

University of Groningen

Emotional and behavioural functioning of children of a parent diagnosed with cancer

Visser, Annemieke; Huizinga, Geertje; Hoekstra, H.J.; van der Graaf, W.T.; Klip, E.C.; Pras, E.; Hoekstra-Weebers, J.E.

Published in:
 Psycho-oncology

DOI:
[10.1002/pon.902](https://doi.org/10.1002/pon.902)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
 Publisher's PDF, also known as Version of record

Publication date:
 2005

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Visser, A., Huizinga, G. A., Hoekstra, H. J., van der Graaf, W. T., Klip, E. C., Pras, E., & Hoekstra-Weebers, J. E. (2005). Emotional and behavioural functioning of children of a parent diagnosed with cancer: A cross-informant perspective. *Psycho-oncology*, 14(9), 746-758. DOI: 10.1002/pon.902

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

EMOTIONAL AND BEHAVIOURAL FUNCTIONING OF CHILDREN OF A PARENT DIAGNOSED WITH CANCER: A CROSS- INFORMANT PERSPECTIVE

ANNEMIEKE VISSER^a, GEA A. HUIZINGA^a, HARALD J. HOEKSTRA^b, WINETTE T.A. VAN DER GRAAF^c,
ED C. KLIP^a, ELISABETH PRAS^d and JOSETTE E.H.M. HOEKSTRA-WEEBERS^{a,c,*}

^a *Department of Health Psychology, Groningen University Medical Centre, The Netherlands*

^b *Department of Surgical Oncology, Groningen University Medical Centre, The Netherlands*

^c *Department of Medical Oncology, Groningen University Medical Centre, The Netherlands*

^d *Department of Radiation Oncology, Groningen University Medical Centre, The Netherlands*

^e *Comprehensive Cancer Centre North-Netherlands, Groningen, The Netherlands*

SUMMARY

This study investigates emotional and behavioural problems in children of parents diagnosed with cancer and examines the relationship with demographic and illness-related variables. Furthermore, agreement and differences between informants regarding child's functioning were examined. Members of 186 families in which a parent had been diagnosed with cancer participated. More emotional problems were reported for latency-aged sons (ill parents) and adolescent daughters (ill parents; self-reports), whereas also better functioning was reported in adolescent children (spouses), compared to the norm group. Age and gender-effects were found: latency-aged sons were perceived as having more emotional problems than adolescent sons (ill parents); adolescent daughters as having more emotional and behavioural problems than adolescent sons (ill parents; self-reports). Results indicated a higher prevalence of problems when the father was ill than when the mother was (spouses and self-reports). The treatment intensity affected adolescent daughter's functioning (spouses), whereas adolescent son's functioning was affected by relapsed disease (self-reports). Adolescents and mothers perceived comparable levels of problems, but fathers perceived problems in children to be less prevalent. Findings suggest that adolescent daughters and latency-aged sons are at risk for emotional problems following the diagnosis of cancer in a parent. The perception of child's functioning and potential influencing variables varied according to informant. Copyright © 2005 John Wiley & Sons, Ltd.

KEY WORDS: emotional and behavioural problems; parental cancer; children; adolescents; cross informant perspective

INTRODUCTION

Cancer has a profound impact on patients, but may also be a significant emotional stressor for children (Rait and Lederberg, 1989). Children may experience stress when confronted with the symptoms of the illness, the consequences and side effects of the treatments, and the threat of a

parent's death (Christ *et al.*, 1994). Alterations in daily family routines due to hospital visits and admissions can also be stressful for children, who may manifest such stress in increased levels of emotional and behavioural problems. Latency-aged children have been shown to function emotionally and behaviourally similar to other children (Heiney *et al.*, 1997; Howes *et al.*, 1994). A number of studies, however, have shown that the adolescent children of cancer patients appear to have more emotional problems than do other adolescents (Birenbaum *et al.*, 1999; Compas *et al.*, 1994; Siegel *et al.*, 1992; Welch *et al.*, 1996). Adolescent daughters whose mothers were ill

*Correspondence to: Psychosocial Services, Groningen University Medical Centre, P.O. Box 30.001, 9700 RB Groningen, The Netherlands. E-mail: j.hoekstra-weebers@psb.azg.nl, j.hoekstra-weebers@ikn.nl

appeared to be particularly vulnerable (Compas *et al.*, 1994; Welch *et al.*, 1996). Other studies have suggested that the functioning of the adolescent children of cancer patients is similar to (Howes *et al.*, 1994; Huizinga *et al.*, 2003)—or even better than—that of other adolescents (Hoke, 2001).

Inconsistencies in the results reported in prior studies may be due to variability in study design. Studies with small samples (e.g. Heiney *et al.*, 1997; Howes *et al.*, 1994), may suffer from bias. Studies vary further according to illness-related characteristics, with some studies focusing on breast cancer patients (Hoke, 2001) and others focusing on patients with various types of cancer (e.g. Compas *et al.*, 1994). In addition, time since diagnosis varied substantially. Additionally, various informants on children's functioning introduce incongruency (Birenbaum *et al.*, 1999; Welch *et al.*, 1996). Parents are important informants, observing children's behaviour over time and in many situations. Parents' reports, however, are based on observable behaviour and the verbal reports of children (Verhulst and van der Ende, 1992). The demands and uncertainties of cancer may make it difficult for a parent to recognize the needs of the children and to provide accurate information about their functioning. The self-reports of adolescents reflect their emotions and behaviours across different situations as well as their internal states (Verhulst and van der Ende, 1992). Yet, children may tend to deny their symptoms (Grills and Ollendick, 2002). Information obtained from a single source may give a one-sided view, while multiple perspectives may provide a more complete picture of the functioning of the child.

Large-scale research is needed to gain a better understanding of the consequences of parental cancer for the behavioural and emotional functioning of children, and to identify individual differences among children in the prevalence of these problems. The goals of this study are (1) to examine the emotional and behavioural functioning of sons and daughters of parents diagnosed with cancer by comparing them to children in a norm group; (2) to investigate whether emotional and behavioural functioning differs according to the age and gender of the child and the gender of the ill parent; (3) to assess the impact of illness-related variables; and (4) to examine the extent to which different informants agree or differ in their perceptions of the functioning of children.

METHODS

Procedure

Cancer patients and their family members were approached at the Groningen University Medical Centre between January 2001 and February 2003. Physicians and oncology nurses offered written information to all eligible patients and an adapted version for their children. Patients were eligible for study participation when diagnosed with cancer between one to five years prior to study entry and if they had children between 4 and 18 years of age who had resided with or had frequent contact with the parent diagnosed with cancer. To be eligible to participate, both parents and children had to be fluent in Dutch. Informed consent was obtained from family members separately, according to the regulations of the Medical Ethical Committee of the Groningen University Medical Centre. After obtaining written informed consent, separate questionnaires and prepaid return envelopes were sent to each participating family member. Family members were instructed to complete the questionnaires independently and not to consult other family members.

Instruments

Parents were asked to complete the Child Behaviour Checklist (CBCL) (Achenbach, 1991a; Verhulst *et al.*, 1996) to assess the emotional and behavioural functioning of children over the preceding six months. Adolescents completed the self-report version of the CBCL, the Youth Self-Report (YSR), designed for children between 11 and 18 years of age (Achenbach, 1991b; Verhulst *et al.*, 1997). The CBCL consists of 120 and the YSR of 102 problem items, each of which has three response options (0 = not true, 1 = somewhat or sometimes true, 2 = very true or often true). To provide a generalizable picture of the problems occurred in children of parents diagnosed with cancer, the present study used the internalizing, externalizing, and total problem scale of the CBCL/YSR. The internalizing scale reflects the internal mental states of children and consists of the narrowband syndromes of withdrawal, somatic complaints, and anxiety/depression. The externalizing scale represents socially unacceptable behaviour and consists of the syndromes of

delinquent and aggressive behaviour. The total problem scale represents the total score derived from the sum of all items and consists of the internalizing and externalizing scales, thought, social, attention problems as well as the scale other problems. In addition, self-reports for boys contained the syndrome of self-destructive problems, and parents' reports for latency-aged children included the syndrome of sex problems. Higher scores denote more problems. Normative data of the CBCL and YSR are available, with separate norms for latency-aged children (aged 4–11 years) and adolescents (aged 11–18 years), and for boys and girls (Verhulst *et al.*, 1997, 1996). The norm data of the CBCL were based on a randomly selected Dutch sample of 1241 parents (95% mothers) who provided information about the functioning of their latency-aged children (623 boys, 618 daughters) and 986 parents (95% mothers) who rated the functioning of their adolescent children (493 boys, 493 daughters). The YSR norm-group consisted of a random selection of 1124 adolescents (560 boys, 564 daughters). Raw scores were used to compare the mean scores of children and the percentage children who were clinically disturbed in the present study with the norm group. Raw scores were transformed into *T*-scores, based on normative data, to assess possible differences between age and gender groups, and between informants, beyond expected differences in the general population. The manual of the CBCL/YSR defines cut-off points for *T*-scores to differentiate youngsters considered to function normally from those considered to have clinically elevated problems (*T*-score > 63). The reliability and validity of the CBCL/YSR has been supported in a wide number of international and national studies. Cronbach's alpha's in the present study for the internalizing, externalizing, and total problem scales of the CBCL and YSR ranged from 0.84 to 0.94.

Analysis

One Sample *T*-Tests were conducted to compare raw scores on the CBCL and the YSR with normative data. Chi-square tests were used to compare the frequencies of latency-aged children and adolescents scoring above and below the cut-off points with the norm-group (Verhulst *et al.*, 1996, 1997).

Independent *T*-Tests were performed to test for differences in *T*-scores between latency-aged children and adolescents. Analyses of variance (ANOVA) were conducted to test for differences in *T*-scores on the CBCL and YSR as a function of the gender of the child and of the ill parent, or as a function of the interaction between these two variables.

Independent *T*-Tests, ANOVA and *Post Hoc* Tests (Scheffé) were computed to examine whether differences in children's functioning (*T*-scores) could be explained by illness-related variables. Length of time since diagnosis was categorized (1 to 2; 2 to 3; 3 to 4 or >4 years after diagnosis). A dichotomous variable was created for the treatment parents received ('surgery only' and 'non-surgical' or multimodal treatments, combining two or more treatment regimens). Duration of treatment was categorized (0–3 months; 4–6 months, >7 months) and a dummy variable was created for recurrence of illness.

Pearson's product-moment correlations were performed to assess relative agreement (*T*-scores) between informants (Bland and Altman, 1986). Intraclass correlation coefficients (ICC) were also calculated to assess pair-wise agreement between informants (absolute agreement). A Pearson correlation coefficient lower than 0.30 indicates poor agreement, a coefficient between 0.30 and 0.50 indicates moderate agreement, and a coefficient higher than 0.50 indicates good agreement (Cohen, 1988). An ICC lower than 0.40 suggests low agreement, a coefficient between 0.40 and 0.75 suggests moderate to good agreement, and ICC above 0.75 suggest excellent agreement (Novella *et al.*, 2001). Finally, Paired *T*-Tests were conducted to assess differences in the mean scores of various informants.

RESULTS

Participants

Of the 476 cancer patients and family members informed about the study, 205 consented to participate (response rate 43%). In 22 percent of the families that declined to participate, the parents indicated that they were too emotionally distressed themselves, did not want to stir up emotions again, or that they wanted to move on and leave the illness behind. In 20 percent the

reason not to participate was because the children lacked interest in the study, parents were afraid for emotional distress of the children, or expected that effects of cancer were small because minimal treatment was needed (for example melanoma), or children were not informed about the diagnosis. Twenty-five percent mentioned a variety of reasons, including business of the children or the parents, or other illnesses in the family. The remaining 33 percent of the families specified no reasons for non-participation. Parents in the families that declined to participate did not differ significantly from participating parents concerning gender of the ill parent, type of cancer, and time since diagnosis.

Some children had been 18 years of age at the time of diagnosis, but were 19 years of age or older during the study period. Because the instruments used were developed for children between the ages of 4 and 18 years, children above the age of

18 years did not complete the questionnaires. The sample for the study therefore consisted of 180 ill parents, 145 spouses, 114 latency-aged children (4–11 years), and 222 adolescents (12–18 years). Child-rearing activities in participating two-parent families were performed by the mothers in 61 percent; by both parents in 35 percent, and by fathers in 4 percent. Demographic characteristics of the study population are summarized in Table 1.

Patients were diagnosed with various types of cancer: breast (53%); gynaecological (11%); skin (10%); haematological (9%); soft tissue and bone tumours (5%); urological (5%); gastrointestinal (2%); and other cancers (including central nervous system or head and neck cancer 5%). The mean time since diagnosis was 2.7 years (S.D. 1.2). Thirty-four patients (19%) had suffered from relapses. Fifteen percent of the ill parents had initially received treatments involving only

Table 1. Demographic characteristics

Parent characteristics					
	<i>N</i>	(%)		<i>N</i>	(%)
<i>Ill parents</i>	180		<i>Spouses</i>	145	
Mothers	146	81	Mothers	32	22
Fathers	34	19	Fathers	113	78
Mean age = 44.3, S.D. = 5.1			Mean age = 44.8, S.D. = 7.3		
Age range = 32–57 years			Age range = 31–65 years		
<i>Highest level of education completed by the ill parent</i>			<i>Highest level of education completed by the spouse</i>		
Low ^a	54	30	Low ^a	43	30
Middle ^b	71	39	Middle ^b	57	39
High ^c	55	31	High ^c	45	31
Child characteristics					
<i>Latency-aged children</i>	114		<i>Adolescents</i>	222	
Daughters	55	48	Daughters	117	52
Sons	59	52	Sons	105	48
Mean age = 7.8 years, S.D. = 1.6			Mean age = 15.0 years, S.D. = 2.3		
Family characteristics					
One-parent families	13	7			
Number of children in a family			Number of children participating in the study per family		
1	28	16	1	69	38
2	90	50	2	79	44
3	45	25	3	23	13
≥4	17	9	≥4	9	5

^aPrimary school or lower vocational degree.

^bLower general secondary education or intermediate vocational education or high school degree.

^cHigher vocational education or university degree.

surgery, and 85 percent had received more intensive treatment regimens consisting of chemotherapy or radiotherapy, or multi-modal treatments combining two or more treatment regimens. The mean duration of treatment was 3.8 months (S.D. 3.0).

Ill fathers did not differ significantly from ill mothers in age, educational level, number of children and one versus two-parent families, or in time since diagnosis, treatment received or recurrence of illness.

Emotional and behavioural functioning

Parent reports regarding latency-aged children. Ill parents reported significantly more internalizing problems in their sons than did parents from the norm population. No other significant differences were found (Table 2).

According to reports from ill parents and their spouses, 23 percent of sons had internalizing problems in the clinical range, as compared to 10 percent in the norm population ($\chi^2 = 10.9$, $p \leq 0.001$; $\chi^2 = 7.4$, $p = 0.006$, respectively). Ill parents rated 20 percent of the sons above the clinical cut-off on the total problem scale, a percentage significantly higher than the 8 percent found in the norm population ($\chi^2 = 10.3$, $p = 0.003$). According to reports from ill parents, 20 percent of daughters had externalizing problems above the cut-off, as compared to 10 percent of girls in the norm population ($\chi^2 = 6.1$, $p = 0.013$). The percentages of children who were scored above the cut-off on the remaining CBCL

scales were comparable with those found in the norm-group.

Parent reports regarding adolescent functioning. Ill parents reported significantly more internalizing problems in adolescent daughters than were reported for girls in the norm population. Ill parents reported similar scores for internalizing problems in sons, and externalizing and total problems in both sons and daughters as those reported for the norm population. Spouses, however, reported significantly lower levels of internalizing and total problems in both adolescent sons and daughters and lower levels of externalizing problems in sons (Table 2).

According to the ill parents, 17 percent of adolescent daughters had scores above the cut-off on the internalizing scale, which was significantly higher than the 8 percent found in the norm population ($\chi^2 = 12.5$, $p \leq 0.001$). No further significant differences were found between the percentages of adolescents whose parents' scores placed them within the clinical range and those found within the norm population.

Adolescent self-reports. Adolescent daughters reported significantly more internalizing and total problems than did their peers in the norm-group (Table 3). Sons reported no more problems than did boys in the norm group.

Compared to adolescent girls in the norm group, a significantly higher percentage of adolescent daughters of cancer patients had scores above the clinical cut-off on the internalizing (23%) and total problem scales (21%) (norm group girls: 8%

Table 2. Descriptive statistics for raw scores on the Child Behaviour Checklist (CBCL) and *T*-Tests for differences between parental scores for latency-aged children and adolescents and those from the norm-group

	Ill parent				Spouse				Norm-group			
	Sons		Daughters		Sons		Daughters		Boys		Girls	
	<i>M</i>	(S.D.)	<i>M</i>	(S.D.)	<i>M</i>	(S.D.)	<i>M</i>	(S.D.)	<i>M</i>	(S.D.)	<i>M</i>	(S.D.)
<i>Latency-aged children</i>												
Internalizing	7.1	(6.9)*	6.2	(4.9)	5.7	(6.5)	5.3	(5.7)	4.8	(4.7)	5.4	(5.5)
Externalizing	8.9	(6.6)	6.8	(6.6)	7.6	(6.0)	6.2	(7.2)	8.6	(6.7)	6.2	(5.9)
Total problems	24.7	(18.6)	20.4	(14.3)	20.8	(16.0)	18.6	(18.0)	22.5	(15.2)	20.0	(16.1)
<i>Adolescents</i>												
Internalizing	5.4	(5.5)	8.5	(7.2)**	4.1	(3.9)**	5.3	(5.0)*	5.7	(5.7)	6.5	(6.0)
Externalizing	6.4	(5.7)	6.1	(5.9)	4.7	(4.2)**	5.2	(4.9)	7.1	(7.1)	5.5	(5.8)
Total problems	18.0	(14.2)	21.5	(17.0)	14.2	(9.7)**	15.2	(12.6)*	20.1	(16.5)	18.7	(14.6)

* $p \leq 0.05$, ** $p \leq 0.001$.

Table 3. Descriptive statistics for raw scores on the Youth Self-Report (YSR) and *T*-Tests for differences with the norm-group

	Adolescents							
	Sons		Norm-group		Daughters		Norm-group	
	<i>M</i>	(S.D.)	<i>M</i>	(S.D.)	<i>M</i>	(S.D.)	<i>M</i>	(S.D.)
Internalizing	8.7	(6.8)	8.6	(5.8)	13.7	(9.6)***	10.8	(7.1)
Externalizing	10.6	(5.7)	11.5	(6.7)	10.6	(6.1)	10.0	(6.1)
Total problems	32.4	(17.3)	33.7	(16.8)	39.6	(21.6)**	34.5	(18.0)

** $p \leq 0.01$, *** $p \leq 0.001$.

on both scales; $\chi^2 = 38.6$, $p \leq 0.001$; $\chi^2 = 27.3$, $p \leq 0.001$, respectively). The percentages of sons in the clinical range were all at norm-group levels.

Gender and age differences (using T-scores)

Age of child. Ill parents reported that latency-aged sons had significantly more internalizing problems than did adolescent sons ($t = 2.3$, $p = 0.023$). No other significant differences were found between latency-aged children and adolescents.

Gender of latency-aged child and parent. Results of the ANOVA performed on the reports of ill parents concerning their latency-aged children revealed no significant gender effects for either the child or the ill parent. For the reports of spouses, however, ANOVA showed significant effects for the gender of the ill parent: more internalizing ($F = 8.2$, $p = 0.005$) and total problems ($F = 9.6$, $p = 0.003$) were reported among latency-aged children when the father was ill than when the mother was ill.

Gender of adolescent and parent. Results of the ANOVA performed on the reports of ill parents showed significant effects for the gender of the adolescent on internalizing ($F = 7.3$, $p = 0.007$), externalizing ($F = 6.5$, $p = 0.012$), and total problems ($F = 8.6$, $p = 0.004$). In addition, interaction effects were found for the gender of both the adolescent and the ill parent on externalizing ($F = 8.4$, $p = 0.004$) and total problems ($F = 8.2$, $p = 0.005$). This means that, according to ill parents, daughters—particularly those whose fathers were ill—were perceived to have more problems than sons. Results of the ANOVA performed on the reports of spouses showed significant effects for the gender of the ill parent:

adolescents had more internalizing ($F = 24.3$, $p \leq 0.001$), externalizing ($F = 4.8$, $p = 0.030$), and total problems ($F = 14.5$, $p \leq 0.001$) when the father was ill than when the mother was ill. In addition, the gender of the adolescent was found to have a significant effect on externalizing problems ($F = 5.6$, $p = 0.019$), suggesting that, according to the spouses, adolescent daughters had more externalizing problems than did sons.

Results of the ANOVA performed on adolescents' self reports showed significant differences as a function of the gender of the ill parent and of the child for internalizing ($F = 9.1$, $p = 0.003$; $F = 5.0$, $p = 0.027$, respectively) and total problems ($F = 5.4$, $p = 0.021$; $F = 4.3$, $p = 0.04$, respectively). This means that adolescent children whose fathers were ill reported having significantly more problems than did adolescent children whose mothers were ill, and that adolescent daughters reported significantly more problems than did adolescent sons.

Illness-related variables

Independent *T*-Tests of the reports of ill parents yielded no significant differences in the level of internalizing, externalizing, and total problems experienced by latency-aged and adolescent children of parents whose treatment had consisted of surgery alone and those experienced by children of parents who had received chemotherapy, radiotherapy, or multi-modality treatment, nor did the self-reports of adolescents. The reports of spouses indicated that adolescent daughters of parents whose treatments had involved only surgery had less externalizing ($t = 2.9$, $p = 0.008$) and total problems ($t = 2.7$, $p = 0.005$) than did adolescent daughters whose parents had received other treatments or combinations of treatments. Latency-aged and adolescent children whose

parents had suffered from recurrent illness were not perceived by their parents to have more problems than were the children of parents who had experienced no recurrent illness. Self-reports from adolescent sons, however, revealed more internalizing ($t = 2.8$, $p = 0.006$) and total problems ($t = 2.4$, $p = 0.019$) when the parent had experienced recurrent illness. Time since diagnosis and duration of treatment did not have significant effects on problems in latency-aged and adolescent sons and daughters.

Informant agreement

Agreement between parents. High correlations were found between the reports of fathers and mothers¹ regarding the internalizing, externalizing, and total problems of their latency-aged children ($r = 0.48$ – 0.75) and adolescents ($r = 0.52$ – 0.65). Comparable levels of agreement were found for parents in the norm group (latency-aged children: $r = 0.54$ – 0.81 ; adolescents: $r = 0.52$ – 0.74). Intraclass correlation coefficients (ICC) showed similar results among latency-aged children and adolescents ($\rho_1 = 0.45$ – 0.75 ; $\rho_1 = 0.43$ – 0.54 , respec-

tively). Paired *T*-Tests showed no significant differences between reports of fathers and mothers with regard to the internalizing, externalizing, and total problems of latency-aged sons. Mothers reported significantly more internalizing and total problems in their latency-aged daughters and in both adolescent sons and daughters than did fathers. According to the mothers, adolescent sons also had more externalizing problems (Table 4). *T*-tests for norm group parents showed one significant difference only: mothers reported more total problems in adolescent daughters than did fathers ($p \leq 0.05$) (Verhulst *et al.*, 1996).

Parent–adolescent agreement. Pearson correlations and ICC showed low to moderate agreement (varying from $r = 0.28$ – 0.40 and $\rho_1 = 0.25$ – 0.40) between the reports of parents and those of adolescents. Levels of agreement between parents and adolescents in the norm group ranged from moderate to high (parents–sons: $r = 0.45$ – 0.55 ; parents–daughters: $r = 0.50$ – 0.63). Paired *T*-Tests showed no significant differences between the mean scores of the mothers and those of adolescent sons and daughters. In contrast, adolescent

Table 4. Informant agreement between fathers and mothers regarding latency-aged child and adolescent functioning using Pearson product moment correlation coefficients, intraclass correlation coefficients, and Paired *T*-Tests

<i>T</i> -scores	Fathers		Mothers		<i>r</i>	ρ_1	<i>t</i>	Mean differences	95% Confidence intervals of the differences
	Mean	(S.D.)	Mean	(S.D.)					
<i>Latency-aged sons</i>									
Internalizing	49.1	(12.8)	53.1	(10.6)	0.48**	0.45**	−1.59	−3.9	−8.05 – 0.16
Externalizing	48.3	(10.6)	49.8	(10.7)	0.75***	0.75***	−1.97	−1.5	−4.05 – 1.05
Total problems	47.1	(13.4)	49.9	(11.3)	0.63***	0.61***	−1.59	−2.8	−6.51 – 0.78
<i>Latency-aged daughters</i>									
Internalizing	48.8	(10.7)	52.3	(10.7)	0.66**	0.63***	−2.46*	−3.5	−6.36 – −0.62
Externalizing	49.6	(10.4)	50.3	(12.5)	0.59***	0.58***	−0.39	−0.6	−4.11 – 2.77
Total problems	47.3	(12.1)	50.7	(11.6)	0.63***	0.61***	−2.11*	−3.4	−6.73 – −0.14
<i>Adolescent sons</i>									
Internalizing	45.1	(9.3)	51.4	(9.3)	0.52***	0.43***	−5.84***	−6.2	−8.35 – −4.11
Externalizing	46.1	(8.9)	50.8	(9.0)	0.61***	0.54***	−5.03***	−4.7	−6.54 – −2.83
Total problems	44.6	(9.5)	50.6	(9.6)	0.65***	0.54***	−6.41***	−6.0	−7.88 – −4.14
<i>Adolescent daughters</i>									
Internalizing	47.5	(10.1)	52.7	(10.2)	0.55***	0.49***	−4.87***	−5.1	−7.25 – −3.04
Externalizing	49.9	(9.8)	51.6	(10.0)	0.55***	0.54***	−1.64	−1.7	−3.76 – 0.37
Total problems	46.6	(11.0)	51.2	(10.6)	0.56***	0.52***	−4.06***	−4.6	−6.79 – −2.33

* $p < 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$.

Table 5. Informant agreement between adolescent sons and daughters and the fathers and mothers using Pearson product moment correlation coefficients, intraclass correlation coefficients, and Paired *T*-Tests

<i>T</i> -scores	Adolescents		Parents		<i>r</i>	ρ_1	<i>t</i>	Mean differences	95% Confidence intervals of the differences
	Mean	(S.D.)	Mean	(S.D.)					
<i>Adolescent sons-fathers</i>									
Internalizing	49.9	(9.4)	44.9	(9.4)	0.31**	0.27**	3.94***	4.97	2.46–7.49
Externalizing	48.7	(8.5)	46.0	(8.9)	0.38***	0.37***	2.42*	2.66	0.47–4.86
Total problems	49.3	(8.7)	44.4	(9.7)	0.28*	0.25**	3.92***	4.94	2.43–7.44
<i>Adolescent sons-mothers</i>									
Internalizing	50.8	(10.5)	51.6	(9.4)	0.36***	0.36***	−0.68	−0.80	−3.15–1.54
Externalizing	49.5	(9.1)	51.1	(9.2)	0.37***	0.37***	−1.52	−1.63	−3.76–0.50
Total problems	50.2	(9.8)	50.7	(9.7)	0.35***	0.36***	−0.43	−0.49	−2.79–1.80
<i>Adolescent daughters-fathers</i>									
Internalizing	53.2	(11.2)	47.4	(10.0)	0.34***	0.29***	4.65***	5.81	3.33–8.29
Externalizing	51.3	(9.7)	49.0	(9.7)	0.36***	0.35***	2.02*	2.29	3.50–4.55
Total problems	52.4	(11.1)	45.9	(11.3)	0.36***	0.31***	5.05***	6.52	3.95–9.09
<i>Adolescent daughters-mothers</i>									
Internalizing	53.6	(11.9)	53.0	(10.5)	0.39***	0.38***	0.52	0.60	−1.67–2.87
Externalizing	51.6	(9.9)	50.9	(9.6)	0.40***	0.40***	1.64	0.68	−1.27–2.62
Total problems	52.7	(11.3)	51.0	(10.9)	0.34***	0.34***	1.46	1.71	−0.61–4.04

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$.

sons and daughters reported significantly more internalizing, externalizing, and total problems than did fathers (Table 5). In the norm group, adolescents reported significantly more problems than did their parents ($p \leq 0.05$). (Agreement/differences between parents and adolescents in the norm group were not examined for fathers and mothers separately (Verhulst and van der Ende, 1992).)

DISCUSSION

A parent's life-threatening illness can have far-reaching consequences for the functioning of children. The current study is the first large-scale research project in the Netherlands to address the incidence of emotional and behavioural problems in children whose parents were diagnosed with cancer between one and five years prior to the study. The study involves separate analyses conducted for latency-aged children and adolescents, and for sons and daughters. In addition, various sources of information are considered, through which a comprehensive image is developed of the functioning of the child.

The primary goal of the study was to examine the emotional and behavioural functioning of sons and daughters of parents diagnosed with cancer by comparing them to a norm population. The results of the present study showed that ill parents reported more internalizing problems for their latency-aged sons than were reported for their norm-group peers. In addition, the percentage of latency-aged sons reported by both ill parents and their spouses as having scores in the clinical range for internalizing problems and total problems was higher (approximately one in five) than that of latency-aged boys in the norm population. Furthermore, reports from ill parents revealed that a greater percentage of latency-aged daughters (also one in five) had externalizing problems in the clinical range. The results of the present study are not in line with previous studies among the latency-aged children of parents diagnosed with cancer, which have reported the functioning of these children to be similar to that of norm-group children (Compas *et al.*, 1994; Howes *et al.*, 1994; Welch *et al.*, 1996). The studies cited here focused only on the CBCL subscales for anxiety/depression and aggression, while the internalizing and externalizing scale used in the present study

includes a wider range of problems. Another explanation might be that the studies cited here were based on children's self-reports, while the present study used parent's reports. Children in the earlier studies also had high scores on a 'lie scale,' which may suggest that the children had attempted to present themselves in favourable or socially desirable ways. Although, the ambiguous results between the current study and prior studies among children of cancer patients, studies aimed at the development of children have suggested that boys in the latency period are at risk for developing problems when confronted with stressors (Keenan and Shaw, 1997; Kraemer, 2000; Simmons *et al.*, 1987). These studies hypothesized that boys' skills in language and social-emotional functioning are not yet matured. As a consequence, boys might be incapable to express personal feelings and preferences efficaciously, which may lead to more distress. More research is needed in order to gain a more thorough picture of the factors influencing and mechanisms underlying the vulnerability of latency-aged sons.

The present study also showed adolescent daughters to have higher mean scores on internalizing problems and that a greater percentage of adolescent daughters had clinically elevated scores on internalizing and total problems than was the case among girls in the norm population. This finding is consistent with other studies (Compas *et al.*, 1994; Grant and Compas, 1995; Welch *et al.*, 1996). The heavier responsibility for household or care-taking tasks in the family experienced by girls during a parent's illness may account for the higher incidence of problems among daughters (Christ *et al.*, 1994; Compas *et al.*, 1994; Grant and Compas, 1995). An alternative explanation for the greater vulnerability of adolescent daughters is the tendency of mothers to share their emotions with their daughters and to lean on their daughters for support (Lichtman *et al.*, 1984). This emotional involvement may be too great a burden for the adolescent daughters (Christ *et al.*, 1994; Compas *et al.*, 1994; Grant and Compas, 1995).

One remarkable finding was that the level of functioning reported by spouses concerning their adolescent sons and daughters was better than that reported by the parents of adolescents in the norm population. More than three-quarters of the spouses in the current study were fathers, while information on the functioning of children from the norm-group was obtained from a majority of mothers. In general, fathers tend to report fewer

problems in their children than do mothers (Bartels *et al.*, 2003; Duhig *et al.*, 2000; Treutler and Epkins, 2003). It is possible that the apparent underreporting of problems in children by the spouses was an artefact of the overrepresentation of male spouses in the present study.

The results described above suggest that parental cancer may have more to do with the prevalence of internalizing problems (e.g. withdrawal, somatic complaints, and anxiety/depression) than with externalizing problems (e.g. delinquent or aggressive behaviour). A study of children of divorced parents showed that children experienced more externalizing than internalizing problems (Hetherington and Stanley-Hagan, 1999). Apparently, different types of stressors trigger problems in different areas, and confrontation with cancer does not necessarily lead to outward-directed behavioural problems, but may lead children to turn inward emotionally.

The second purpose of the present study was to investigate whether the prevalence of problems was related to the age and gender of the child or to the gender of the ill parent. The results of the present study indicated that latency-aged sons suffered more internalizing problems than did adolescent sons. This is in contrast to previous studies, which have found adolescents to experience more emotional problems than latency-aged children (Christ *et al.*, 1994; Compas *et al.*, 1994; Welch *et al.*, 1996). The contradictions in these results may be due to differences in the informants that were consulted. The present study was based on the reports of parents, while the earlier studies relied on the self-reports of children.

Regarding the gender of the adolescents and that of the parents, effects depended on the informant who provided the information about child's functioning. According to the ill parents and adolescents themselves, adolescent daughters experienced more problems than did adolescent sons. In addition to the explanations offered above, differences between sons and daughters may be due to the higher sensitivity of adolescent daughters (as compared to sons) to interpersonal concerns and stressful life-events involving others (Gore *et al.*, 1993; Grant *et al.*, 2003; Nolen-Hoeksema, 2001). It has also been suggested that adolescent daughters are more likely than sons to respond to stressful events with ineffective coping strategies (Nolen-Hoeksema and Jackson, 2001). Furthermore, it is possible that, as a consequence of gender role socialization, daughters are encour-

aged to express emotions, but sons are stimulated to control their emotions (Eisenberg *et al.*, 1998; Garside and Klimes-Dougan, 2002).

Reports from spouses demonstrated that latency-aged children and adolescents had more problems when the father was diagnosed with cancer than when the mother was ill. Adolescents' self-reports also showed that adolescents had more problems when the father was ill. These findings were not in concordance with previous research that showed adolescent daughters of ill mothers to be the most vulnerable (Compas *et al.*, 1994; Grant and Compas 1995; Lichtman *et al.*, 1984; Welch *et al.*, 1996). Because of the small number of ill fathers in the present study, these results may be due to coincidence and must be interpreted with caution. More attention will be paid to these gender effects in parental reports later on in this paper.

The third goal of the study was to study the relationship between illness-related variables (time since diagnosis, initial treatment regimen, duration of treatments, and recurrence of illness) and the functioning of children. According to parents, the functioning of latency-aged children appeared not to have been affected by these illness-related variables. In general, this was also found for adolescents. The self-reports of adolescent sons, however, revealed more problems when the parent had experienced a recurrence of the illness, and spouses reported that adolescent daughters functioned less well when the parent had received a more intensive treatment than surgery alone. The literature on the impact of illness-related variables is limited. The results of the few studies conducted on this topic indicated that not the objective characteristics of the illness (e.g. stage of illness, 5-year survival rates, time since diagnosis) but the child's perception of the severity and stressfulness of the illness were related to emotional problems (Compas *et al.*, 1994, 1996). For this reason, recurrence of illness and an intensive treatment regimen may be indicative of the adolescents' perceptions of the severity or stressfulness of a life-threatening illness such as cancer.

The fourth purpose of the present study was to examine agreement among the reports of mothers and fathers, and between parents and adolescents. Interparental correspondence was found to be moderate to high, which corresponds to findings from other studies (Duhig *et al.*, 2000; Verhulst *et al.*, 1996). Further analyses demonstrated significant discrepancies in mean scores

between fathers and mothers. In general, mothers reported more internalizing and total problems in latency-aged daughters and in adolescent sons and daughters than did fathers. The finding that mothers reported more problems than did fathers was consistent with the results of a meta-analysis (Duhig *et al.*, 2000), but was in conflict with other studies that found fathers and mothers to report similar levels of problems (Sourander *et al.*, 1999; Stanger and Lewis, 1993; Verhulst *et al.*, 1996).

The low to moderate agreement between the reports of parents and adolescents found in the present study was also documented in studies among parents and adolescents in other situations (Achenbach *et al.*, 1987; Birenbaum *et al.*, 1999; Thompson *et al.*, 1993). Furthermore, adolescents reported experiencing more problems than their fathers had reported, while the level of problems reported by adolescents and mothers was comparable. This last finding is remarkable, because studies among a community sample found that adolescents reported experiencing more problems than their parents perceived them to have (Sourander *et al.*, 1999; Stanger and Lewis, 1993; Verhulst and van der Ende, 1992; Zukauskienė *et al.*, 2004). These studies, however, did not examine differences between reports of adolescents and those of fathers and mothers separately.

Our study suggests that fathers underreport the problems of their children. In general, children tend to behave more obediently toward their fathers than toward their mothers (Duhig *et al.*, 2000), which may obscure the fathers' perceptions of the emotional and behavioural problems their children truly have. The fathers in the present study may have been so focused on the illnesses of their wives and on the changes in responsibilities that their attention to the functioning of their children may have been affected further. In contrast with earlier studies (Stanger and Lewis, 1993), mothers seem to have agreed with their adolescents regarding the level of problems their children had experienced. It is plausible that mothers may have a better perception of the child's functioning than do fathers, as they are more often responsible for childcare, and therefore spend more time with their children and talk with them more often. The mothers in the present study may have been even more concerned than mothers in the general population, due to the impact that the illness may have had on their children. As a consequence, they may have been even more

attentive to problems in their children's functioning. Future research should focus more on parent-child agreement following stressful situations and on the mechanisms that determine agreement or change in patterns of agreement.

Every study has its strengths and limitations, as did the present study. First, although the data in this study were derived from a large sample, 57 percent of the families approached for the study declined to participate. Although no differences between respondents and non-participants were found on demographic and illness-related variables, a sample bias may exist. Second, this study is based on cross-sectional data; such a design gives information at one point in time and does not reflect the dynamic interaction of potentially influencing variables. A longitudinal study design may give insight into change over time and causality. Third, 62 percent of the children had siblings who also participated. Although children from the same family share genes and environment, they may react differently to a stressful event (Plomin *et al.*, 2001). Therefore, no restrictions were made in the inclusion of number of children per family. Future studies may consider the use of multilevel analysis to gain insight into within-family and between-family variation in the functioning of children. Fourth, the results of the current and previous studies suggest that future research should focus on the consequences of parental cancer for sons and daughters, and latency-aged children and adolescents separately. Specifically, future studies should pay more extensive attention to the identification of potential risk and resilience factors for children. In this case, studies could focus on the temperament of the child, the coping styles, the parent-child relationship, psychological functioning of the parent, family functioning or other stressful events in a more in-depth qualitative manner. In addition to the objective, quantitative methods, qualitative research could also contribute to a description of feelings and experiences of children.

The questionnaire used was not designed for the specific purpose of diagnosing emotional and behavioural problems of children of parents diagnosed with cancer. In this context the use of this screening instrument is experimental. Although this is a limitation, the fact that we have discovered the greater vulnerability of latency-aged sons and adolescent daughters with this generic questionnaire demonstrates its usefulness with this population. For the lack of other

adequately normed instruments we see using it as a viable alternative to receiving no attention at all in clinical practice. When children score within the clinical range this is an indication that psychosocial aspects should receive attention.

The current results may heighten the awareness of health care providers that parental cancer may affect children. Parents should be supported in recognizing specific concerns and needs of their children, in particular those of latency-aged sons and adolescent daughters. It is important to realize that parents may struggle with what they will tell the children and how parenting responsibilities can be combined with their illness. Insight into risk and resilience factors of children may help to develop a tailored support program for children and parents.

ACKNOWLEDGEMENT

This study was financially supported by the Dutch Cancer Society (grant number RUG 2000-2333).

NOTES

1. Pearson correlations computed for ill parent-spouses yielded similar results.

REFERENCES

- Achenbach TM. 1991a. *Manual for the Child Behaviour Checklist/4-18 and 1991 Profiles*. University of Vermont, Department of Psychiatry: Burlington, VT.
- Achenbach TM. 1991b. *Manual for the Youth Self-Report and 1991 Profiles*. University of Vermont, Department of Psychiatry: Burlington, VT.
- Achenbach TM, McConaughy SH, Howell CT. 1987. Child/adolescent behavioural and emotional problems: Implications of cross-informant correlations for situational specificity. *Psychol Bull* **101**: 213-232.
- Bartels M, Hudziak JJ, Boomsma DI, Rietveld MJH, Van den Oord EJCG. 2003. A study of parent ratings of internalizing and externalizing problem behaviour in 12-year-old twins. *J Am Acad Child Adolesc Psychiat* **42**: 1351-1359.
- Birenbaum LK, Yancey DZ, Phillips DS, Chand N, Huster G. 1999. School-age children's and adolescents' adjustment when a parent has cancer. *Oncol Nurs Forum* **26**: 1639-1645.
- Bland JM, Altman DG. 1986. Statistical methods for assessing agreement between two methods of clinical measurement. *The Lancet* **36**: 307-310.

- Christ GH, Siegel K, Sperber D. 1994. Impact of parental terminal cancer on adolescents. *Am J Orthopsychiat* **64**: 604–613.
- Cohen J. 1988. *Statistical Power Analysis for the Behavioural Sciences*. Erlbaum: Hillsdale, NJ.
- Compas BE, Worsham NL, Epping-Jordan JE *et al.* 1994. When mom or dad has cancer: Markers of psychological distress in cancer patients, spouses, and children. *Health Psychol* **13**: 507–515.
- Compas BE, Worsham NL, Ey S, Howell DC. 1996. When mom or dad has cancer: II. Coping, cognitive appraisals, and psychological distress in children of cancer patients. *Health Psychol* **15**: 167–175.
- Duhig AM, Renk K, Epstein MK, Phares V. 2000. Interparental agreement on internalizing, externalizing, and total behaviour problems: A meta analysis. *Clin Psychol* **7**: 435–453.
- Eisenberg N, Cumberland A, Spinrad TL. 1998. Parent socialization of emotion. *Psychol Inquiry* **9**: 241–273.
- Garside R, Klimes-Dougan B. 2002. Socialization of discrete negative emotions: Gender differences and links with psychological distress. *Sex Roles* **47**: 115–128.
- Gore S, Aseltine R, Colten M. 1993. Gender, social-relational involvement, and depression. *J Res Adolesc* **3**: 101–125.
- Grant KE, Compas BE. 1995. Stress and anxious-depressed symptoms among adolescents: Searching for mechanisms of risk. *J Consult Clin Psychol* **63**: 1015–1021.
- Grant KE, Compas BE, Stuhlmacher AF, Thurm AE, McMahon SD, Halpert JA. 2003. Stressors and child and adolescent psychopathology: Moving from markers to mechanisms of risk. *Psychol Bull* **129**: 447–466.
- Grills AE, Ollendick TH. 2002. Issues in parent-child agreement: The case of structured diagnostic interviews. *Clin Child Fam Psychol Rev* **5**: 57–83.
- Heiney SP, Bryant LH, Walker S, Parrish RS, Provenzano FJ, Kelly KE. 1997. Impact of parental anxiety on child emotional adjustment when a parent has cancer. *Oncol Nurs Forum* **24**: 655–661.
- Hetherington EM, Stanley-Hagan M. 1999. The adjustment of children with divorced parents: A risk and resiliency perspective. *J Child Psychol Psychiat* **40**: 129–140.
- Hoke LA. 2001. Psychosocial adjustment in children of mothers with breast cancer. *Psycho-Oncology* **10**: 361–369.
- Howes MJ, Hoke L, Winterbottom M, Delafield D. 1994. Psychosocial effects of breast cancer on the patient's children. *J Psychosoc Oncol* **12**: 1–21.
- Huizinga GA, Van der Graaf WT, Visser A, Dijkstra JS, Hoekstra-Weebers JE. 2003. Psychosocial consequences for children of a parent with cancer: A pilot study. *Cancer Nurs* **26**: 195–202.
- Keenan K, Shaw D. 1997. Developmental and social influences on young girls' early problem behavior. *Psychol Bull* **121**: 95–113.
- Kraemer S. 2000. The fragile male. *Br Med J* **321**: 1609–1612.
- Lichtman RR, Taylor SE, Wood JV, Bluming AZ, Dosik GM, Leibowitz RL. 1984. Relations with children after breast cancer: The mother daughter relationship at risk. *J Psychosoc Oncol* **2**: 1–19.
- Nolen-Hoeksema S. 2001. Gender differences in depression. *Curr Dir Psychol Sci* **10**: 173–176.
- Nolen-Hoeksema S, Jackson B. 2001. Mediators of the gender difference in rumination. *Psychol Women Q* **25**: 37–47.
- Novella JL, Jochum C, Jolly D *et al.* 2001. Agreement between patients' and proxies' reports of quality of life in Alzheimer's disease. *Qual Life Res* **10**: 443–452.
- Plomin R, Asbury K, Dip PG, Dunn J. 2001. Why are children in the same family so different? Nonshared environment a decade later. *Can J Psychiat* **46**: 225–233.
- Rait D, Lederberg M. 1989. The family of the cancer patient. In *Handbook of Psychooncology*, Holland JC, Rowland JH. (eds). Oxford University Press: New York; 585–597.
- Siegel K, Mesagno FP, Karus D, Christ G, Banks K, Moynihan R. 1992. Psychosocial adjustment of children with a terminally ill parent. *J Am Acad Child Adolesc Psychiat* **31**: 327–333.
- Simmons R, Burgeson R, Carlton-Ford S, Blyth D. 1987. The impact of cumulative change in early adolescence. *Child Develop* **58**: 1220–1234.
- Sourander A, Helstela L, Helenius H. 1999. Parent-adolescent agreement on emotional and behavioural problems. *Soc Psychiat Psychiatr Epidemiol* **34**: 657–663.
- Stanger C, Lewis M. 1993. Agreement among parents, teachers, and children on internalizing and externalizing behavior problems. *J Clin Child Psychol* **22**: 107–115.
- Thompson RJ Jr, Merritt KA, Keith BR, Murphy LB, Johndrow DA. 1993. Mother-child agreement on the child assessment schedule with nonreferred children: A research note. *J Child Psychol Psychiat* **34**: 813–820.
- Treutler CM, Epkins CC. 2003. Are discrepancies among child, mother, and father reports on children's behavior related to parents' psychological symptoms and aspects of parent-child relationships? *J Abnorm Psychol* **31**: 13–27.
- Verhulst FC, van der Ende J, Koot HM. 1997. *Handleiding voor de Youth Self-Report (YSR)*. Manual for the YSR. Erasmus University/Dept of Child and Adolescent Psychiatry, Sophia Children's Hospital: Rotterdam, The Netherlands.
- Verhulst FC, van der Ende J, Koot HM. 1996. *Handleiding voor de CBCL/4-18*. Manual for the CBCL/4-18. Sophia kindziekenhuis/Academisch Ziekenhuis Rotterdam/Erasmus Universiteit Rotterdam: Rotterdam, The Netherlands.
- Verhulst FC, van der Ende J. 1992. Agreement between parents' reports and adolescents' self-reports of

- problem behavior. *J Child Psychol Psychiat* **33**: 1011–1023.
- Welch AS, Wadsworth ME, Compas BE. 1996. Adjustment of children and adolescents to parental cancer. Parents' and children's perspectives. *Cancer* **77**: 1409–1418.
- Zukauskiene R, Pilkauskaite-Valickiene R, Malinauskiene O, Krataviciene R. 2004. Evaluating behavioral and emotional problems with the Child Behavior Checklist and Youth Self-Report scales: Cross-informant and longitudinal associations. *Medicina* **40**: 169–177.