



# Mother–child communication about possible cancer recurrence during childhood cancer survivorship

Lexa K. Murphy<sup>1</sup>  | Lauren C. Heathcote<sup>2</sup>  | Kemar V. Prussien<sup>1</sup> | Erin M. Rodriguez<sup>3</sup> | Jackson A. Hewitt<sup>4</sup> | Laura E. Schwartz<sup>5</sup> | Amanda C. Ferrante<sup>2</sup> | Cynthia A. Gerhardt<sup>6</sup> | Kathryn Vannatta<sup>6</sup> | Bruce E. Compas<sup>1</sup>

<sup>1</sup>Department of Psychology & Human Development, Vanderbilt University, Nashville, Tennessee, USA

<sup>2</sup>Department of Anesthesiology, Perioperative, and Pain Medicine, Stanford University School of Medicine, Palo Alto, California, USA

<sup>3</sup>Department of Psychology, University of Texas at Austin, Austin, Texas, USA

<sup>4</sup>Department of Psychology, University of British Columbia, Vancouver, British Columbia, Canada

<sup>5</sup>Department of Psychology, University of Memphis, Memphis, Tennessee, USA

<sup>6</sup>The Research Institute at Nationwide Children's Hospital and The Ohio State University, Columbus, Ohio, USA

## Correspondence

Lexa K. Murphy, Department of Psychology & Human Development Vanderbilt University Peabody 552, 230 Appleton Place Nashville, TN 37203, USA.

Email: [lexamurphy@gmail.com](mailto:lexamurphy@gmail.com)

## Funding information

National Cancer Institute, Grant/Award Number: R01CA118332

## Abstract

**Objective:** Providing opportunities to communicate about possible cancer recurrence may be adaptive for youth in remission, yet parents may experience difficulty guiding discussions related to fears of cancer recurrence (FCR). This study aimed to characterize mother–child discussions about potential cancer recurrence during post-treatment survivorship and to determine predictors of maternal communication.

**Methods:** Families ( $N = 67$ ) were recruited after the child's initial cancer diagnosis (age 5–17 years) and mothers self-reported their distress (post-traumatic stress symptoms; PTSS). During survivorship 3–5 years later, mothers were video-recorded discussing cancer with their children. Presence and length of discussion about potential cancer recurrence, triggers for FCR, expressed affect, and conversational reciprocity were examined. Hierarchical regressions were used to assess maternal PTSS near the time of cancer diagnosis and child age as predictors of maternal communication.

**Results:** Three-quarters of dyads spontaneously discussed risk for or fears about cancer recurrence; mothers initiated the topic more frequently than their children. Dyads discussed internal (bodily symptoms) and external (medical, social) triggers of FCR. Higher maternal PTSS at diagnosis predicted significantly lower levels of maternal positive affect ( $\beta = -0.36, p = 0.02$ ) and higher levels of maternal negative affect ( $\beta = 0.30, p = 0.04$ ) during discussion of recurrence 3–5 years later. Older child age significantly predicted higher levels of maternal negative affect ( $\beta = 0.35, p = 0.02$ ). Higher maternal PTSS at diagnosis predicted shorter discussions about recurrence for younger children ( $\beta = 0.27, p = 0.02$ ).

**Conclusions:** Understanding predictors and characteristics of mother–child discussions about recurrence can guide family-based FCR interventions, particularly those promoting communication as a supportive tool. Both maternal PTSS and child age are important to consider when developing these interventions.

## KEYWORDS

cancer survivorship, fear of cancer recurrence, parent-child communication, pediatric cancer, post-traumatic stress

## 1 | INTRODUCTION

Psychosocial support to manage and cope with fear of cancer recurrence (FCR) is a key unmet need in survivors of childhood cancer.<sup>1,2</sup> A recent study found that 62% of adolescent and young adult cancer survivors reported clinically significant levels of fears that their cancer will return.<sup>3</sup> Further, data suggest that FCR is higher among survivors of childhood cancer than among survivors of adult cancer.<sup>4</sup> In survivors of childhood cancer, higher FCR is associated with a range of difficulties that include impaired psychological functioning, poor health-related quality of life, greater healthcare utilization, and maladaptive health behaviors.<sup>5–8</sup> There is a critical need for more research on FCR in childhood cancer survivors to guide targeted intervention.

Social context, including family communication, is recognized as an important but understudied factor across theoretical models of FCR<sup>9,10</sup> and is outlined in the Social-Cognitive Processing Model.<sup>11,12</sup> These theories propose that opportunities to communicate with close family members may serve to regulate FCR and promote psychological adjustment by facilitating cognitive and emotional processing.<sup>13,14</sup> In adults, communication about fears of recurrence between partners been shown to uniquely influence these fears for both patients and their spouses. In particular, the inhibition of disclosure of cancer-related concerns predict greater fear of cancer recurrence in couples.<sup>15</sup> In addition, inhibiting self-disclosure of the partner's concerns by hiding or denying their cancer-related concerns is associated with increased fear of recurrence for the patient.<sup>16</sup> Within the context of a parent-child relationship, open communication about potential for cancer recurrence may also be adaptive and promote children's ability to process their own emotions. A recent study found that coping strategies such as familial integration and maintaining social support are significantly associated with lower fear of progression in mothers of children with cancer.<sup>17</sup> Yet, to our knowledge, no prior research has directly examined parent-child communication about cancer recurrence.

Parents often report fear related to their child's possible cancer recurrence (including cancer recurrence, relapse, or secondary malignancy).<sup>18</sup> Consequently, parents may have a difficult time knowing when and how to discuss this with their children. Near the time of an initial cancer diagnosis, parents report that talking to their children about cancer presents a significant source of stress.<sup>19</sup> A recent study that conducted focus groups to examine parents' preferences regarding cancer communication found that parents expressed uncertainty about how to guide discussions about cancer and what to share with their children about illness and treatment.<sup>20</sup> Studies on parent-child communication in cancer more broadly have found that parental distress, including depression and post-traumatic stress symptoms (PTSS), near the time of their child's cancer diagnosis can impair parent-child communication about cancer months later. Specifically, parental distress (anxiety, depression, post-traumatic stress) predicts higher levels of negative communication (e.g., withdrawn or intrusive communication styles) and lower levels of positive communication (e.g., warmth, validation), which is subsequently

linked to child distress.<sup>21,22</sup> PTSS specific to child cancer diagnosis is particularly important to consider, as there is research suggesting early trauma symptoms impact how a stressor is subsequently remembered.<sup>23</sup> It is possible that parental distress may also affect parent-child communication about the possibility of cancer recurrence during survivorship, such that parents who experience more intense PTSS during the early stage of their child's cancer treatment may have a difficult time initiating a conversation about recurrence with their child and discussing it at length.

Children's developmental level may also play a role in parent-child communication about cancer recurrence. Parents of older children may have different goals for the discussion, for example preparing their children to take on greater medical role responsibility,<sup>24</sup> and therefore spend more time discussing the possibility of a recurrence and speak more openly about their own worries about recurrence. This would be consistent with prior research indicating that parents express more of their own negative emotions when communicating with older children.<sup>25</sup> Similarly, older children may ask or want to know more about their disease. Further, it is possible that child age moderates the relation between parental PTSS and communication,<sup>21</sup> such that parents who reported higher PTSS at diagnosis may have even greater difficulty discussing risk for cancer recurrence with children who are younger in age. This would be consistent with a prior study that found that mothers of younger children report that communicating about cancer is significantly more stressful than mothers of older children,<sup>19</sup> and with prior research that has found that mothers with PTSS are likely to demonstrate avoidant/withdrawn patterns of interactions with younger as compared with older children.<sup>26</sup>

To our knowledge, no prior studies have characterized the content, reciprocity, or predictors of parent-child communication about risk for cancer recurrence during childhood cancer survivorship. In the current study, mothers self-reported PTSS near the time of their child's initial cancer diagnosis. Three to five years later, post-treatment during cancer survivorship, mothers completed a semi-structured video-recorded communication task with their children focused on cancer. Because the goal of this study was to examine how conversations about cancer recurrence naturally unfold, dyads were not prompted to discuss recurrence. The first aim of this study was to characterize both mothers' and children's communication about cancer recurrence during survivorship: how frequently the topic of cancer recurrence occurred, how long mother-child dyads discussed it, possible triggers for FCR, and conversational reciprocity (who brought up the topic of recurrence, who changed the topic away from cancer recurrence) using theoretical models of FCR and established coding schemes.<sup>19,27,28</sup> The second aim of this study was to identify predictors of maternal communication about cancer recurrence. We expected that over and above the influence of treatment intensity, both maternal PTSS and child age would predict how mothers guided discussions about recurrence during survivorship. Finally, we also tested child age as a potential moderator of the relation between maternal PTSS and maternal communication.

## 2 | METHODS

### 2.1 | Participants

This study is part of a larger study examining family adaptation to childhood cancer (BLINDED). Participants were recruited from two pediatric oncology centers in the United States, in the Southeast and the Midwest. Child criteria for inclusion in the larger study ( $N = 297$ ) were<sup>1</sup>: age 5 to 17 years at the time of a new or recurrent cancer diagnosis,<sup>2</sup> receiving treatment through the pediatric oncology division,<sup>3</sup> English-speaking, and<sup>4</sup> no developmental disability and not on hospice care. Criteria for inclusion in this sub-study were<sup>1</sup> the initial study diagnosis was a new cancer diagnosis at the time of study entry (i.e., no relapse or secondary cancers;  $N = 35$  excluded),<sup>2</sup> completion of parent-child communication task during family assessments completed 3-to-5-years post-diagnosis ( $N = 172$  lived too far away from study centers or declined), and<sup>3</sup> child not in treatment at follow-up (i.e., child post-treatment in survivorship,  $N = 15$  excluded). Due to the small number of fathers who completed the task ( $N = 8$ ), this study focused on mother-child communication ( $N = 67$ ). Mothers who completed the communication task did not differ significantly from those who did not on child age, maternal age, or maternal PTSS ( $p$ 's > 0.10). See Table 1 for participant demographics.

### 2.2 | Procedure

Institutional Review Boards of the children's hospitals approved all study procedures (Vanderbilt IRB#041135 and IRB#030145; Nationwide Children's Hospital IRB05-00039). Families were originally recruited in the hospital or clinic near the time of the child's initial cancer diagnosis ( $M = 2.2$   $SD = 1.7$  months); mothers self-reported PTSS family and sociodemographic variables; and child medical factors were extracted from medical charts. Families were contacted again during survivorship, three to five years after diagnosis, and invited to complete a communication task ( $M = 3.74$  years after initial diagnosis,  $SD = 0.67$  years). Child age at time of communication task ranged from 8–20 years ( $M = 14.16$  years). Families who participated in this task did not differ from those who declined on maternal PTSS at diagnosis, study site, initial child cancer diagnosis, child treatment intensity, family income, or history of recurrence during the study period ( $p$ 's > 0.05). Informed consent and assent were obtained from participants, and families were compensated at each time point.

### 2.3 | Measures

#### 2.3.1 | Medical factors

Mothers reported on child diagnosis and treatment at baseline and medical chart reviews were conducted to extract additional medical information during the study period. The term "recurrence" is used

TABLE 1 Participant demographics ( $N = 67$ )

	M (SD) or N (%)
Child age at diagnosis	10.01 (3.63)
Mother age at diagnosis	38.19 (6.84)
Child sex	
Male	36 (54%)
Female	31 (46%)
Child race	
White	55 (82%)
Black	9 (13%)
Asian	1 (2%)
Other	2 (3%)
Child ethnicity	
Hispanic	4 (6%)
Non-Hispanic	63 (94%)
Annual family income	
<\$25,000	11 (16%)
\$25,000–\$50,000	20 (30%)
\$50,000–\$100,000	22 (33%)
>\$100,000	10 (15%)
Not reported	4 (6%)
Child diagnosis	
Leukemia	28 (42%)
Lymphoma	16 (24%)
Brain tumor	4 (6%)
Other solid tumor	19 (28%)

throughout the paper and is inclusive of cancer recurrence, relapse, or secondary malignancy. Treatment intensity was measured with the Intensity of Treatment Rating Scale [ITR-3<sup>29</sup>]; this is a standardized rating scale that includes the child's diagnosis, stage/risk level, and treatment modality (1 = *least intensive* to 4 = *most intensive*). This was completed by research assistants after medical chart review and, when necessary, physician consult and considers.

#### 2.3.2 | Maternal post-traumatic stress

Maternal PTSS was measured with the Impact of Events Scale-Revised (IES-R<sup>30</sup>) two months after the child's initial cancer diagnosis. The IES-R asks mothers to rate items "using your child's cancer and treatment as the stressful event." Twenty-two items assess symptoms of hyperarousal, intrusion/re-experiencing, and avoidance on a 5-point Likert Scale (0 = *Not at all*, 4 = *Extremely*); 33 is considered a conservative cut-off indicative of likely PTSD diagnosis,<sup>31</sup> however

the total score was used in all analyses. Internal consistency in the current sample was excellent (Cronbach's  $\alpha = 0.94$ ).

### 2.3.3 | Mother–child communication about risk for cancer recurrence

The communication task occurred in a private room at the children's hospital or in a private area in the family's home. Research assistants asked mother–child dyads to have a conversation about the child's cancer in whatever way felt natural for their family for 15 min; the task was videotaped. Mothers received a cue card with prompts to help guide the discussion as needed. Questions were open-ended and did not ask about recurrence.<sup>1</sup>

The full 15 min mother–child discussion was transcribed. Individual utterances [defined as a unit of speech with complete semantic and syntactic content, akin to a spoken sentence;<sup>19</sup>] were identified for mothers and children. Recurrence content was defined as utterances pertaining to possibility of recurrence; plans for a possible recurrence; thoughts of recurrence; triggers for thoughts of recurrence; emotional, social, cognitive, or behavioral impacts of those thoughts of recurrence; as well as coping with possibility of recurrence. This included discussion of recurrence of the same cancer or a secondary malignancy, but did not include discussion pertaining to initial cancer diagnosis. For the purposes of this study, each transcribed utterance from the full 15 min discussion was coded as either yes (recurrence content) or no (not recurrence content). Two post-doctoral level coders coded 20% of the transcripts for reliability (98% agreement) then coded the rest independently. Recurrence content was the focus of coding and analysis described below.

#### *Length of cancer recurrence discussion*

Length of cancer recurrence discussion of recurrence was measured by number of utterances for each individual.<sup>19</sup>

#### *Affect during discussion*

Positive and negative affect were measured with the Iowa Family Interaction Scale [IFIRS;<sup>28</sup>]. For the purposes of this study, the coding system was adapted to focus on verbal communication behaviors. Frequency and intensity of affect was measured on a 9-point Likert Scale (1 = *absent*, 9 = *mainly characteristic*). Positive affect was measured with the IFIRS positive mood scale and negative affect was measured with the IFIRS anxiety and sadness scales (combined into a single scale for the purposes of this study). As such, positive affect measures the degree to which the individual verbally expresses contentment, happiness, and optimism (feeling positive, feeling confident). Negative affect measures the degree to which the individual verbally expresses anxiety (nervousness, fear, tension, stress, worry, concern) or sadness (despondence, unhappiness, depression, regret). Only the discussion pertaining to cancer recurrence was coded, and each mother and child were coded separately. See Table 2 for details and examples. All transcripts were double-coded and agreement was 80%.

#### *Triggers for fear of cancer recurrence*

Discussion of triggers for FCR was measured with a coding scheme developed for the current study and based on theoretical models of FCR<sup>27,32</sup> drawing from both quantitative and qualitative coding practices. Unlike the more general discussion about recurrence, the purpose of this coding scheme was to capture triggers of worry and fear specifically. This includes statements endorsing worry about triggers and questioning the conversational partner about whether he/she worries about triggers. The mother and child each received a yes or no code for three types of triggers: internal cues, external-medical cues, and external-social cues. See Table 2 for details and examples. All transcripts were double-coded and agreement was 96%.

#### *Conversational reciprocity*

We examined turn-taking during the course of the discussion about recurrence, specifically who initiated the topic and who changed the topic.<sup>19,33,34</sup> The number of times mothers and children each<sup>1</sup> initiated the topic of cancer recurrence and<sup>2</sup> changed the topic away from cancer recurrence was tallied. See Table 2 for details and examples.

## 2.4 | Statistical analyses

Statistical analyses were conducted with IBM SPSS.<sup>35</sup> Independent samples t-tests and two-tailed bivariate correlations were conducted for preliminary analyses. To address Aim 1, descriptive statistics were calculated; paired sample t-tests were conducted to compare mother and child communication variables. To address Aim 2, linear and ordinal regression analyses were conducted controlling for medical factors in Step 1 and examining child age and maternal PTSS in Step 2 as predictors of communication variables. Length of cancer recurrence discussion (number of utterances) was controlled for in regressions predicting affect, as affect ratings are based in part on intensity/duration. A Child Age X Maternal PTSS interaction was tested in Step 3; both variables were centered before creating the interaction term. Linear regression was used for continuous dependent variables and ordinal regression was used for triggers for FCR as the dependent variables were limited to 0–3 types of triggers. Post-hoc probing of interactions was conducted with the Johnson-Neyman technique<sup>36</sup> in PROCESS.<sup>37</sup> Power analyses indicated that with  $N = 67$ ,  $\alpha = 0.05$ , and power = 0.80, effect sizes greater than  $f^2 = 0.12$  could be detected.

## 3 | RESULTS

### 3.1 | Descriptives and preliminary analyses

Near the time of the child's cancer diagnosis, mothers' self-reported PTSS was moderately elevated (IES-R  $M = 26.95$ ,  $SD = 17.12$ ; 36% above clinical cut-off). Six percent of the sample had cancer treatment classified as least intensive, 47% moderately intensive, 36% very

TABLE 2 Communication variable definitions, examples, and descriptives

Affect during discussion <sup>a</sup>	Definition	Example	M (SD)		Range	
			M	C	M	C
Positive affect	Extent to which the child or mother conveys positive affect about possibility of cancer recurrence and/or ability to cope with a potential recurrence. Adapted from the IFIRS positive mood code. Ranges 1–9.	Mother: “That makes me feel good that someone’s always checking up (to) to make sure that if it did come back that we would know about it and we could do something.” Child: “I have a good feeling. Especially since (like) as we keep progressing every scan that I keep getting clear results.”	2.71 (2.34)	2.84 (2.01)	1–9	1–8
Negative affect	Extent to which the child or mother conveys sadness/anxiety about possibility of cancer recurrence and/or ability to cope with a potential recurrence. Adapted from combined IFIRS sadness and anxiety codes. Ranges 1–9.	Mother: “What affects my life is that I have to worry every day is it going to come back or is it you know...” Child: “When I had to go a month and a half last time instead of just a month between clinics I was super anxious.”	3.51 (3.06)	3.18 (2.26)	1–9	1–8
Triggers for fear of recurrence <sup>b</sup>	Definition	Example	n (%)			
			M	C	M	C
Internal cues—bodily sensations	Mother or child discusses bodily sensations such as pain or nausea as triggers for fear of cancer recurrence.	Mother: “I guess it affects my life because I feel like (um you know) if she complains of a stomach ache the first thing that jumps in my mind is the cancer back?” Child: “I think that you always fear that every time that you have an ache or a pain.”	n = 10 (20%)	n = 5 (10%)		
External cues—medical	Mother or child discusses external medical cues (e.g., doctors’ appointments, scans, or blood tests) as triggers for fear of cancer recurrence.	Mother: “And granted we’re still going through scans and stuff and my stomach still hits the floor when (you know) it’s time for scans again. We don’t sleep the night before. We worry until we hear the results. Um as a parent it never goes away. The worry.” Child: “If we weren’t in the hospital I wouldn’t really think anything of it. But since we’re here it kind of creates like a presence.”	n = 15 (30%)	n = 9 (18%)		
External cues—social	Mother or child discusses external social cues (e.g., seeing another person with cancer, encountering advertisements for cancer fundraisers) as triggers for fear of cancer recurrence.	Mother: “I don’t like when other people talk about people who’s got cancer...I try not to think about it all the time and then when people bring it up. And it’s always the first thing that hits my mind.” [Mother: “What is it like for you to know somebody like friends like [name] who wasn’t able to beat cancer and they’re in heaven? Does that scare you?”] Child: “A little bit... it could be me.”	n = 6 (12%)	n = 3 (6%)		
Conversational reciprocity <sup>c</sup>	Definition	Example	M (SD)		Range	
			M	C	M	C
Initiating topic of cancer recurrence	The amount of times the mother or child initiates conversation about potential cancer recurrence	<i>Mother initiating the topic</i> Child: “I’m still thinking about all the bad things I went through.” Mother: “Mhm do you ever think that it may come back?” <i>Child initiating the topic</i> Mother: “What are the things that we face now because you’ve had cancer?” Child: “Um worries if it’s going to come back or not.”	1.12 (1.19)	0.39 (0.67)	0–5	0–2

TABLE 2 (Continued)

Conversational reciprocity <sup>c</sup>	Definition	Example	M (SD)		Range			
			M	C	M	C		
Changing topic away from cancer recurrence	The amount of times the mother or child changes the topic of conversation away from potential cancer recurrence	<p><i>Mother changing the topic</i></p> <p>Child: "Well we face... that it might come back"</p> <p>Mother: "You not wanting to play sports anymore."</p> <p><i>Child changing the topic</i></p> <p>Mother: "I hope that it's gone for good and we just keep coming back to [hospital name] for our checkups."</p> <p>Child: "I need to check my hair in the camera."</p>	0.97	(1.04)	0.51	(0.82)	0-4	0-4

Abbreviations: C, child; M, mother.

<sup>a</sup>IFIRS (Melby & Conger, 2001).<sup>28</sup>

<sup>b</sup>Adapted from Heathcote & Eccleston, 2017<sup>27</sup>; Fardell et al., 2016.<sup>32</sup>

<sup>c</sup>Rodriguez et al., 2012.<sup>19</sup>

intensive, and 11% most intensive. Eleven children (16%) had a relapse or recurrence during the study period (all were off-treatment prior to the communication task). Preliminary analyses were conducted to examine associations between primary study variables (communication variables, mother's PTSS) and sociodemographic/clinical factors (study site, sex of the child, family income, type of cancer diagnosis, time since cancer diagnosis, history of relapse, and treatment intensity). Mothers whose child had a cancer recurrence during the study period discussed more triggers for FCR ( $t = -2.01, p = 0.05$ ). In bivariate analyses, older child age was significantly associated with greater maternal observed negative affect ( $r = 0.31, p = 0.03$ ). There were no other significant associations or trends ( $p$ 's > 0.10).<sup>2</sup>

### 3.2 | Aim 1: Characterizing mother and child discussion of cancer recurrence

The length of discussions about cancer recurrence ranged 0–72 utterances ( $M = 14.64, SD = 17.80$ ). Forty-nine dyads (73%) discussed the possibility of cancer recurrence. Mothers made significantly more statements about cancer recurrence than children ( $M_{\text{mother}} = 8.36$  utterances,  $M_{\text{child}} = 6.28$  utterances;  $t = 2.52, p = 0.01$ ).

Descriptives for primary communication variables are reported in Table 2. Mothers and children demonstrated a range of positive and negative affect during discussion about cancer recurrence. For both mothers and their children, mean negative affect and mean positive affect did not differ significantly. In addition, there were no significant differences between either type of affect for mothers and children. Mothers both initiated the topic of cancer recurrence and changed the topic away from cancer recurrence significantly more frequently than their children did ( $t = 4.25, p < 0.001$ ;  $t = 2.71, p < 0.01$ , respectively). Mothers were also more likely to discuss internal-symptom triggers ( $\chi^2 = 2.23, p = 0.02$ ) and external-medical triggers ( $\chi^2 = 2.45, p = 0.01$ ) for FCR than their children; there were no significant differences for mothers and children on discussion of external-social triggers

( $\chi^2 = 1.73, p = 0.08$ ). Maternal PTSS was not significantly associated with frequency of initiation of the topic of recurrence nor frequency of changing the topic away from recurrence ( $p$ 's > 0.10).

### 3.3 | Aim 2: Predictors of maternal discussion of cancer recurrence

Five hierarchical linear regressions were conducted predicting aspects of maternal discussion of cancer recurrence: length of maternal discussion, topic initiation, negative affect, positive affect, and triggers for FCR (see Table 3). The regressions predicting maternal affect controlled for length of cancer recurrence discussion (number of utterances). After accounting for medical factors in Step 1, results from Step 2 indicated that the addition of maternal PTSS and child age explained additional variance for length of cancer recurrence discussion [ $\Delta R^2 = 0.12, p = 0.02$ ; Cohen's  $f^2 = 0.14$ ], positive affect [ $\Delta R^2 = 0.11, p = 0.05$ ; Cohen's  $f^2 = 0.12$ ], and negative affect [ $\Delta R^2 = 0.17, p = 0.008$ ; Cohen's  $f^2 = 0.20$ ]. Results from Step 3 indicate that the Maternal PTSS X Child Age interaction term explained additional variance for length of cancer recurrence discussion only [ $\Delta R^2 = 0.07, p = 0.03$ ; Cohen's  $f^2 = 0.08$ ].

In the final model predicting length of maternal discussion about recurrence, both maternal PTSS ( $\beta = -0.31, p = 0.02$ ) and Maternal PTSS X Child Age ( $\beta = 0.27, p = 0.02$ ) were significant predictors. Post-hoc probing with Johnson-Neyman indicated that mothers with high levels of PTSS had shorter conversations about recurrence, but this effect was only seen for younger children (the association was nonsignificant for mothers of older children,  $p$ 's > 0.05 at age 15 and above; see Figure 1).

In the final model predicting maternal positive affect, length of cancer recurrence discussion ( $\beta = 0.20, p = 0.05$ ) and maternal PTSS ( $\beta = -0.36, p = 0.02$ ) were each significant predictors. Longer discussion and lower maternal PTSS near the child's diagnosis were each related to higher levels of positive affect.

TABLE 3 Predictors of maternal discussion of cancer recurrence

	Length of maternal discussion <sup>b</sup>		# Times mother initiates topic <sup>b</sup>		Maternal PA during discussion <sup>c</sup>		Maternal NA during discussion <sup>c</sup>		Mother discusses triggers for FCR <sup>b,d</sup>	
	$\beta$	$R^2\Delta$	$\beta$	$R^2\Delta$	$\beta$	$R^2\Delta$	$\beta$	$R^2\Delta$	Odds ratio	$\chi^2$
Step 1	-	0.06	-	0.05	-	0.17	-	0.18	-	5.86
Length of discussion <sup>a</sup>	-	-	-	-	0.39*	-	0.32**	-	-	-
History of recurrence	0.07	-	0.01	-	-0.09	-	-0.02	-	1.08	-
Treatment intensity	0.01	-	-0.06	-	-0.06	-	0.05	-	0.30	-
Time since diagnosis	-0.21	-	-0.21	-	-0.10	-	0.19	-	0.67	-
Step 2	-	0.12*	-	0.01	-	0.11*	-	0.17**	-	9.08
Length of discussion <sup>a</sup>	-	-	-	-	0.24*	-	0.50**	-	-	-
History of recurrence	0.03	-	-0.01	-	-0.05	-	-0.04	-	1.01	-
Treatment intensity	0.05	-	-0.05	-	-0.07	-	0.05	-	0.15	-
Time since diagnosis	-0.17	-	-0.20	-	-0.07	-	0.06	-	0.74	-
Child age	-0.09	-	0.00	-	-0.08	-	0.35*	-	0.14	-
Maternal PTSS	-0.35**	-	-0.10	-	-0.36*	-	0.30*	-	0.01	-
Step 3	-	0.07*	-	0.06	-	0.02	-	0.00	-	11.39
Length of discussion <sup>a</sup>	-	-	-	-	0.20*	-	0.49**	-	-	-
History of recurrence	0.07	-	0.03	-	-0.04	-	-0.04	-	1.18	-
Treatment intensity	0.08	-	-0.03	-	-0.05	-	0.06	-	0.28	-
Time since diagnosis	-0.17	-	-0.20	-	-0.06	-	0.06	-	0.75	-
Child age	-0.09	-	0.00	-	-0.07	-	0.35*	-	0.13	-
Maternal PTSS	-0.31*	-	-0.07	-	-0.36*	-	0.30*	-	0.00	-
Maternal PTSS X Child age	0.27*	-	0.25	-	0.13	-	0.03	-	0.01	-

Note: Maternal distress measured with IES-R; Child age at time of discussion; Treatment Intensity measured with ITR-3; M = Mother; C=Child; PA=Positive Affect and NA=Negative Affect, both measured with the IFIRS; PTSS=Post-traumatic stress symptoms.

<sup>a</sup>Length of cancer recurrence discussion (number of utterances) was controlled for in regressions predicting affect only.

<sup>b</sup>N = 67.

<sup>c</sup>N = 49.

<sup>d</sup>Triggers ranged 0–3, Ordinal regression conducted.

\*\* $p < 0.01$  and \* $p < 0.05$ .

In the final model predicting maternal negative affect, length of cancer recurrence discussion ( $\beta = 0.49$ ,  $p = 0.002$ ), child age ( $\beta = 0.35$ ,  $p = 0.02$ ), and maternal PTSS ( $\beta = 0.30$ ,  $p = 0.04$ ), were each significant predictors. Longer discussion, older child age, and greater maternal PTSS were each related to higher levels of negative affect.

There were no significant predictors of maternal initiation of the topic of recurrence or triggers for FCR; the final models did not explain a significant amount of variance.

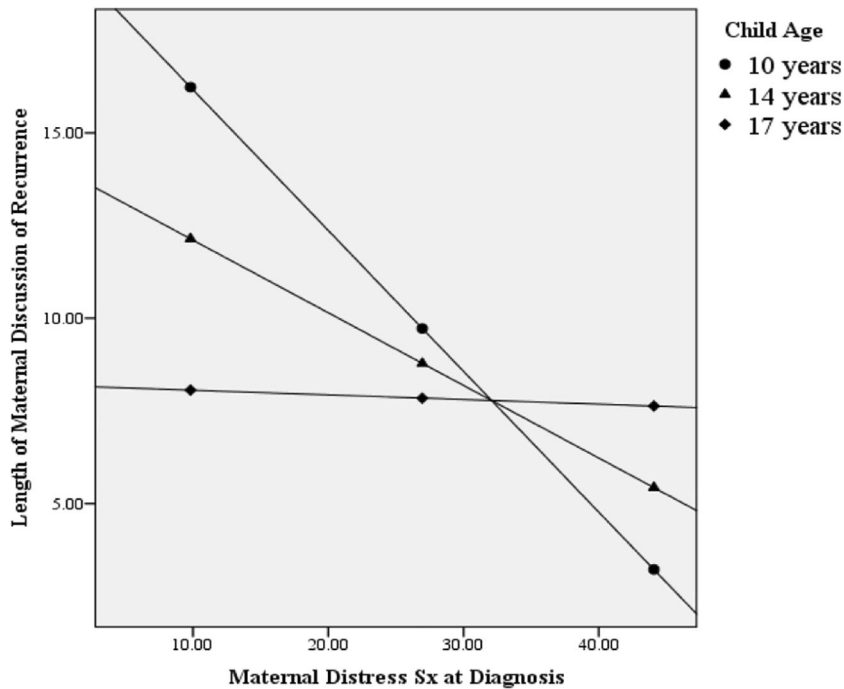
## 4 | DISCUSSION

Given that some childhood cancer survivors report high levels of FCR,<sup>3</sup> examining communication about recurrence is an important step in better understanding the experience of survivors. This

represents the first study to directly examine family communication about possible cancer recurrence in a sample of pediatric cancer survivors. Although mothers and children in this study were not prompted to discuss recurrence, the topic came up in almost three-quarters of dyads. Findings indicate that both mothers and children expressed a range of positive and negative affect about the possibility of recurrence and discussed multiple triggers of FCR. Importantly, results from this study demonstrate that maternal PTSS near the time of initial child cancer diagnosis and child age both impact maternal communication about cancer recurrence years later during survivorship.

Results from Aim 1 provide detailed information about how possible cancer recurrence is discussed by mothers and children during survivorship. Conversations ranged considerably in length, from a single utterance from a single member of the mother-child





**FIGURE 1** Child age moderates the relation between maternal distress at diagnosis and length of discussion of cancer recurrence. Notes: Length of cancer recurrence discussion measured in utterances ( $M = 14.64$ ,  $SD = 17.80$ ). Maternal distress measured with IES-R ( $M = 26.95$ ,  $SD = 17.12$ ). Child age at time of discussion ( $M = 10.0$  years,  $SD = 3.63$  years); child ages selected after Johnson-Neyman probe

dyad to 72 utterances, and both mothers and children demonstrated a range of positive and negative affect. Further, that the longer recurrence was discussed, the higher levels of both positive and negative affect that were expressed. This suggests that providing opportunities for youth to discuss recurrence at length are important for parents to understand the range of emotions their children may experience. Results also suggest that mothers are generally directing these conversations; they discussed recurrence at greater length than their children and both initiated the topic of recurrence and changed the topic away from recurrence more frequently than their children. This is consistent with studies that indicate parents generally lead discussions about pediatric illness, even with older adolescents.<sup>21</sup> This also suggests that interventions aimed at improving parent-child communication about recurrence should likely be delivered to parents.

Triggers for FCR have been described theoretically<sup>27,32</sup> and examined in survivors of adult cancers,<sup>38</sup> but this is the first time they have been examined in survivors of pediatric cancer. Results from this study indicate that both mothers and children discuss internal cues (e.g., aches and pains), external medical cues (e.g., doctors' appointments, scans), and external social cues (e.g., friends who have cancer) that trigger thoughts and concerns about cancer recurrence. Although it is important to note that *discussion* of triggers differs from the internal cognitive-affective experience of triggers, this study nonetheless provides important information about what triggers are discussed in the context of mother-child relationships.

The second aim of this study was to identify predictors of maternal communication about cancer recurrence. Hypotheses for this aim were partially supported. Controlling for medical factors, higher maternal PTSS near the time of a child's diagnosis significantly predicted higher levels of negative affect and lower levels of

positive affect during survivorship. These findings are consistent with prior research showing that maternal PTSS affects mother-child communication months after an initial diagnosis<sup>21,22</sup> and extends these findings three to five years later into survivorship. This adds to the growing body of research suggesting that mothers who have experienced post-traumatic stress are at heightened risk for more avoidant/withdrawn patterns of communication with children,<sup>26</sup> and is consistent with research indicating that early trauma symptoms impact how an event is remembered.<sup>23</sup> Interestingly, child age significantly moderated the relation between maternal PTSS and length of maternal discussion about recurrence; maternal PTSS significantly predicted shorter discussions for mothers of children 15 years and younger, but there was a nonsignificant association between PTSS and length of cancer recurrence discussion (number of utterances) for mothers of older children/adolescents. Mothers of younger children may see their child as more vulnerable—and are also younger themselves—which may make them less willing to engage in a discussion of recurrence. In contrast, mothers of older children may be more willing to engage in these discussions regardless of early PTSS, perhaps due to their child's increased age and competence<sup>39</sup>; alternately, they may view difficult discussions about illness as a necessary developmental task for older children.<sup>24</sup>

There were no significant predictors of mothers' initiation of the topic of cancer recurrence or recognition of different triggers for FCR. Given that mothers are more likely than their children to bring up the topic of recurrence and discuss triggers for their fears, and given that initiating conversations about recurrence is potentially adaptive for cancer survivors,<sup>13,14</sup> it will be important to identify predictors of these communication behaviors. For example, factors such as maternal coping and child distress could be examined in



future studies. It is also notable that of the medical factors examined—history of recurrence during the time of the study, treatment intensity, and time since diagnosis—none significantly predicted any maternal communication outcomes. This aligns with findings in the broader psycho-oncology literature indicating that medical factors are often only moderately or weakly associated with survivorship outcomes such as fear of cancer recurrence. However, given the relatively small subsample of children who reported a history of recurrence, this finding should be interpreted with caution and warrants further investigation.<sup>40,41</sup>

#### 4.1 | Study limitations

Limitations include a restricted range of diversity. The current sample reflected an overrepresentation of White families and, due to the limited number of fathers who participated, a focus on maternal communication. In addition, early predictors of subsequent communication focused on maternal PTSS. It is possible that other factors, such as maternal coping and child PTSS, could also impact communication about recurrence during survivorship. While maternal depression near the time of diagnosis was not significantly associated with maternal communication in this study, it may be that depression symptoms measured closer in time to the communication task would be associated with maternal affect.

#### 4.2 | Clinical implications

Results of this study may inform interventions to both prevent and reduce fears of recurrence in childhood cancer. First, findings suggest that preventive interventions targeting maternal PTSS near the time of the child's cancer diagnosis may have long-lasting effects that extend into cancer survivorship, or contribute to communication patterns that persist post-treatment. Second, interventions delivered during survivorship that target FCR should consider the social context of pediatric cancer. Intervening early with family members to build communication skills may provide a supportive social context for survivors to discuss concerns related to risk for cancer recurrence. Results from this study suggest that psychological factors such as parental PTSS, as well as child age, are especially important to consider in the development of such interventions.

### 5 | CONCLUSIONS

After an experience of childhood cancer, providing opportunities for children to discuss their fears and concerns about the possibility of a cancer recurrence may be adaptive. In this study we characterized communication about this topic between mothers and their children, including identifying triggers of fear of cancer recurrence and longitudinal predictors of maternal communication style. This data can

be used to guide family-based FCR interventions, particularly those promoting communication as a supportive tool.

#### ACKNOWLEDGEMENTS

This work was supported by a grant from the National Cancer Institute (R01CA118332), a gift from Patricia and Rodes Hart, and intramural funding from The Research Institute at Nationwide Children's Hospital.

#### CONFLICTS OF INTEREST

Authors have no conflicts of interest to disclose.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

#### ORCID

Lexa K. Murphy  <https://orcid.org/0000-0003-2644-4366>

Lauren C. Heathcote  <https://orcid.org/0000-0001-6013-7402>

#### ENDNOTES

<sup>1</sup> "What have we each learned about cancer and how it is treated? What parts of your cancer and its treatment have been the hardest for each of us? What kinds of feelings or emotions have we each had since we found out you had cancer? What are the ways we each try to deal with these feelings and emotions? What is it about cancer that has most affected each of our lives? How do we each feel about what might happen in the next year and after that? If we were writing a book about cancer for other children and parents, what would we each include?"

<sup>2</sup> Given the association between maternal depression and child communication,<sup>21</sup> preliminary analyses were also conducted examining the association between maternal depressive symptoms near the time of diagnosis (measured with the Beck Depression Inventory-2<sup>nd</sup> edition) and communication variables. Maternal depression symptoms were not significantly correlated with any of the outcome measures (length of maternal discussion, number of times mother initiated topic, maternal positive affect, maternal negative affect, or discussion of triggers;  $p$ 's > 0.07).

#### REFERENCES

1. Barnett M, McDonnell G, DeRosa A, Schuler T, Philip E, Peterson L, et al. Psychosocial outcomes and interventions among cancer survivors diagnosed during adolescence and young adulthood (AYA): a systematic review. *J Canc Survivorship*. 2016;10(5):814-831.
2. Park JL, Brandelli Y, Russell KB, Reynolds K, Li Y, Ruether D, et al. Unmet needs of adult survivors of childhood cancers: Associations with developmental stage at diagnosis, cognitive impairment, and time from diagnosis. *J Adolesc Young Adult Oncol*. 2018;7(1):61-71.
3. Thewes B, Kaal SEJ, Custers JAE, Manten-Horst E, Jansen R, Servaes P, et al. Prevalence and correlates of high fear of cancer recurrence in late adolescents and young adults consulting a specialist adolescent and young adult (AYA) cancer service. *Support Care Canc*. 2018;26(5):1479-1487.
4. Shay LA, Carpentier MY, Vernon SW. Prevalence and correlates of fear of recurrence among adolescent and young adult versus older adult post-treatment cancer survivors. *Support Care Canc*. 2016; 24(11):4689-4696.

5. LeClair JN, Chamberlin KW, Clement J, Holle LM. Documentation of medical marijuana use in cancer patients. *J Oncol Pharm Pract.* 2020;26(5):1117-1127.
6. Otto AK, Soriano EC, Siegel SD, LoSavio ST, Laurenceau JP. Assessing the relationship between fear of cancer recurrence and health care utilization in early-stage breast cancer survivors. *J Canc Survivorship.* 2018;12(6):775-785.
7. Wroot H, Afzal AR, Forbes C, Russell KB, Trepanier L, Patton M, et al. Fear of cancer recurrence among survivors of childhood cancer. *Psycho Oncol.* 2020;29(7):1132-1140.
8. Yang Y, Li W, Wen Y, Wang H, Sun H, Liang W, et al. Fear of cancer recurrence in adolescent and young adult cancer survivors: A systematic review of the literature. *Psycho Oncol.* 2019;28(4):675-686.
9. Sharpe L, Curran L, Butow P, Thewes B. Fear of cancer recurrence and death anxiety. *Psycho Oncol.* 2018;27(11):2559-2565.
10. Curran L, Sharpe L, Butow P. Anxiety in the context of cancer: A systematic review and development of an integrated model. *Clin Psychol Rev.* 2017;56:40-54.
11. Lepore SJ. A social-cognitive processing model of emotional adjustment to cancer. In: Baum A, Andersen BL, eds. *Psychosocial Interventions for Cancer.* Washington, DC: American Psychological Association; 2001:99-116.
12. Lepore SJ, Revenson TA. Social constraints on disclosure and adjustment to cancer. *Soc Pers Psychol Compass.* 2007;1(1):313-333.
13. Cohee AA, Adams RN, Fife BL, Von Ah DM, Monahan PO, Zoppi KA, et al. Relationship between depressive symptoms and social cognitive processing in partners of long-term breast cancer survivors. *Oncol Nurs Forum.* 2017;44(1):44-51.
14. Cohee AA, Adams RN, Johns SA, Von Ah D, Zoppi K, Fife B, et al. Long-term fear of recurrence in young breast cancer survivors and partners. *Psycho Oncol.* 2017;26(1):22-28.
15. Soriano EC, Pasipanodya EC, LoSavio ST, Otto AK, Perndorfer C, Siegel SD, et al. Social constraints and fear of recurrence in couples coping with early stage breast cancer. *Health Psychol.* 2018;37(9):874-884.
16. Perndorfer C, Soriano EC, Siegel SD, Laurenceau JP. Everyday protective buffering predicts intimacy and fear of cancer recurrence in couples coping with early-stage breast cancer. *Psycho Oncol.* 2019;28(2):317-323.
17. Clever K, Schepper F, Maier S, Christiansen H, Martini J. Individual and dyadic coping and fear of progression in mothers and fathers of children with hematologic cancer. *Fam Process.* 2020;59(3):1225-1242.
18. Mikrut EE, Panjwani AA, Cipollina R, Revenson TA. Emotional adjustment among parents of adolescents and young adults with cancer: the influence of social constraints on cognitive processing and fear of recurrence. *J Behav Med.* 2020;43(2):237-245.
19. Rodriguez EM, Dunn MJ, Zuckerman T, Vannatta K, Gerhardt CA, Compas BE. Cancer-related sources of stress for children with cancer and their parents. *J Pediatr Psychol.* 2012;37(2):185-197.
20. Gilmer TP, O'Connor PJ, Sperl-Hillen JM, Rush WA, Johnson PE, Amundson GH, et al. Cost-effectiveness of an electronic medical record based clinical decision support system. *Health Serv Res.* 2012;47(6):2137-2158.
21. Murphy LK, Preacher KJ, Rights JD, Rodriguez EM, Bemis H, Desjardins L, et al. Maternal communication in childhood cancer: Factor Analysis and relation to maternal distress. *J Pediatr Psychol.* 2018;43(10):1114-1127.
22. Murphy LK, Rodriguez EM, Schwartz L, Bemis H, Desjardins L, Gerhardt CA, et al. Longitudinal associations among maternal communication and adolescent posttraumatic stress symptoms after cancer diagnosis. *Psycho Oncol.* 2016;25(7):779-786.
23. Durand F, Isaac C, Januel D. Emotional memory in post-traumatic stress disorder: A systematic PRISMA review of controlled studies. *Front Psychol.* 2019;10:303.
24. Reed-Knight B, Blount RL, Gilleland J. The transition of health care responsibility from parents to youth diagnosed with chronic illness: a developmental systems perspective. *Fam Syst Health.* 2014;32(2):219-234.
25. Sillars A, Holman AJ, Richards A, Jacobs KA, Koerner A, Reynolds-Dyk A. Conversation and conformity orientations as predictors of observed conflict tactics in parent-adolescent discussions. *J Fam Commun.* 2014;14(14):16-31.
26. Scheeringa MS, Zeanah CH. A relational perspective on PTSD in early childhood. *J Trauma Stress.* 2001;14(4):799-815.
27. Heathcote LC, Eccleston C. Pain and cancer survival: a cognitive-affective model of symptom appraisal and the uncertain threat of disease recurrence. *Pain.* 2017;158(7):1187-1191.
28. Melby JN, Conger RD. *The Iowa Family Interaction Rating Scales: Instrument Summary.* 2001.
29. Kazak AE, Hocking MC, Ittenbach RF, Meadows AT, Hobbie W, DeRosa BW, et al. A revision of the intensity of treatment rating scale: classifying the intensity of pediatric cancer treatment. *Pediatr Blood Canc.* 2012;59(1):96-99.
30. Creamer M, Bell R, Failla S. Psychometric properties of the impact of event scale - revised. *Behav Res Ther.* 2003;41(12):1489-1496.
31. Rash CJ, Coffey SF, Baschnagel JS, Drobos DJ, Saladin ME. Psychometric properties of the IES-R in traumatized substance dependent individuals with and without PTSD. *Addict Behav.* 2008;33(8):1039-1047.
32. Fardell JE, Thewes B, Turner J, Gilchrist J, Sharpe L, Smith A, et al. Fear of cancer recurrence: a theoretical review and novel cognitive processing formulation. *J Canc Survivorship.* 2016;10(4):663-673.
33. Gelman SA, Waxman SR, Kleinberg F. The role of representational status and item complexity in parent-child conversations about pictures and objects. *Cognit Dev.* 2008;23(2):313-323.
34. Mentis M. Topic management in discourse: Assessment and intervention *Top Lang Disord.* 1994;May.
35. SPSS. *SPSS for Windows v.19.* Chicago, IL: SPSS Inc.; 2010.
36. Hayes AF, Matthes J. Computational procedures for probing interactions in OLS and logistic regression: SPSS and SAS implementations. *Behav Res Methods.* 2009;41(3):924-936.
37. Hayes AF. *PROCESS: A versatile computational tool for observed variable mediation, moderation, and conditional process modeling.* 2012.
38. Sharpe L, Thewes B, Butow P. Current directions in research and treatment of fear of cancer recurrence. *Curr Opin Support Palliat Care.* 2017;11(3):191-196.
39. Jerman P, Constantine NA. Demographic and psychological predictors of parent-adolescent communication about sex: a representative statewide analysis. *J Youth Adolesc.* 2010;39(10):1164-1174.
40. Yang Y, Wen Y, Bedi C, Humphris G. The relationship between cancer patient's fear of recurrence and chemotherapy: A systematic review and meta-analysis. *J Psychosom Res.* 2017;98:55-63.
41. Simard S, Thewes B, Humphris G, Dixon M, Hayden C, Mireskandari S, et al. Fear of cancer recurrence in adult cancer survivors: a systematic review of quantitative studies. *J Canc Survivorship.* 2013;7(3):300-322.

**How to cite this article:** Murphy LK, Heathcote LC, Prussien KV, et al. Mother-child communication about possible cancer recurrence during childhood cancer survivorship. *Psycho-Oncology.* 2021;30:536-545. <https://doi.org/10.1002/pon.5600>