for the APPO study.

Measures

Measures are organized by administration during leukemia treatment (INTX) and those from the longitudinal follow-up (OFFTX). Both mothers and fathers completed the measures.

Measures Administered During APPO Study, 1992–1995 (INTX)
Langner Symptom Checklist (Langner, 1962). This is a 22-item scale that assesses symptoms of anxiety and depression in adults and an established measure of general mental health. The Langner assesses psychological demoralization rather than clinical and has been shown to be predictive of future help-seeking disorder (Dohrenwend, Shrout, Egri, & Mendelson, 1980). In this study, we use it as a proxy for anxiety. Conbach's alphas were strong for the total scale (.82–.90).

Perception of Procedures Questionnaire (PPQ; Kazak, Penati, Waibel, & Blackall, 1996). This is a 19-item 7-point Likert-type scale consisting of five subscales. The scales used for this study were Parental Distress, Child's Distress-During, Child's Distress-Before. Cronbach's alphas were strong for the total scale (.86–.89) and for the subscales (.82–.95).

Measures Administered at Follow-Up, 1998–1999 (OFFTX)
State-Trait Anxiety Inventory (STAI, Speilberger, 1983). The 20-item STATE (current) scale of the STAI was used. The STAI has high internal consistency and adequate construct and discriminative validity across diverse samples (Novy, Nelson, Goodwin, & Rowzee, 1993). Higher scores indicate higher levels of anxiety.

Social Network Reciprocity and Dimensionality Assessment Tool (SRNDAT; Kazak, 1987). This is a self-administered social network assessment. We used network size, determined from respondent report of number of helpful persons.

Impact of Event Scale-Revised (IES-R; Weiss & Marmar, 1997). The IES-R is a leading assessment instrument for PTSD symptoms in response to a specific traumatic event. It consists of 22 items rated on a 4-point scale for frequency of occurrence during the previous week and has three subscales, Intrusion, Avoidance, and Hyperarousal. Only the total IES-R score was used for this study. The IES-R manual reports high internal consistency (.80–.91), with higher scores indicating more symptoms.

Post Traumatic Growth Inventory (Tedeschi & Calhoun, 1996; PTGI). The PTGI measures how parents feel that they have changed as a result of their child's illness and focuses on positive outcomes. It is a 21-item 6-point Likert self-report inventory with five subscales. The subscales have good internal consistency (range = .67–.85). Because the subscales contained few items and were highly intercorrelated, we used the total score.

Pediatric Anxiety and Avoidance Scale (PAAS). This scale, which has 15 items, was developed for this study to assess anxiety and avoidance symptoms related to medical care in parents of childhood cancer survivors. PAAS items were derived from the Impact of Traumatic Stressors Interview Schedule (ITSIS; Kazak, Stuber, Barakat, & Meeske, 1996). They include situations frequently endorsed as distressing (e.g., follow-up appointments, seeing sick children) and examples of situations that were avoided (e.g., thinking about the child's medical future, talking with others about the child's illness and treatment). Parents rate the degree of anxiety, on a 5-point scale, that they encounter in each situation and then indicate whether or not they avoid or have thought about avoiding each item (yes/no responses). If an item is endorsed, parents indicate on a 5-point scale the number of times they have avoided. Sample Cronbach's alphas for the total and subscale scores were acceptable (α = .72–.74). Because the two subscales were correlated (r = .47), we used the total score derived from adding the subscales.

Children's Hospital of Philadelphia Self-Efficacy Scale (CHOP-SES). This 46-item scale was developed to assess parental perceptions of self-efficacy specific to medical care. Parents rated, on a 5-point scale, their degree of confidence in five categories: (1) fol-

low-up (15 items, e.g., coming back for oncology follow-up appointments); (2) routine physical (10 items, e.g., routine check-ups); (3) dental (10 items, e.g., going to the dentist); (4) emergency (10 items, e.g., handling emergency health demands); and (5) coping (12 items, how confident parents feel using strategies to help their child when upset in a medical situation). Sample Cronbach's alphas were acceptable (α = .77–.79). Because the five subscales were highly intercorrelated (r = .76–.90), we generated the sum of subscales scores for a total self-efficacy score, which was used for the regression analyses. Initial analyses of the subscales showed that they were significantly negatively skewed. Therefore, we used a loglinear transformation of the variable for subsequent analyses.

Results

Descriptive data on the new scales developed for this study (PAAS, CHOP-SES) are summarized briefly. There were no significant differences between the treatment groups for the follow-up variables with regard to the original APPO study. Therefore, the original study group is not treated as a variable in these analyses. Hierarchical multiple regressions were performed for the predictions of PTSS from INTX to OFFTX and for the hypothesis testing associations at OFFTX. All analyses were conducted for mothers and fathers separately. Variables were put into the regression in a stepwise fashion. The order of entry was based on previous models of PTSS (Kazak, Stuber, et al., 1998). In each instance, anxiety was entered as a single predictor, based on prior findings related to parental anxiety and PTSS. A second set of predictors included individual beliefs and attributions associated with cancer treatment (distress associated with treatment, posttraumatic growth, self-efficacy, perceived social support). The third predictor was length of time since treatment ended.

To test predictions of PTSS at OFFTX from data collected INTX, we used the IES-R as a measure of PTSS. The Langner Symptom Checklist and PPQ were used as measures of anxiety and beliefs, respectively. As the PPQ had multiple subscales, we first computed Pearson-product correlations and entered subscales most highly correlated with the criterion into regression equations. For all regression analyses, we entered variables in three steps, removing variables with p > .10 and retaining those with

Table I. Descriptive Statistics for the Pediatric Anxiety and Avoidance Scale (PAAS) and the Children's Hospital of Philadelphia Self-Efficacy Scale (CHOP-SES)

	Mothers (*N* = 62)		Fathers (*N* = 39)	
Scale	M ± SD	Range	M ± SD	Range
PAAS				
Anxiety	34.12 ± 9.10	16–56	32.11 ± 10.60	15–59
Avoidance	13.59 ± 10.71	0–45	11.38 ± 10.78	0–38
Total score	47.41 ± 17.21	16–84	43.26 ± 19.97	15–93
CHOP-SES				
Follow-up	64.45 ± 9.12	34–75	62.58 ± 7.63	46–74
Routine				
physical	45.08 ± 6.22	27–50	44.64 ± 4.70	35–50
Dental	45.88 ± 5.86	29–50	46.05 ± 4.96	33–50
Emergency	47.61 ± 7.92	24–55	48.14 ± 5.51	33–55
Coping	52.70 ± 7.90	28–60	52.00 ± 6.50	35–60
Total score	203.88 ± 25.89	117–230	200.72 ± 20.56	78–151

PAAS: Pediatric Anxiety and Avoidance Scale; CHOP-SES: Children's Hospital of Philadelphia Self-Efficacy Scale; PAAS and CHOP-SES total scores used in all analyses.

$p < .10$ before adding variables from our next step. We followed this same decision rule for retaining or eliminating variables at each step. The exploratory analyses followed a similar progression but utilized data only at OFFTX.

PAAS and CHOP-SES

Means, standard deviations, and ranges for the PAAS and CHOP-SES total and subscale scores are presented in Table I. Examination of scores on the PAAS indicated variability (by medical situation) in the amount of anxiety reported. Mothers (95%) and fathers (98%) positively endorsed the item "thinking about my child's medical future" as a source of mild to severe anxiety. Similarly, elevated anxiety was reported with respect to the item "seeing other children who look sick" (mothers, 87 %; fathers, 82%). Scores on avoidance on the PAAS were generally low. However, a small subset (mothers, 4%; fathers 3%) reported having avoided making follow-up appointments for their child. Similarly, 3% of mothers and fathers endorsed the item indicating that they avoided going to the appointments.

Overall, scores were high for both mothers and fathers on the CHOP-SES, indicating that they feel self-efficacious regarding health care generally. Mothers reported the highest degree of self-efficacy (92%) when taking their child to the dentist, and the least when taking their child to follow-up visits (85%). Fathers reported the highest self-efficacy

Table II. Hierarchical Regression Predicting Maternal and Paternal PTSS (INTX to OFFTX)

Step and Variables	ΔR²	F	Final β
Mothers (*N* = 66)			
Step 1: Anxiety	.20	12.33****	
Langner[a]			.46****
Step 2: Beliefs about cancer treatment	.08	8.91***	
Parental distress (PPQ)[a]			.23*
Step 3: Treatment variable	.17	9.00***	
Time[a]			−.36**
Fathers (*N* = 47)			
Step 1: Anxiety	−.26	.42	
Langner[a]			−.14
Step 2: Beliefs about cancer treatment	.51	3.61*	
PPQ/distress before treatment[a]			.23
PPQ/distress during treatment[a]			.47*
Step 3: Treatment variable	−.34	.39	
Time[a]			.14

Each model used three conceptual steps (Anxiety, Beliefs about cancer treatment, Treatment variable); under each step are the one or more variables used to measure the concept along with their individual betas. Langner: Langner Symptom Checklist; PPQ: Perception of Procedures Questionaire, Time: Time off Treatment in Months.
[a]These variables are the only ones used in the best regression model.
*$p < .10$.
**$p < .05$.
***$p < .01$.
****$p < .001$.

when taking their child to the emergency room (96%) and the least when taking their child to follow-up appointments (84%).

With respect to perceived self-efficacy for coping with medical late effects and the possibility of relapse, mothers and fathers reported lower self-efficacy. For example, 13% of mothers and 16% of fathers reported that they felt very little or no self-efficacy regarding their ability to cope with the medical late effects of cancer. Parents felt even less efficacious about their ability to deal with relapse; 53% of mothers and 56% of fathers reported very little or no self-efficacy if they had to face their child's relapse.

INTX Variables in Predicting PTSS (OFFTX)
Mothers

The final overall model was significant, $F(3, 26) = 8.99$, $p < .01$, and accounted for 45% of the variance in symptoms of posttraumatic stress (Table II). Anxiety at INTX was the most significant individual predictor of PTSS at OFFTX ($p < .001$). Beliefs about treatment, as measured by the mother's level of distress on the PPQ, added significantly to anxiety

in the prediction of subsequent PTSS ($p < .01$), yet was not a significant individual contributor to the model. The treatment-related variable, time off of treatment, further added to the variance accounted for in the IES-R total score ($p < .01$) and was also a significant individual contributor ($p < .05$).

Fathers

The final model (anxiety, distress during procedures, child distress during procedures, time off treatment) was significant and accounted for 25% of the variance, $F(2, 14) = 3.61$ $p = .05$ (Table II). However, no variable by itself was significantly associated with PTSS.

Anxiety and Avoidance at OFFTX
Mothers

The mothers' regression model of self-efficacy, posttraumatic growth, and duration of treatment was significant and accounted for 53% of the variance in anxiety and avoidance, as measured by the PAAS, $F(3, 38) = 16.3$, $p < .001$ (Table III). Trait anxiety (STAI; $p < .01$), self-efficacy (CHOP-SES; $p < .001$), and posttraumatic growth ($p < .01$) were all significant individual predictors.

Duration of the child's treatment was added in the last step. Although there was only a trend toward its significance as an individual predictor, it did significantly contribute toward the variance in the PAAS score when entered with self-efficacy and growth related to experiencing a traumatic event ($p < .001$).

Fathers

The fathers' model of anxiety, posttraumatic growth, social support, and duration of treatment was significant, $F = 14.5$, $p < .0001$, and accounted for 73% of the variance in the PAAS ($p < .001$) (Table III). Anxiety was significantly associated with paternal anxiety and avoidance on the PAAS ($p < .05$). Self-efficacy (CHOP-SES), growth related to the experience of a traumatic event, and social support were added on the second step, making a significant contribution to the variance in PAAS ($p < .01$). Medically related self-efficacy was not a significant individual predictor for fathers. However, both the growth and social support scores were significant individual predictors of the PAAS total score ($p < .01$, $p < .05$, respectively). Duration of treatment was included in the last step, further increased the variance accounted for in PAAS scores, ($p < .001$),

Table III. Correlates of Maternal and Paternal Anxiety and Avoidance at OFFTX

Step and Variables	ΔR^2	F	Final β
Mothers ($N = 66$)			
Step 1: Anxiety	.20	16.04***	
STAI			.46***
Step 2: Beliefs about cancer treatment	.25	15.86****	
CHOP-Self-Efficacy Scale total score[a]			−.67****
PTGI[a]			.38***
Step 3: Treatment variables	.08	16.30****	
Duration of treatment[a]			.20*
Fathers ($N = 47$)			
Step 1: Anxiety	.17	7.31**	
STAI[a]			.45**
Step 2: Beliefs about cancer treatment	.33	6.82***	
CHOP-Self-Efficacy Scale total score[a]			−.27
Posttraumatic Growth Inventory total score[a]			.55***
SNRDAT/network[a]			−.36**
Step 3: Treatment variables	.23	14.52****	
Duration of treatment[a]			.39***

Each model used three conceptual steps (Anxiety, Beliefs about cancer treatment, Treatment variables); under each step are the one or more variables used to measure the concept along with their individual betas. STAI: State subscale of the State/Trait Anxiety Inventory, SNRDAT: Social Network Reciprocity and Dimensionality Assessment Tool.
[a]These variables are in final regression model.
*$p < .10$.
**$p < .05$.
***$p < .01$.
****$p < .001$.

and made a significant contribution individually ($p < .01$).

Discussion

Childhood cancer remains active in the lives of families after treatment ends. The data from this study support our earlier research indicating the presence of PTSS in mothers and fathers of survivors and its relationship to individual, family, and treatment variables. More important, the data suggest the potential for predicting long-term psychological sequelae from parental anxiety and distress during treatment. The longitudinal design provided a unique opportunity to begin to identify predictive pathways to long-term family adjustment. In addition, these longitudinal data allowed us to look in more depth at the PTSS symptom of avoidance. Finally, by exploring self-efficacy, we were able to identify a promising and pragmatic construct for fu-

ture work related to medical follow-up for these patients and their families.

In general, the data offer additional support for the association between parental anxiety during treatment and ongoing PTSS after treatment ends. Elevated levels of parental anxiety and distress and specific perceptions of distress during their children's treatment were associated with reports of PTSS after treatment ends. Because general anxiety and specific treatment-related traumas (e.g., procedures) are likely to be interrelated, it is difficult to tease apart the contribution of specific events to the larger picture of fear that parents experience during treatment. One possible clue may be found in the gender differences; anxiety was a significant predictor of PTSS for mothers but not fathers. In the APPO study, mothers accompanied their children more frequently to procedures than fathers. Fathers may have had less direct exposure to specific traumatic events of treatment and thus less anxiety-related PTSS.

Overall there was more anxiety than avoidance rated by parents on the PAAS, consistent with the good overall psychological health and competency of parents of children who have had cancer. A small number of individuals reported considerable anxiety when faced with follow-up care demands. Some have avoided making or keeping follow-up appointments for their children. Although not frequent, these behaviors could have serious medical and psychological consequences if they contribute to nonadherence with postcancer treatment recommendations.

Interestingly, avoidance was one of the primary reasons for study refusal. The families in this study have now completed two studies related to psychological well-being; they appear to be relatively well connected to the hospital and willing to face the anxiety associated with the cancer treatment experience. Although it was beyond the scope of this study to directly address, families who refused the study (or those for whom we do not have an accurate address) may be more avoidant than these study participants, resulting in a potential underreporting of avoidance.

If precursors of parental avoidance could be identified, strategies to maintaining closer contact and approaching families for follow-up care could be developed. For example, it cannot be determined from this study whether those parents who report higher levels of distress are characterized by generally higher neuroticism than those who report lower levels of distress. As a related point, we do not know the extent to which families have sought professional help for anxiety and related concerns. Such individuals (and families) may tend to respond similarly to other stressors (as well as health-related ones), although their child's cancer is likely to remain an issue that easily arouses anxiety. However, families might be coached to expect and tolerate increases in anxiety prior to follow-up contacts and learn ways of balancing their resumption of "normal" life after cancer with these inevitable distressing reminders.

Indeed, parents in this longitudinal study reported high levels of self-efficacy, generally and specifically with respect to a range of medically related demands. Interestingly, the least self-efficacy was reported for items related to follow-up care. Clinically, parents report increased levels of anxiety and distress before these appointments due to the fears associated with discovery of a second malignancy, late reoccurrence, or other medical late effect related to the disease or its treatment. These data suggest the need to address self-efficacy in this specific context. It may be helpful, for example, for health care team members to anticipate and predict that parents will feel anxious and perhaps avoid making these appointments. Clarifying possible predictors of avoidance may be helpful in preventing delays in seeking health care, or in promoting adherence to subsequent treatments often prescribed for medical late effects of childhood cancer (e.g., medication for cardiac, pulmonary, and renal disease or growth deficiency, anticipating difficulties with fertility). Normalizing these reactions may enhance self-efficacy and broaden the range of beliefs that influence parental and family behavior. High self-efficacy in medical situations also proved to be a significant predictor of low anxiety and avoidance for mothers but not for fathers. Several studies have related high self-efficacy with fewer posttraumatic stress disorder symptoms (Paunovic, 1998; Saigh, Mroueh, Zimmerman, & Fairbank, 1995).

The data related to perceived benefit further illustrate the complexity of these relationships. That is, higher scores on the PTGI predicted anxiety and avoidance in both mothers and fathers. Linear relationships between optimism and anxiety and avoidance may be overly simplified. Families may construct stories about the cancer experience that include positive outcomes (e.g., "we are stronger as

a result of this"). However, elevations in anxiety and avoidance may still coexist with these more optimistic frameworks and may be more powerful at certain times than perceptions of benefit. For example, individuals who are distressed may seek meaning for their situation. This does not, however, relieve the anxiety and avoidance that accompanies the distress. The data are consistent with those in other studies supporting a positive correlation between perceived benefit and PTSD symptoms (Tedeschi & Calhoun, 1996).

Although differences between mothers and fathers are apparent throughout the data, the interpretation is quite complex and difficult to make at this point. There may be gender- or role-specific factors that influence long-term adjustment and PTSS. Over time, the ways in which the cancer experience is absorbed by families may also be quite different. That is, in some families, cancer is rarely spoken of and remains below the level of day-to-day awareness. In others, the cancer experience defines the family structure and function on a daily basis, in ways that may either increase or decrease family connectedness and individual distress. It would be important to understand more fully, for example, how families help prepare their children for assuming more responsibility for their ongoing medical care and acknowledging the health risks associated with cancer and its treatment, and the extent to which anxiety, avoidance, and self-efficacy are transmitted intergenerationally. Data from a cohort of young adults who had cancer as children and adolescents suggest that PTSS and other distress may be more apparent in young adulthood than in earlier developmental periods (Hobbie et al., 2000). These young adults must learn to cope with PTSS and develop strategies for assuring ongoing attention to their medical needs.

The strongest take-home message from the data is that anxiety during treatment (particularly for mothers) is predictive of later PTSS. The opportunity for preventive interventions exists with the interrelated goals of reducing PTSS and enhancing follow-up care. In addition to self-efficacy, these data support the use of beliefs and the application of cognitive behavioral approaches in pediatric oncology. Understanding parental beliefs during treatment may facilitate the formulation of helpful cognitive frameworks after treatment ends. However, integration of beliefs within the context of the family will require further work with family systems, in addition to individual family members (Kazak et al., 1999).

As more children and adolescents are aggressively and successfully treated for cancer, the long-term implications for their well-being, and for that of their families, will be increasingly recognized as important. Attention to the psychosocial needs of families during cancer treatment, particularly with respect to parental anxiety, may help prevent later evidence of PTSS. For example, how and when information is presented may be particularly important for highly anxious parents. Recognizing how parental responses relate to their beliefs around treatment may also be helpful as families develop long-term approaches for integrating cancer into their lives, and future. These suggestions are also feasible for families whose treatment has ended, with ongoing attention to self-efficacy, avoidance, and beliefs in the development of interventions for this growing population.

Acknowledgments

References

American Psychiatric Association. (1994). Diagnostic and statistical manual of mental disorders (4th ed.). Washington, DC: Author.

Bandura, A. (1997). *Self-efficacy: The exercise of control.* New York: W. H. Freeman.

Barakat, L., Kazak, A., Meadows, A., Casey, R., Meeske, K., & Stuber, M. (1997). Families surviving childhood cancer: A comparison of posttraumatic stress symptoms with families of healthy children. *Journal of Pediatric Psychology, 22,* 843–859.

Butler, R., Rizzi, L., & Handwerger, B. (1996). The assessment of posttraumatic stress disorder in pediatric cancer patients and survivors. *Journal of Pediatric Psychology, 21,* 499–504.

Dohrenwend, B., Shrout, P., Egri, G., & Mendelson, F. (1980). Nonspecific psychological distress and other

dimensions of psychopathology. *Archives of General Psychiatry, 37,* 1129–1138.

Hobbie, W., Stuber, M., Meeske, K., Wissler, K., Rourke, M., Ruccione, K., Hinkle, A., & Kazak, A. (2000). Symptoms of posttraumatic stress in young adult survivors of childhood cancer. *Journal of Clinical Oncology, 18,* 4060–4066.

Kazak, A. (1987). Families with disabled children: Stress and social networks in three samples. *Journal of Abnormal Child Psychology, 15,* 137–146.

Kazak, A., & Barakat, L. (1997). Brief report: Parenting stress and quality of life during treatment for childhood leukemia predicts child and parent adjustment after treatment ends. *Journal of Pediatric Psychology, 22,* 749–758.

Kazak, A., Barakat, L., Alderfer, M., Rourke, M., Meeske, K., Gallagher, P., Cnaan, A., & Stuber, M. (under review). Posttraumatic stress in survivors of childhood cancer and their mothers: Development and validation of the Impact of Traumatic Stressors Interview Schedule (ITSIS).

Kazak, A., Penati, B., Boyer, B., Himelstein, B., Brophy, P., Waibel, M. K., Blackall, G., Daller, R., & Johnson, K. (1996). A randomized controlled prospective outcome study of a psychological and pharamacological intervention protocol for procedural distress in pediatric leukemia. *Journal of Pediatric Psychology, 21,* 615–631.

Kazak, A., Penati, B., Brophy, P., & Himelstein, B. (1998). Pharmacologic and psychologic interventions for procedural pain. *Pediatrics, 102,* 59–66.

Kazak, A., Penati, B., Waibel, M. K., & Blackall, G. (1996). The perception of procedures questionnaire: Psychometric properties of a brief parent report measure of procedural distress. *Journal of Pediatric Psychology, 21,* 195–207.

Kazak, A., Simms, S., Barakat, L., Hobbie, W., Foley, B., Golomb, V., & Best, M. (1999). Surviving Cancer Competently Intervention Program (SCCIP): A cognitive-behavioral and family therapy intervention for adolescent survivors of childhood cancer and their families. *Family Process, 38,* 175–192.

Kazak, A., Stuber, M., Barakat, L., & Meeske, K. (1996). Assessing posttraumatic stress related to medical illness and treatment: The Impact of Traumatic Stressors Interview Schedule (ITSIS). *Families, Systems and Health, 14,* 365–380.

Kazak, A., Stuber, M., Barakat, L., Meeske, K., Guthrie, D., & Meadows, A. (1998). Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancer. *Journal of the American Academy of Child and Adolescent Psychiatry, 37,* 823–831.

Kupst, M. J., Natta, M., Richardson, C., Schulman, J., La-

vigne, J., & Das, L. (1995). Family coping with pediatric leukemia: Ten years after treatment. *Journal of Pediatric Psychology, 20,* 601–617.

Kupst, M. J., & Schulman, J. (1988). Long-term coping with pediatric leukemia. *Journal of Pediatric Psychology, 13,* 7–22.

Langner, T. (1962). A 22 item screening score of psychiatric symptoms indicating impairment. *Journal of Health and Human Behavior, 3,* 269–276.

Manne, S., Du Hamel, K., Gallelli, K., Sorgen, K., & Redd, W. (1998). Posttraumatic stress disorder among mothers of pediatric cancer survivors: Diagnosis, comorbidity, and utility of the PTSD checklist as a screening instrument. *Journal of Pediatric Psychology, 23,* 357–366.

McFarlane, A. (2000). Posttraumatic stress disorder: a model of longitudinal course and the role of risk factors. *Journal of Clinical Psychiatry, 61*(Suppl. 5), 15–20.

McMillen, J. C., Smith, E., & Fisher, R. (1997). Perceived benefit and mental health after three types of disaster. *Journal of Consulting and Clinical Psychology, 65,* 733–739.

Novy, D., Nelson, D., Goodwin, J., & Rowzee, R. (1993). Psychometric comparibility of the State-Trait Anxiety Inventory for different ethnic subpopulations. *Psychological Assessment, 5,* 343–349.

Paunovic, N. (1998). Cognitive factors in the maintenance of PTSD. *Scandinavian Journal of Behaviour Therapy, 27,* 167–178.

Pelcovitz, D., Goldenberg, B., Kaplan, S., Weinblatt, H., Madel, F., Meyers, B., & Viniguerra, V. (1996). Posttraumatic stress disorder in mothers of pediatric cancer survivors. *Psychosomatics, 37,* 116–126.

Powers, S. (1999). Empirically supported treatments in pediatric psychology: Procedure-related pain. *Journal of Pediatric Psychology, 24,* 131–154.

Saigh, P., Mroueh, M., Zimmerman, B., & Fairbank, J. (1995). Self-efficacy expectations among traumatized adolescents. *Behavior Research and Therapy, 33,* 701–704.

Spielberger, C. (1983). *Manual for the State-Trait Anxiety Inventory.* Palo Alto, CA: Consulting Psychologists Press.

Streisand, R., Rourke, M., Katz, M., Stein, J., & Kazak, A. (1999, April). *Understanding reasons for refusal for childhood cancer intervention programs.* Florida Child Health Psychology Conference, Gainesville, FL.

Tedeschi, R., & Calhoun, L. (1996). The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9,* 455–472.

Weiss, D., & Marmar, C. (1997). The Impact of Event Scale-Revised. In J. P. Wilson and T. M. Keane (Eds.), *Assessing psychological trauma and PTSD* (pp. 399–411). New York: Guilford.