

Adolescents' Emotional Reactions to Parental Cancer: Effect on Emotional and Behavioral Problems

Stacey M. Gazendam-Donofrio,¹ PhD, Harald J. Hoekstra,² MD, PhD, Winette T. A. van der Graaf,³ MD, PhD, Harry B. M. van de Wiel,¹ PhD, Annemieke Visser,¹ PhD, Gea A. Huizinga,¹ PhD, and Josette E. H. M. Hoekstra-Weebers,^{1,4,5} PhD

¹Wenckebach Institute, ²Department of Surgical Oncology, University of Groningen, ³Department of Medical Oncology, Radboud University Nijmegen Medical Center, Nijmegen, ⁴SHARE, University Medical Center Groningen, University of Groningen, and ⁵Comprehensive Cancer Center Northeast Netherlands, Groningen

All correspondence concerning this article should be addressed to Stacey Donofrio, Faculty of Behavioral and Social Sciences, University of Groningen, Grote Kruisstraat 2/1, 9712 TS Groningen, The Netherlands. E-mail: s.m.donofrio@rug.nl

Received December 4, 2010; revisions received September 5, 2010; accepted September 6, 2010

Objectives We examined adolescents' emotional reactions to parental cancer and explored relationships between emotional reactions and adolescents' emotional/behavioral problems. **Methods** Two studies were performed: retrospective and prospective. A total of 221 adolescents (105 sons) of 138 patients (retrospective) and 70 adolescents (31 sons) of 70 patients (prospective) participated. Adolescents reported on cancer-specific uncertainty, loneliness, helplessness and positive emotions (Situation-Specific Emotional Reactions Questionnaire), and filled in the Youth Self-Report once retrospectively during the period of 1–5 year(s) after diagnosis and three times prospectively during the first year (4 months post-diagnosis, 6 and 12 months after T1). **Results** Emotional reactions were similar between pro- and retrospective studies. Prospectively, uncertainty and helplessness decreased over time. Uncertainty and loneliness related significantly to adolescents' dysfunction (prospective and retrospective). Relationships between emotions and functioning were stronger and more often significant for daughters. Prospectively, adolescents' post-diagnosis emotional reactions were largely unrelated to later functioning. **Conclusions** Uncertainty and loneliness related to adolescents' emotional and behavioral problems. Daughters' emotions seem more strongly related to functioning than sons'.

Key words adolescents; emotional reactions; parental cancer; uncertainty.

Having a parent with cancer can be very distressing for a child. While literature on children of ill parents is not extensive, research has shown that developmental stage is a risk factor for distress. Adolescents may be more at risk than younger children for becoming distressed as they are old enough to be aware of and understand what the parent is going through and existential issues that may arise (Armsden & Lewis, 1993; Pedersen & Revenson, 2005; Weihs & Politi, 2005). Parents may shield older children less than younger children and may lean on them emotionally or for support with practical issues such as helping run

the household. According to the family systems illness model (Rolland, 2005), parental cancer in families with adolescents may put extra demands on a family already undergoing a transition in the family's development; the potential clash between the "normal" challenges of a family in transition and the demands of the parent's illness underlines the importance of examining how adolescents function when a parent has cancer.

In addition to child's developmental stage, the stage of the parent's illness is important in examining how children adjust (Rolland, 2005). During the crisis stage, stress may

be high as the family copes with the uncertainty of the parent's cancer and adjusts to changes in daily life (Kornreich, Mannheim, & Axelrod, 2008; Northouse, Templin, & Mood, 2002). Between 20 and 32% of adolescent boys and girls were reported to experience clinically-elevated levels of emotional and behavioral problems throughout the first year after a parent was diagnosed with cancer (Visser et al., 2005). A total of 35% of adolescent daughters and 21% of adolescent sons have also been found to suffer from post-traumatic stress symptoms (PTSS) after a parent's cancer, up to 5 years after the parent's diagnosis (Huizinga, Visser, Hoekstra et al., 2005; Huizinga et al., 2009). During the first year, the parent's prognosis may not be clear, leading to feelings of uncertainty, which has been linked to distress (Steele, Tripp, Kotchick, Summers, & Forehand, 1997). Uncertainty may also arise when the patient ends treatment and moves into the follow-up phase. Parents often do not bring their children to the hospital for appointments with the specialist and research has shown that many parents do not tell the children everything about their cancer (Barnes et al., 2000; Fitch, Bunston, & Elliot, 1999). Adolescents may feel especially uncertain about their parent's cancer if they feel their parents are not being entirely open. Uncertainty about the parent's illness may influence the child's appraisal of the situation, leading him/her to view the illness as threatening (Mischel, 1999), which may elicit negative emotions (Lazarus & Folkman, 1984). Loneliness may arise if they cannot share their experiences with others (Hamama, Ronen, & Feigin, 2000) such as friends who they believe may not be able to relate to the situation (Davey, Askew, & Godette, 2003). During periods in which parents may be admitted to the hospital, they are away from the house and children must adjust to their ill parent being unavailable for a few days or longer. Side effects of treatment may result in the parent not being able to engage in activities with their children as they did before. Loneliness could also result from parents spending less time with their children as a way to shield children from their distress. On the other hand, adolescents may withdraw from contact with their parents as a way to shield their parents from their own distress (Davey et al., 2003). Feeling helpless with regard to the parent's illness may also be related to adolescent distress. Adolescents often take on additional responsibilities when a parent is ill (Armistead, Klein, & Forehand, 1995). Healthy partners describe their inability to help the ill parent as being very stressful (Davey et al., 2003). Adolescents who feel helpless may label this as failing their parent, which could result in depression (Vanheule & Hauser, 2008). Positive emotions could

indicate that the child does not appraise the parent's illness as threatening and may be able to see the bright side of the situation; it may have an adaptive function (Walsh, 1996, 2003).

It is important to note that many children show resilience and report functioning well after a parent has been diagnosed with cancer. However, there is still a large percentage of children that has difficulty with the stress of parental cancer; it is important to identify children who may not adjust well and develop emotional or behavioral problems as well as to better understand how the family responds to a parent's cancer. Children whose father is ill and adolescent daughters experience more dysfunction (Thastum et al., 2009). Child gender is considered a moderator in adjusting to parental cancer (Su, Ryan-Wenger, & Nancy, 2007); adolescent daughters are at higher risk for dysfunction (Visser et al., 2005). Family environment (Gazendam-Donofrio et al., 2007), presence of problems in communication between the patient and his/her children (Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005) and adolescents' personality (Visser, Huizinga, Hoekstra, van der Graaf, & Hoekstra-Weebers, 2007) have also been identified as possible risk factors for dysfunction. Compas et al. (Compas et al., 1994) report that the relationship between characteristics of the illness and treatment and adolescents' functioning is limited. How strongly children experience negative emotions (e.g., uncertainty, loneliness, or helplessness) about their parent's cancer may have an effect on whether children experience emotional or behavioral problems (Lewis, 1996). The purpose of this study was to explore the relationship between the children's cancer-specific emotional reactions and the presence of emotional and behavioral dysfunction.

In this study, we first aimed to examine adolescents' emotional reactions to their parent's cancer. During the course of the first year, we hypothesized that negative reactions would be strongest shortly after diagnosis and would decrease over time as the parent's prognosis became more certain or the treatment ended. As the year progressed and the family moved from the crisis stage to the chronic (Rolland, 2005), we hypothesized that children would experience an increase in positive emotions (i.e., pride about how they were managing or comfort in becoming closer as a family) they felt about their parent's illness. We also hypothesized that, in comparisons between children whose parent was diagnosed more than 1 year previously and those whose parent was diagnosed less than a year ago, we would see similar emotional reactions between children for whom the parent's diagnosis was further in the past and children assessed at the end of

the first year. We secondly examined possible relationships between emotional reactions and demographic and cancer-related variables in this study. Based on previous findings about functioning (Thastum et al., 2009; Visser et al., 2005), we believed that children might react differently depending on, for example, whether their mother or father was ill. As daughters seem to experience more dysfunction and use more emotional expression (Su et al., 2007), our hypothesis was that adolescent girls' emotional response would be stronger than the boys' response. As noted above, the relationship between characteristics of the illness and treatment and adolescents' functioning seems to be limited (Compas et al., 1994). We wanted to explore possible relationships between illness and treatment characteristics and the adolescents' emotional reactions. Our third aim was to investigate concurrent and prospective relationships between adolescents' emotional reactions to their parent's cancer and their emotional and behavioral functioning. According to Lazarus and Folkman's model on stress and coping (1984), the emotional reaction to a stressor can determine whether a person experiences an event as stressful. Based on this model, we hypothesized that a negative emotional response to the parent's illness would be related to higher levels of emotional and behavioral problems. Literature on resiliency has shown that children who have a positive outlook seem to adjust better (Walsh, 1996). Therefore, we expected that positive emotions would be negatively related to problems. This study is part of a larger study examining adolescent and younger children's emotional and behavioral functioning and parents' quality of life when a parent has cancer (Gazendam-Donofrio et al., 2009; Visser, Huizinga, Hoekstra, van der Graaf, Gazendam-Donofrio et al., 2007).

Method

Recruitment

This study had two components: a retrospective study and a longitudinal, prospective study. Oncologists and oncology nurses recruited participants at the University Medical Center Groningen in the Netherlands during a 2-year period. Inclusion criteria for both studies were fluency in Dutch, and having children 4–18 years of age at time of diagnosis. In the retrospective study, patients being treated or seen in follow-up who had been diagnosed 1–5 years previously were approached to participate. For the longitudinal study, all new patients being treated for cancer were approached shortly after diagnosis and informed about the study. Families in the prospective study were eligible for inclusion if the patient had been diagnosed no longer than

4 months before and was expected by the oncologist to survive the first year. This criterion was added by the ethical review board to prevent an additional burden on families with a particularly poor prognosis.

Procedure and Participants

Parents in both studies were given written information about the study for themselves and an information folder adapted for the children. Families were included in the study if the patient and at least one child agreed to participate. After obtaining separate informed consent from family members, questionnaires and pre-paid return envelopes were mailed individually to participating parents and children ≥ 11 years one time for the retrospective study and three times for the prospective study. The first measurement (T1) of the prospective study took place within the first 4 months after diagnosis; the following measurements took place 6 (T2) and 12 months (T3) after T1. Family members were asked to fill in questionnaires separately and to not confer about their answers.

This paper focuses on the subset of families with adolescent children (11–18 years), as these children were able to complete questionnaires themselves. In the retrospective study, 209 of the 476 families with children approached participated (44%). Of the 209 participating families, 138 had adolescent children (Table I). A total of 221 adolescents (53% girls) from these 138 families participated. Mean time since patient's diagnosis was 2.8 years (± 1.2). Eighty-one percent of the 138 patients were female. Patients had various cancer diagnoses, including breast (54%), gynecological (11%), skin (9%), hematological (8%), urological (5%), sarcoma/bone (5%), head/neck (3%), gastrointestinal (3%), and central nervous system (2%). Thirty-six patients (26%) had recurrent disease; remaining patients had no evidence of disease.

In the prospective study, 222 families with children aged between 4 and 18 years were approached; 112 agreed to participate (50%). Of those 112 families, 74 participated (66%) at T2; 70 (63%) at T3. The 70 families who participated in the study at T1, T2 and T3 are the focus of this article. In each of these families an adolescent participated ($n = 70$, 56% girls). Almost two-thirds of the 70 patients were female (63%). Breast cancer was the most prevalent type of parental cancer (36%), followed by gastrointestinal (11%), skin (11%), gynecological (10%), urological (10%), sarcoma/bone (9%), hematological (7%), and head/neck (6%). At T3, one patient had a recurrence and was still being treated; the other patients had completed treatment and were in follow-up. Demographic and illness-related information is summarized in Table I.

Table 1. *Demographics and Illness-Related Characteristics*

	Retrospective	Prospective	
	Total sample: Number of patients = 138 Number of adolescents = 221	Total sample: Number of patients = 70 Number of adolescents = 70	
Patients' gender			
Men, N (%)	26 (19%)		26 (37%)
Women, N (%)	112 (81%)		44 (63%)
Patients' age in years M (SD)	45.4 (4.2)		42.5 (5.1)
Range	33–55		33–55
Type of treatment, N (%)			
Ongoing	113 (82%)	T1	
		Ongoing	54 (77%)
Surgery	24 (17.5%)	Surgery	16 (23%)
Not reported	1 (0.5%)	T2	
		Ongoing	57 (82%)
		Surgery	8 (11%)
		Completed	5 (5%)
		T3	
		Ongoing	1 (1%)
		Surgery	0 (0%)
		Completed	69 (99%)
Time since diagnosis, months, M (SD)	35.6 (14.4)	T1	2.3 (1.0)
		T2	7.7 (1.4)
		T3	13.8 (1.8)
Adolescents' gender, N (%)			
Boys	105 (48%)		31 (44%)
Girls	116 (52%)		39 (56%)
Adolescents' age in years, M (SD)	15.5 (2.0)		14.0 (2.2)
Range	11–18		11–18
Number of participating children per family, M	2.2		1
Families with one child, N (%)	72 (52%)		70
Two children	53 (38%)		0
Three or more children	13 (9%)		0

Many families approached for the prospective and retrospective studies who did not participate gave explanations including not being interested, a good or poor prognosis, having not informed the children and, in the retrospective study, “having moved on”. In the retrospective study, there were no significant differences between participants and nonparticipants in patient gender, type of cancer or time since diagnosis. Nonparticipating families in the prospective study differed from participating families with regard to type of cancer ($\chi^2 = 41.7$, $df = 130$, $p < .001$), with gynecological cancers significantly more prevalent in nonparticipating families ($\chi^2 = 10.5$, $df = 13$, $p < .001$). The percentage of patients with urological cancer and sarcomas was significantly higher in participating families ($\chi^2 = 18.1$, $df = 15$, $p < .001$ and $\chi^2 = 6.5$, $df = 12$, $p < .01$, respectively). There were no significant differences between participants

and nonparticipants with regard to patient gender. Our sample reflects the statistic that in the age range 30–50 years, women are diagnosed with cancer more frequently than men (Comprehensive Cancer Center, 2010).

In the prospective study, we found that patients and spouses in families lost to attrition after T1 were not significantly different from those who remained in the study regarding demographic information or quality of life reported at T1. Adolescents did not differ in emotional or behavioral functioning according to self-reports at T1. Regarding emotional reactions, adolescents who dropped out reported more helplessness at T1 than those who remained in the study ($t = -3.14$, $df = 69$, $p = .002$); in uncertainty, loneliness or positive emotions, no differences were found.

Measures

Situation-Specific Emotional Reactions

Adolescents completed the Situation-specific Emotional Reaction Questionnaire-child (SSERQ-c), an instrument originally developed to assess parental adjustment to pediatric cancer (Grootenhuis & Last, 1997). It was adapted for children (Houtzager et al., 2004). In this study it was used to measure adolescents' emotional reactions specific to the parent's cancer on four sub-scales. A factor analysis performed for the use of this instrument in the current study confirmed the four factors found by Houtzager et al. (2004). Uncertainty was measured with eight items, for example, *I am afraid my parent will not get better* (scores range 0–32). The helplessness sub-scale consisted of eight items, e.g., *I feel frustrated that I cannot change the situation* (range 0–32). Loneliness is measured by seven items, e.g., *I feel like I cannot talk to anyone* (range 0–28). Finally, the positive emotions sub-scale consists of three items, e.g., *I am proud I can deal with the situation* (range 0–12). Items are scored on a four-point scale. Higher scores denote stronger emotions about the parent's cancer. The SSERQ-c was shown to be reliable, with Cronbach's alphas in this study above 0.70 (range .70–.92) for all subscales at all measurements except for positive emotions at T2 ($\alpha = .65$). As the SSERQ is an illness-specific questionnaire, no normative data are available.

Emotional and Behavioral Functioning

Adolescents reported on their emotional and behavioral functioning with the Youth Self-Report (YSR; Achenbach, 1991; Verhulst et al., 1996); the questionnaire contains 102 items. In this study, the internalizing (internal mental state—withdrawal, somatic complaints and anxiety/depression), externalizing (socially unacceptable behavior—delinquency and aggressiveness) and total problem (total of internalizing, externalizing and other scales including thought, social and attention problems) scales were used to provide a picture of the problems occurring in children of parents diagnosed with cancer. The YSR's reliability and validity have been supported in a great number of studies. In this study, Cronbach's alphas for the internalizing, externalizing and total problem scales ranged from .84 to .94 from T1 to T3 and for the retrospective study. Data on the children's functioning from both the longitudinal and retrospective studies has been previously published (Visser et al., 2005; Visser, Huizinga, Hoekstra, van der Graaf, Gazendam-Donofrio et al., 2007).

Demographic information and information about patient's diagnosis and treatment were gathered. We created a dichotomous variable to measure possible effects of patients' treatment. This was based on the idea that

surgical treatment alone would mean that treatment was completed more quickly and would therefore be less distressing for the family than longer-term treatment, which we defined as all single-modal non-surgical treatments (chemo- or radiotherapy) or multi-modal treatments (combinations of surgery, chemo- or radiotherapy, or other therapies).

Analysis

Before the start of the study, a power analysis was performed for each study to determine how large the sample size should be for both studies. Based on an alpha of .05, a power of .80 and an effect size of .50 (Cohen, 1988), it was determined that each sample should include at least 51 participants. Descriptive analyses were performed to explore the adolescents' emotional reactions. *T*-tests were used to compare the prospective and retrospective emotional reactions. We used repeated measures ANOVAs to analyze changes in emotional reactions in the prospective study. To examine clinical relevance of differences between the studies and of change between measurements, effect sizes were computed using Cohen's *d* (Cohen, 1988). Effect sizes $\geq .50$ were considered clinically relevant, .20–.49 were considered small (Cohen, 1988). Relationships between emotions and demographic information or parents' illness-related variables were analyzed with Pearson's and Spearman's correlations, *t*-tests and ANOVAs. Pearson's correlation coefficients were computed to explore concurrent relationships between emotional reactions and emotional and behavioral functioning for both studies. Correlation coefficients $< .30$ were considered weak, between .30 and .50 moderately strong and $> .50$ strong (Cohen, Cohen, West, & Aiken, 2003). Due to the number of analyses, a Bonferroni correction was applied; significance was reduced to .007 for ANOVAs and .009 for correlations. To examine the prospective predictive effects of emotional reactions on emotional and behavioral functioning, multiple regression analyses were performed (T2 or T3 functioning and T1 emotions, controlling for T1 functioning). Hierarchical multiple regression analyses were computed to examine how well change in emotional reactions over time was associated with change in emotional and behavioral functioning. T1 problems (either total problems, internalizing, or externalizing depending on which T2 or T3 problem functioning was being examined) was entered in Step 1, followed by T1 emotional reactions in Step 2. In Step 3, emotional reactions at T2 or T3 were entered (Cohen & Brook, 1987). We chose to perform this type of analysis because it takes the level of

baseline scores into account; when using delta scores to analyze change, the information about the baseline emotional reaction and functioning is lost.

Results

Adolescents' Emotional Reactions to their Parent's Cancer

Emotional reactions of adolescents in the retrospective study are summarized in Table II. In the prospective study, adolescents' uncertainty and helplessness decreased significantly over time. Loneliness and positive emotions remained stable throughout the year. Adolescents' emotional reactions during the first year were similar to adolescents whose parent was diagnosed with cancer 1–5 years previously, with three exceptions; at T3, adolescents in the prospective study reported less uncertainty ($ES = .53$), helplessness ($ES = .61$) and loneliness ($ES = .36$) than adolescents in the retrospective study.

Emotional Reactions and Demographic and Illness-related Variables

In the retrospective study, emotional reactions were unrelated to the patient's gender. Daughters reported more helplessness than sons ($t = 3.10$, $df = 193$, $p = .002$, $ES = .44$). In the prospective study, we found no significant differences between the adolescents' emotional reactions depending on the patient's gender. With regard to the child's gender, daughters reported more helplessness ($t = 2.58$, $df = 61$, $p = .012$, $ES = .43$) and positive emotions ($t = 3.45$, $df = 61$, $p = .001$, $ES = .15$) at T2 than sons.

With regard to illness-related variables, in the retrospective study, children of parents who had received surgical treatment reported significantly more positive emotions ($M = 8.1$, $SD = 2.4$) than children whose parent received longer-term treatment ($M = 6.9$, $SD = 2.4$) ($t = 2.49$, $df = 191$, $p = .013$, $ES = .50$). Time

since diagnosis was unrelated to emotional reactions. In the prospective study, the adolescents' reactions were unrelated to type of treatment the parent underwent.

Emotional Reactions and Adolescents' Functioning

Concurrent Relationships

Separate analyses were performed for boys and girls (Table III). In the retrospective study, uncertainty was significantly correlated to sons' and daughters' total problems and internalizing. Loneliness was significantly related to both genders' total problems, internalizing and externalizing. Daughters' helplessness was significantly related to total problems and internalizing. Positive emotions were unrelated to both genders' functioning.

In the prospective study, uncertainty was significantly related to daughters' total problems and internalizing at all three measurements. With sons, uncertainty was strongly related to their internalizing at T1 and externalizing at T2. Additionally, loneliness was significantly related to daughters' internalizing at T1 and to total problems, internalizing and externalizing at T2 and T3. Loneliness was not significantly related to sons' functioning. Helplessness and positive emotions were not significantly related to adolescent functioning at any measurement throughout the year.

Prospective Relationships between Emotional Reactions and Functioning

Additional analyses were performed with the prospective study data (Table IV). T1 total problems, internalizing and externalizing significantly strongly predicted T2 and T3 functioning in both daughters and sons (Table IV, Step 1). Emotional reactions at T1 did not account for a significant increment in the explained variance in either sons' or daughters' T2 or T3 functioning (Table IV, Step 2). None of the emotional reactions were independently associated with sons' or daughters' functioning.

Table II. *Adolescents' SSERQ Scores, Prospective and Retrospective, Changes Over Time and Comparison Between Studies*

	Retrospective group	Prospective group			Repeated measures ANOVA <i>F</i>
		T1 <i>M (SD)</i>	T2 <i>M (SD)</i>	T3 <i>M (SD)</i>	
Uncertainty	13.1 (4.1)	13.1 (3.8)	11.9 (4.3)	11.0 (3.8)*	14.24 [#] ($ES = .20$)
Helplessness	17.8 (4.9)	17.1 (3.9)	16.6 (4.5)	15.0 (4.3)*	10.61 [#] ($ES = .16$)
Loneliness	10.1 (3.3)	9.7 (2.9)	9.3 (3.1)	9.0 (2.8)*	1.79
Positive emotions	7.2 (2.5)	6.9 (2.7)	6.9 (2.3)	6.6 (2.6)	1.07

* $p \leq .007$ for t -test comparing prospective and retrospective emotional reactions (adjusted with Bonferroni correction). [#] $p \leq .001$ for repeated-measures ANOVA; ES refers to size of change over time.

Table III. Correlation Coefficients for Concurrent Relationships Between SSER-Q and Adolescents' Functioning Measured by YSR, for Sons and Daughters Separately

	Retrospective			Prospective					
	Total problems	T1		T2		T3		Total problems	Externalizing
		Internalizing	Externalizing	Internalizing	Externalizing	Internalizing	Externalizing		
Uncertainty									
Daughters	.48**	.51**	.26	.59**	.73**	.34	.79**	.88**	.53**
Sons	.34**	.41**	.22	.21	.50*	-.05	.47	.39	.51**
Helplessness									
Daughters	.29*	.31**	.17	.19	.35	-.07	.33	.40	.19
Sons	.25	.25	.22	.00	-.06	.07	.02	-.21	.28
Loneliness									
Daughters	.57**	.63**	.33**	.42*	.53**	.29	.66**	.73**	.50*
Sons	.55**	.55**	.42*	.06	.24	-.05	.38	.39	.31
Positive emotions									
Daughters	.06	.00	.10	.19	.33	.06	.25	.26	.13
Sons	-.04	-.03	.09	-.19	-.32	-.12	-.01	-.11	.03

* $p \leq .009$ (adjusted with Bonferroni correction), ** $p \leq .001$.

Changes in emotional reactions occurring between T1 and T2 accounted for a significant increment in the explained variance in daughters' T2 total problems and internalizing (r^2 change = .21 and r^2 change = .25, respectively). Changes in emotional reactions did not account for a significant increment in explained variance of daughters' externalizing (Table IV, Step 3). Increased uncertainty in the first 6 months had a unique effect on daughters' increase in total problems and internalizing. In sons, change in emotions was not significantly related to change in functioning from T1 to T2.

Change in emotional functioning occurring between T1 and T3 accounted for a significant increment in the variance in daughters' total problems and internalizing (r^2 change = .10 and r^2 change = .07, respectively) and sons' internalizing problems (r^2 change = .13) (Table IV, Step 3). An increase in daughters' uncertainty was uniquely associated with an increase in total problems. An increase in sons' helplessness was uniquely associated with an increase in sons' internalizing.

Discussion

The present study explored adolescents' emotional reactions to a parent's cancer, and investigated relationships between children's emotional reactions and their emotional and behavioral functioning. Parental cancer can have a very distressing effect on children and risk factors need to be identified in order to develop services for families facing this disease. We found that emotional reactions on a group level were lower than or near the median. Throughout the first year after diagnosis, uncertainty and helplessness decreased statistically significantly; loneliness and positive emotions remained stable. Uncertainty and loneliness appear to be the emotions most strongly concurrently related to adolescents' emotional and behavioral functioning. During the first year after diagnosis, daughters' negative reactions are more strongly associated with dysfunction than boys' emotional reactions. Emotional reactions shortly after diagnosis do not seem to predict long-term dysfunction. Change in emotions over the year, in particular increased uncertainty, was associated with increased dysfunction in daughters.

The first aim of this study was to explore adolescents' emotional reactions specific to their parent's cancer. It is noteworthy that emotional reactions in both studies do not seem to have been intense, falling at or below the median of the range of possible scores. Adolescents do not feel strongly uncertain about their parent's illness nor do they feel extremely helpless, lonely or positive. The

Table IV. Hierarchical Multiple Regression Analyses of Emotional Reactions and Behavioral and Emotional Functioning

	Total problems (T2)					Internalizing (T2)					Externalizing (T2)				
	Partial β	R^2	R^2 change	F change	p	Partial β	R^2	R^2 change	F change	p	Partial β	R^2	R^2 change	F change	p
6 months after parent's diagnosis															
Daughters															
Step 1:		.49	.49	31.2	<.001		.58	.58	43.52	<.001		.52	.52	33.34	<.001
T1 problems															
Step 2: T1		.54	.05	0.8	n.s.		.59	.02	0.38	n.s.		.57	.06	0.93	n.s.
Uncertainty	.08					.19					.02				
Helplessness	.93					-.08					.17				
Loneliness	.13					.00					.12				
Pos. emotions	.08					.09					-.05				
Step 3: T2		.75	.21	4.95	.005		.84	.25	9.48	<.001		.66	.09	1.57	n.s.
Uncertainty	.78*					.93*					.39				
Helplessness	-.31					-.26					-.26				
Loneliness	-.07					.00					-.02				
Pos. emotions	.26					-.14					.38				
Sons															
Step 1:		.69	.69	48.48	<.001		.52	.52	22.93	<.001		.48	.48	19.02	<.001
T1 problems															
Step 2: T1		.78	.08	1.59	n.s.		.64	.12	1.45	n.s.		.55	.07	0.67	n.s.
Uncertainty	-.10					-.21					.08				
Helplessness	.03					.04					-.11				
Loneliness	-.26					-.28					.24				
Pos. emotions	-.03					.08					.14				
Step 3: T2		.83	.05	1.02	n.s.		.72	.07	0.85	n.s.		.71	.16	1.81	n.s.
Uncertainty	.21					.20					.10				
Helplessness	-.18					-.28					.14				
Loneliness	.97					.12					-.09				
Pos. emotions	.02					-.14					.15				
(continued)															

(continued)

Table IV. Continued

	Total problems (T2)					Internalizing (T2)					Externalizing (T2)				
	Partial β	R ²	R ² change	F change	p	Partial β	R ²	R ² change	F change	p	Partial β	R ²	R ² change	F change	p
12 months after parent's diagnosis															
Daughters															
Step 1:															
T1 problems		.67	.67	67.74	<.001		.76	.76	106.23	<.001		.66	.66	66.15	<.001
Step 2: T1		.70	.04	0.89	n.s.		.78	.02	0.82	n.s.		.69	.04	0.87	n.s.
Uncertainty	.14					.11					.06				
Helplessness	-.14					-.09					-.05				
Loneliness	.08					.08					.16				
Pos. emotions	.11					.11					.03				
Step 3: T3		.81	.10	3.46	.02		.85	.07	3.02	.04		.75	.05	1.36	n.s.
Uncertainty	.59*					.40					.29				
Helplessness	-.17					-.17					.11				
Loneliness	.01					.11					.08				
Pos. emotions	-.04					-.09					.02				
Sons															
Step 1:															
T1 problems		.79	.79	82.09	<.001		.71	.71	54.49	<.001		.56	.56	28.04	<.001
Step 2: T1		.82	.03	0.78	n.s.		.75	.03	0.60	n.s.		.63	.07	0.88	n.s.
Uncertainty	.09					-.08					.08				
Helplessness	-.09					.04					.03				
Loneliness	.13					.00					.23				
Pos. emotions	.13					.15					.09				
Step 3: T3		.87	.05	1.17	n.s.		.87	.13	3.39	.04		.67	.04	0.41	n.s.
Uncertainty	.29					.44					.17				
Helplessness	-.06					.45*					.19				
Loneliness	-.19					.13					.04				
Pos. emotions	.23					.10					.19				

Notes. n.s. = not significant. In Step 1, T1 problems refers to total problems, internalizing or externalizing depending on which variable was examined.
* $p \leq .01$.

mildness of the emotional reaction of adolescents in the group 1–5 years after diagnosis may be because of the time that had passed since diagnosis. During the first year, it may be that the children tried to remain neutral in their reaction, cautiously watching their parent. Past research has examined relationships between uncertainty about parental illness and functioning (Steele et al., 1997) but did not report the level of uncertainty children experienced. Future research could follow children from shortly after parent's diagnosis to longer-term survivorship to better understand changes in the adolescents' reactions over time. Additionally, the scale measuring positive emotions only contains three questions. It may be helpful to include more questions about possible positive reactions to their parent's illness to better understand resiliency.

Our hypothesis that negative emotions would decrease and positive emotions would increase over the course of the first year was partially supported. Adolescents' feelings of uncertainty and helplessness about their parent's situation lessened significantly during the first year following diagnosis. By the end of the year, all but one patient had completed treatment, which may mean that adolescents felt more certainty about their parent's prognosis. The families' daily routines may have stabilized and the adolescents' lives may have largely returned to normal. At the end of the first year after diagnosis, patients report functioning at levels comparable to the norm (Gazendam-Donofrio et al., 2009). Adolescents may not need to provide as much emotional or practical help as they might have earlier in the year, which could lead to a decrease in feelings of helplessness. It is interesting that the adolescents' positive emotions did not increase over time. Overall, most children showed resiliency during the stress of their parent's cancer (Visser et al., 2005). It seems, though, that they do not develop a more positive outlook on the situation; scores remained in the middle of the range.

Interestingly, we found that adolescents reported significantly lower levels of uncertainty and helplessness 1 year after their parent's diagnosis than adolescents in the retrospective study who were assessed an average of 2.5 years after parent's diagnosis. Cancer survivors report being uncertain and fearful for recurrence (Wonghongkul et al., 2006). It might be that children's concern for their parent's well-being increases as active treatment ends and the patient moves into the follow-up phase. The finding that adolescents reported significantly more loneliness 1–5 years after diagnosis than adolescents did at the end of the first year is interesting considering that adolescents in that group view their family as very cohesive (Gazendam-Donofrio et al., 2007). It may be that, while they consider

their family bond to be tighter than their peers do, they feel like no one outside the family understands what they have been through.

Our second aim was to investigate possible relationships between emotional reactions and demographic and illness-related variables. In the retrospective study, adolescents whose parent received only surgical treatment reported stronger positive emotions than those whose parent received longer-term treatment. This could be related to their parent's estimated chance of survival. While no effects of treatment on adolescents' functioning were found (Gazendam-Donofrio et al., 2009), it could be that many children whose parent only underwent surgery witnessed fewer outward signs of illness. In the prospective study, children's emotional reactions were unrelated to the type of treatment the parent underwent. Their reactions were also unrelated to the patient's gender. It would seem that simply knowing their parent has cancer has the most distressing effect on them during the first year; type of cancer or treatment may be just details to them. This is in line with earlier research (Compas et al., 1994).

No effects of the ill parent's gender were found, but their own gender does seem to play a small role. In the retrospective study, we found that daughters reported more helplessness than sons. Prospectively, we also found that daughters felt more helpless than sons at 6 months after diagnosis. It might be that daughters are more focused on their ill parent than sons or that they were asked to take on more responsibility or to try to help their family more (Welch et al., 1996). Adolescent daughters have been identified as a high-risk group for developing problems (Compas et al., 1994; Wellisch & Gritz, 1996). However, it may also be that daughters are more inclined to report their fears than sons (Davey et al., 2003). In the middle of the first year, daughters were more positive than sons. This could be a sign that daughters are using emotion-based coping (Compas, Worsham, Ey & Howell, 1996) or trying to focus on the positive aspects of the situation (Kennedy & Lloyd-Williams, 2009).

Thirdly, we examined concurrent relationships between how adolescents reacted emotionally and their emotional and behavioral functioning. Our findings partially support our hypothesis. We expected based on previous findings (Hamama et al., 2000; Steele et al., 1997) and based on Lazarus and Folkman's stress, appraisal and coping theory (1984) that uncertainty, helplessness and loneliness would relate positively to emotional and behavioral problems and that positive emotions would be negatively related to problems. Retrospectively, we found that daughters' and sons' emotional reactions are similarly related to their functioning. Uncertainty and loneliness were

significantly related to their total problems and their internalizing. Their worries and fears about their parent's illness and their feelings of being alone are associated with withdrawal, somberness or somatic complaints. This seems to be conform earlier research (Steele et al., 1997). It seems that adolescents who appraise the situation negatively experience emotional problems, in line with Lazarus and Folkman's model on stress (1984).

Prospectively, we found that concurrent relationships between emotional reactions and functioning were more often and more strongly significant for daughters than for sons. Again, uncertainty and loneliness were most strongly related to their functioning. It seems that girls' emotions have a stronger effect on how they function than boys'. This may be because girls more often engage in emotion-focused coping (Li, DiGiuseppe, & Froh, 2006), which can result in higher rates of depression. Daughters' uncertainty and loneliness due to their parent's cancer are also expressed in the form of delinquent or aggressive behavior. In general, children of cancer patients are not considered to be at risk for externalizing problems (Osborn, 2007), although we found a higher percentage of adolescent daughters experiencing externalizing problems above the cut-off than in a norm group (Visser et al., 2005). Uncertainty and loneliness may elevate daughters' risk of developing externalizing problems.

Adolescents' positive emotions during the first year and later were unrelated to their functioning. In contrast to our expectations, it seems that positive emotions about their parent's illness do not protect children from developing problems. Girls and boys were neither comforted nor distressed by their positive emotions. It may be that children do not yet comprehend that it is allowable to experience positive emotions without feeling guilty. As mentioned above, future research should expand the number of questions in this scale to more fully understand this.

While concurrent relationships show that emotional reactions affect the adolescents' functioning (especially for daughters), emotional reactions shortly after diagnosis are not predictive of later emotional or behavioral problems. Emotional reactions are associated with adolescents' emotional and behavioral functioning more in the short term, i.e., functioning at 6 months is related to emotional reactions at 6 months, not to the intensity of reactions experienced half a year earlier. Emotional reactions experienced earlier in the year do not seem to be a risk factor for adolescents' emotional and behavioral problems. A change in emotional reactions does not strongly predict dysfunction in sons. For daughters, change in emotions is significantly associated with increased total problems and

emotional dysfunction; in particular, increased uncertainty seems to be associated with dysfunction.

The presence of emotional and behavioral problems shortly after diagnosis is the strongest predictor of functioning later in the year, indicating that existing dysfunction may continue. When considering how to best service families after a parental cancer diagnosis, intervention efforts should focus on adolescents with emotional or behavioral dysfunction at the time of their parent's diagnosis. Under the extra stress of the illness, already present dysfunction may continue or become exacerbated.

One of this study's limitations is the response rate. In both study groups, half of the eligible families declined to participate. The reasons given varied widely, which prevent us from determining the effects non-response may have had on our data. Some families did not participate because they were experiencing problems; however, families also declined because the prognosis was positive or because they wanted to move on with their lives. Additionally, families whose parent was not expected to survive the first year were excluded from this study by the ethical review board. Only patients with a relatively good prognosis participated; a possible effect of this exclusion may be limited generalizability. The presence of a number of children from the same family in the retrospective data (48% of children had at least one sibling in the study) could have also had an effect on the generalizability of our results as children share environmental factors. In line with this concern, it should be noted that a possible limitation of home-based participation is that no research assistant is present to answer questions or to ensure that family members followed instructions and did not confer on answers. A follow-up study should consider asking families to fill in questionnaires in the hospital. A second possible limitation is the attrition between prospective measurements. Adolescents who dropped out of the study reported more helplessness than those who remained, which may suggest that adolescents who remained in the study experienced more moderate emotional reactions. Researchers examining families shortly after a cancer diagnosis should consider ways to ensure that attrition is low.

In conclusion, feelings of uncertainty and loneliness seem to be the emotions most strongly concurrently associated with adolescents' emotional and behavioral functioning. While retrospectively, emotional reactions relate to sons and daughters similarly, during the first year after diagnosis, daughters' negative reactions are more strongly associated with their functioning than sons'. It could be helpful for clinicians to inform parents about this risk and to encourage them to talk openly and realistically about the illness with their adolescent children or to consider ways to

make them feel less lonely. Daughters might benefit from interaction with peers facing the same challenges. Group interventions have been found to be useful for children who feel alone, particularly adolescents (Diareme et al., 2007). Dysfunction shortly after diagnosis predicted later dysfunction more strongly than emotional reactions. This should be taken into account when developing services for families facing parental cancer. Research should explore intervention options such as psycho-education and peer support to help children cope with their parent's cancer in order to understand which types of intervention (e.g., individual, group or through internet) would be most helpful.

Funding

Dutch Cancer Society (grant no. 2000–2333) and the IJsselmond Foundation for Health Care Research.

Conflicts of interest: None declared.

References

- Achenbach, T. (1991). *Manual for the Youth Self Report and 1991 profiles*. Burlington, Vermont: University of Vermont, Department of Psychiatry.
- Armistead, L., Klein, K., & Forehand, R. (1995). Parental physical illness and child functioning. *Clinical Psychology Review*, 15, 409–422.
- Armsden, G., & Lewis, F. (1993). The child's adaptation to parental medical illness: Theory and clinical implications. *Patient Education and Counseling*, 22, 153–165.
- Barnes, J., Kroll, L., Burke, O., Lee, J., Jones, A., & Stein, A. (2000). Qualitative interview study of communication between parents and children about maternal breast cancer. *The Western Journal of Medicine*, 173, 385–389.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (rev. ed.). Hillsdale, New Jersey: Erlbaum.
- Cohen, J., Cohen, P., West, S., & Aiken, L. (2003). *Applied multiple regression/correlational analyses for the behavioral sciences* (3rd ed.). Mahwah, New Jersey: Lawrence Erlbaum Associates Publishers.
- Cohen, P., & Brook, J. (1987). Family factors related to the persistence of psychopathology in childhood and adolescence. *Psychiatry*, 50, 332–345.
- Compas, B. E., Worsham, N., Epping-Jorden, J., Grant, K., Mireault, G., Howell, D., & Malcarne, V. L. (1994). When mom or dad has cancer: Markers of psychological distress in cancer patients, spouses, and children. *Health Psychology*, 13, 507–515.
- Compas, B. E., Worsham, N. L., Ey, S., & Howell, D. C. (1996). When mom or dad has cancer: II. Coping, cognitive appraisals, and psychological distress in children of cancer patients. *Health Psychology*, 15, 167–175.
- Comprehensive Cancer Center (2010). Cancer incidence in the Netherlands by gender. <http://www.ikcnet.nl/uploaded/FILES/Landelijk/cijfers/Incidentie%202003/A4%201999-2003.xls> [On-line].
- Davey, M., Askew, J., & Godette, K. (2003). Parent and adolescent responses to non-terminal parental cancer: A retrospective, multiple-case pilot study. *Family Systems & Health: The Journal of Collaborative Family Healthcare*, 21, 245–258.
- Diareme, S., Tsiantis, J., Romer, G., Tsalamani, E., Anasontzi, S., Paliokosta, E., & Kolaitis, G. (2007). Mental health support for children of parents with somatic illness: A review of the theory and intervention concepts. *Family Systems & Health: The Journal of Collaborative Family Healthcare*, 25, 98–118.
- Fitch, M., Bunston, T., & Elliot, M. (1999). When mom's sick: Changes in a mother's role and in the family after her diagnosis of cancer. *Cancer Nursing*, 22, 58–63.
- Gazendam-Donofrio, S., Hoekstra, H., van der Graaf, W., van de Wiel, H., Visser, A., Huizinga, G., & Hoekstra-Weebers, J. E. H. M. (2007). Family functioning and adolescents' emotional and behavioral problems: When a parent has cancer. *Annals of Oncology*, 18, 1951–1956.
- Gazendam-Donofrio, S., Hoekstra, H., van der Graaf, W., Visser, A., Huizinga, G., & Hoekstra-Weebers, J. (2009). Parent-child communication patterns during the first year after a parent's cancer diagnosis the effect on parents' functioning. *Cancer*, 115, 4227–4237.
- Grootenhuis, M., & Last, B. (1997). Parents' emotional reactions related to different prospects for the survival of their children with cancer. *Journal of Psychosocial Oncology*, 15, 43–62.
- Hamama, R., Ronen, T., & Feigin, R. (2000). Self-control, anxiety, and loneliness in siblings of children with cancer. *Social Work in Health Care*, 31, 63–83.
- Houtzager, B., Oort, F., Hoekstra-Weebers, J., Caron, H., Grootenhuis, M., & Last, B. (2004). Coping and family functioning predict longitudinal

- psychological adaptation of siblings of childhood cancer patients. *Journal of Pediatric Psychology*, 29, 591–605.
- Huizinga, G., Visser, A., van der Graaf, W., Hoekstra, H., Gazendam-Donofrio, S., & Hoekstra-Weebers, J. (2009). Stress response symptoms in adolescents during the first year after a parent's cancer diagnosis. *Supportive Care in Cancer*. Advance online publication, doi:10.1007/s00520-009-0764-6.
- Huizinga, G., Visser, A., van der Graaf, W., Hoekstra, H., & Hoekstra-Weebers, J. (2005). The quality of communication between parents and adolescent children in the case of parental cancer. *Annals of Oncology*, 16, 1956–1961.
- Huizinga, G. A., Visser, A., Hoekstra, H., van der Graaf, W., Klip, E., Pras, E., & Hoekstra-Weebers, J. E. H. M. (2005). Stress response symptoms in adolescent and young adult children of parents diagnosed with cancer. *European Journal of Cancer*, 41, 288–295.
- Kennedy, V., & Lloyd-Williams, M. (2009). How children cope when a parent has advanced cancer. *Psycho-oncology*, 18, 886–892.
- Kornreich, D., Mannheim, H., & Axelrod, D. (2008). How children live with parental cancer. *Primary Psychiatry*, 15, 64–70.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Lewis, F. (1996). The impact of breast cancer on the family: Lessons learned from the children and adolescents. In L. Baider, C. Cooper, & A. Kaplan De-Nour (Eds.), *Cancer and the family* (pp. 271–288). Chichester, UK: John Wiley & Sons.
- Li, C., DiGiuseppe, R., & Froh, J. (2006). The roles of sex, gender, and coping in adolescent depression. *Adolescence*, 41, 409–415.
- Mischel, M. (1999). Uncertainty in chronic illness. *Annual Review of Nursing Research*, 17, 269–294.
- Northouse, L. L., Templin, T., & Mood, D. (2002). Couples' adjustment to breast disease during the first year following diagnosis. *Journal of Behavioral Medicine*, 24, 115–136.
- Osborn, T. (2007). The psychosocial impact of parental cancer on children and adolescents: A systematic review. *Psycho-oncology*, 16, 101–126.
- Pedersen, S., & Revenson, T. (2005). Parental illness, family functioning, and adolescent well-being: A family ecology framework to guide research. *Journal of Family Psychology*, 19, 404–409.
- Rolland, J. (2005). Cancer and the family: An integrative model. *Cancer, Supplement: Cancer Survivorship: Resilience Across the Lifespan*, 104, 2584–2595.
- Steele, R., Tripp, G., Kotchick, B., Summers, P., & Forehand, R. (1997). Family members' uncertainty about parental chronic illness: The relationship of hemophilia and HIV infection to child functioning. *Journal of Pediatric Psychology*, 22, 577–591.
- Su, Y., Ryan-Wenger, N., & Nancy, A. (2007). Children's adjustment to parental cancer: A theoretical model development. *Cancer Nursing*, 30, 362–381.
- Thastum, M., Watson, M., Kienbacher, C., Piha, J., Steck, B., Zachariae, R., . . . Romer, G. (2009). Prevalence and predictors of emotional and behavioural functioning of children where a parent has cancer. A multinational study. *Cancer*, 115, 4030–4039.
- Vanheule, S., & Hauser, S. (2008). A narrative analysis of helplessness in depression. *Journal of the American Psychoanalytic Association*, 56, 1309–1330.
- Verhulst, F., van der Ende, J., & Koot, H. (1996). *Manual for the Youth Self Report*. Rotterdam, the Netherlands: Erasmus University, Department of Child and Adolescent Psychiatry.
- Visser, A., Huizinga, G., Hoekstra, H., van der Graaf, W., Gazendam-Donofrio, S., & Hoekstra-Weebers, J. (2007). Emotional and behavioral problems in children of parents recently diagnosed with cancer: A longitudinal study. *Acte Oncologica*, 46, 67–76.
- Visser, A., Huizinga, G., Hoekstra, H., van der Graaf, W., & Hoekstra-Weebers, J. (2007). Temperament as a predictor of internalising and externalising problems in adolescent children of parents diagnosed with cancer. *Supportive Care in Cancer*, 15, 395–403.
- Visser, A., Huizinga, G., Hoekstra, H., van der Graaf, W., Klip, E., Pras, E., & Hoekstra-Weebers, J. E. H. M. (2005). Emotional and behavioural functioning of children of a parent diagnosed with cancer: A cross-informant perspective. *Psycho-oncology*, 14, 1–12.
- Walsh, F. (1996). The concept of family resilience: Crisis and challenge. *Family Process*, 35, 261–281.
- Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process*, 42, 1–18.
- Weihs, K., & Politi, M. (2005). Family development in the face of cancer. In D. Crane, & E. Marshall (Eds.), *Handbook of Families and Health*.

- Interdisciplinary Perspectives* (pp. 3–18).
Sage Publications.
- Welch, A., Wadsworth, M., & Compas, B. E. (1996).
Adjustment of children and adolescents to parental
cancer: Parents' and children's perspectives. *Cancer*,
77, 1409–1418.
- Wellisch, D., & Gritz, E. (1996). Psychological concerns
and care of daughters of breast cancer patients.
In L. Baider, C. Cooper, & A. Kaplan-De Nour
(Eds.), *Cancer and the Family* (1st ed., pp. 289–304).
John Wiley & Sons Ltd.
- Wonghongkul, T., Dechaprom, N., Phumivichuate, L.,
& Losawatkul, S. (2006). Uncertainty appraisal
coping and quality of life in breast cancer survivors.
Cancer Nursing, 29, 250–257.