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Stress response symptoms in adolescent and young adult children of parents diagnosed with cancer

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Abstract

The aim of this study was to assess stress response symptoms in children of parents diagnosed with cancer 1–5 year prior to study entry. The impact of event scale was used to measure stress response symptoms in terms of intrusion and avoidance; the youth self-report assessed emotional and behavioural functioning; the state-trait anxiety inventory for children measured trait-anxiety. Participants included 220 adolescents (aged 11–18 years) and 64 young adults (aged 19–23 years) from 169 families. Twenty-one percent of the sons and 35% of the daughters reported clinically elevated stress response symptoms. Daughters, particularly those whose mothers were ill, reported significantly more intrusion and avoidance than did sons. Intrusion among daughters was positively related to age. Stress response symptoms in both sons and daughters were significantly associated with trait anxiety, but not with intensity of treatment or time since diagnosis. Daughters whose parents suffered from recurrent illness reported more symptoms than did daughters whose parents had a primary disease. Children (daughters in particular) with clinically elevated stress response symptoms reported significantly more problems of internalising and cognition than did their norm group peers. One-fifth of the sons and more than one-third of the daughters expressed clinically elevated stress response symptoms. These children also reported internalising and cognitive problems. Daughters appeared to be more at risk than sons.

Keywords: Children; Parental cancer; Stress response symptoms; PTSD

1. Introduction

During the last 20 years, awareness of the prevalence of posttraumatic stress disorder (PTSD) in children and adolescents has increased [1]. In the past, it was thought that children had only temporary psychological reac-

tions following traumatic experiences. However, when researchers began to ask the children themselves about their experiences, in addition to obtaining information from parents and teachers, they found that children and adolescents who had experienced traumatic events were actually at risk of developing PTSD [2]. PTSD refers to a cluster of symptoms that include persistent episodes of re-experiencing the event through recurrent, intrusive and distressing thoughts and nightmares (intrusion); persistent avoidance of discussion of the

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event, withdrawal from friends and usual activities (avoidance); and persistent symptoms of increased arousal (hyper-arousal) [3,4]. A variety of other emotional and behavioural problems have been observed in children with PTSD: irritability, separation anxiety (even in adolescents), anxiety, depression, somatic complaints and sleep disorders. Children may also experience cognitive difficulties, including diminished concentration and memory disorders [5–7].

Life-threatening illnesses such as cancer represent stressful life events for patients, and may lead to PTSD [8]. Cancer is usually an ongoing rather than a discrete event [9]. Patients experience a sequence of stress periods, beginning with the initial diagnosis of cancer and continuing throughout medical treatment to recovery. Moreover, after completing treatment, patients continue to have clinical follow-ups and may receive additional therapy or treatment in case of recurrence. The Diagnostic and Statistic Manual of Mental Disorders (DSM-IV-TR) [4] defines a traumatic event as 'an actual or threatened death or serious injury; or a threat to the physical integrity of self or others'. Cancer in a parent can be considered as a traumatic experience for children, rendering them susceptible to PTSD, resulting from the diagnosis of cancer, witnessing the parent's treatment and accompanying side-effects, and the continuing threat of losing the parent through death from the disease.

The prevalence of PTSD in children confronted with cancer has been examined among survivors of childhood cancer [10–12] and among siblings of childhood cancer patients [13]. The literature focusing on the prevalence of PTSD in children of cancer patients is limited.

Several possible prognostic factors of PTSD in children and adolescents have been studied, including gender, developmental factors and personality characteristics. Results on the effect of gender of the child on PTSD of non-cancer PTSD-studies were contradictory. Some found more symptoms among girls than boys [14,15], while others found no gender differences [16,17]. One study among children of cancer patients suggests that girls experience more stress response symptoms than boys. Particularly, adolescent girls whose mothers have cancer, appear to be most at risk for developing stress response symptoms [18]. Age and other developmental factors may also be related to the level of stress response symptoms. Cognitive capabilities that develop with increasing age have an important impact on the way children remember information about traumatic events, because knowledge determines a child's understanding and influences their perception of events [19]. Findings for a relationship between age and PTSD are inconsistent [20]. In the case of parental cancer, older children reported fewer intrusive thoughts about their parent's cancer,

but reported more avoidance symptoms than did younger children [21]. Adolescents and young adults who perceived their parent's cancer to be more serious reported having more stress response symptoms [18]. Cognitive appraisals of the seriousness of the illness seem to have had greater effects on the development of stress response symptoms than did objective characteristics of the cancer, including the length of time since diagnosis and type of treatment [18]. Finally, although research on the relationship between the personality traits of children and PTSD is scarce, it is known from studies among childhood cancer survivors that (trait) anxiety is a risk factor for the development of PTSD [10,22,23].

The primary goal of the present study was to examine the prevalence of stress response symptoms among adolescent and young adult children who have a parent with cancer. A second goal was to gain insight into the relationship between the degree of stress response symptoms reported by children and various variables (children's perception of the seriousness of the parent's illness, trait anxiety and cancer-related variables). The third goal was to examine relationships between the stress response symptoms experienced by adolescents and their emotional and behavioural functioning, and to investigate whether adolescents with clinical or non-clinical stress response symptoms differ in their emotional-behavioural functioning from adolescents in a norm group.

2. Patients and methods

2.1. Procedure

During the period from January 2001 to February 2003, physicians or nurses provided information about the study to all eligible patients consecutively hospitalised at or visiting the outpatient clinics of the departments of Surgical Oncology, Medical Oncology, Radiation Oncology, and Gynaecological Oncology of the Groningen University Medical Centre, the Netherlands. Patients were eligible if they met the following criteria: (1) they had been diagnosed with cancer one to five years prior to study entry; (2) they had children between 4 and 18 years of age, who resided with them at the time of diagnosis; (3) they were fluent in Dutch. Parents received written information about the study, and an adapted version for their child/children. In addition, informed consent forms and prepaid return envelopes were provided separately for each family member. After obtaining written informed consent, researchers mailed a separate questionnaire and prepaid return envelope to each participating family member. Family members were asked to complete the questionnaire independently, and not to consult other family members. The Medical Ethics Committee of the Groningen University Medical Centre approved the study.

2.2. Participants

A total of 476 eligible families were approached about participating in the study and 205 families (43%) consented to participate. Of the 271 families that declined participation, 22% did so for parental reasons, including: "we do not want to stir up emotions again" and "we want to move on and leave the illness behind". Twenty percent did so because of the children, including: "they lack interest in the study", "it would be too emotionally distressing for them", or "they are not aware it is cancer". Twenty-five percent stated a variety of reasons, including: "too busy in school or at work", and "other illnesses in the family". Thirtythree percent did not specify a reason. There was no significant difference between the ill parents of the families who did not participate in this study and those who did, with respect to gender, tumour type, and time since diagnosis.

The present study focuses on the responses of children themselves. Children 11 years of age and older completed the questionnaires. As a consequence, the sub-sample for the present study consisted of 220 adolescents (56% daughters, age range 11-18 years) and 64 young adults (63% daughters, age range 19–23 years) from 169 families. Most of the ill parents (94%) had spouses, implying that most of the children came from two-parent families. Parents were diagnosed with a variety of cancers, including breast cancer (53%), gynaecological cancer (11%), skin cancer (11%), haematological malignancies (8%), sarcoma/bone cancer (5%), urological cancer (4%) and other malignancies (8%). Seven fathers (23%) and 28 mothers (20%) had suffered a recurrence of disease. The mean period of follow-up after diagnosis was 2.9 years (± 1.2). For the present study, surgical treatment alone was defined as non-intensive treatment. Other single-modal treatments (either chemotherapy or radiotherapy) and multi-modal treatments (a combination of two or more of the modalities: surgery, chemotherapy, radiotherapy, hormonal treatment or immuno-therapy) were defined as intensive treatment. This classification was made based on our expectations of what children experience. Based on our clinical experience, we expect chemotherapy, radiotherapy or multimodal treatment to be more distressing for children, because the parents are more often absent from home, and children are confronted with more visible side-effects longer than when a parent is treated with surgery alone. Eighty-two percent of the patients had received an intensive treatment; the remaining patients had received a non-intensive treatment. Characteristics of children, ill parents and healthy parents are described in Table 1.

Table 1 Demographic characteristics

	n (%)
Children	
Sons	120 (42)
Daughters	164 (58)
Mean age 16.4 years (±3.1), range 11–23 years	
Ill parents	
Fathers	30 (18)
Mothers	139 (82)
Mean age 45.7 years (±4.5), range 34–57 years	
Healthy parents	
Fathers	107 (79)
Mothers	28 (21)
Mean age 46.4 (±5.4), range 32–66 years	
Marital status ill parents	
Married/cohabiting	159 (94)
Divorced/single	10 (6)
Family structure	
One child	32 (19)
Two children	81 (48)
Three children	41 (24)
Four or more children	15 (9)
Highest education completed (ill parents)	
Lower education ^a	52 (31)
Middle education ^b	82 (49)
High education ^c	35 (21)
Highest education completed (healthy parents)	
Lower education ^a	40 (30)
Middle education ^b	63 (47)
High education ^c	32 (24)

- ^a Elementary school, lower vocational education.
- ^b Lower general secondary education, intermediate vocational education and high school.
 - ^c Higher vocational education and university.

2.3. Measures

The Dutch version of the Impact of Event Scale (IES) was used to assess stress response symptoms of children [24-26]. The IES is a self-report questionnaire that is commonly used nationally and internationally to assess the extent to which children and adults are bothered by memories of a major life-event [27]. Completion of the IES does not require a clinician for administration, it is brief, and often used in cancer populations [9]. The IES is the most frequently used questionnaire in the Netherlands to assess post-traumatic stress symptoms. Children rated the frequency of intrusive thoughts (7 items) and avoidance (8 items) with respect to parental cancer during the previous seven days. Total distress can be computed by summing all items. Answers could be given on a 4-point scale, ranging from "not at all" (0) to "rarely" (1), "sometimes" (3), and "often" (5) (intrusion: range 0-35, avoidance: range 0-40, total distress: range 0-75), with higher scores indicating more symptoms. The Dutch version of the IES has a cut-off point for the total score of 26, above which a respondent is considered to have clinically elevated stress response symptoms. The IES is considered to be an index of stress response symptoms and not an index of PTSD symptoms, because it provides no information about hyperarousal, which is a criterion for the DSM IV-TR diagnosis of PTSD [18]. Cronbach's α for the IES in the present study ranged from 0.86 to 0.91 for intrusion, avoidance and total distress for both sons and daughters.

The Dutch version of the Youth Self-Report (YSR) [28,29] was used to obtain children's reports of their emotional and behavioural problems during the past six months. The YSR is the youth version of the child behaviour checklist (CBCL), intended for children from 11 to 18 years of age. Norm values are available for a random sample of Dutch boys and girls (560 boys, 564 girls) [29]. The YSR consists of problem items, divided into the following eight syndrome scales: withdrawal (7 items), somatic complaints (9 items), anxiety/depression (16 items), social problems (8 items), thought problems (7 items), attention problems (9 items), delinquent behaviour (11 items) and aggressive behaviour (19 items). Items were rated on a 3-point scale ranging from 0 (not true) to 2 (very true or often true). For this study, the Cronbach's α for the syndrome-scales of the YSR ranged from 0.54 (thought problems) to 0.89 (anxiety/ depression) for daughters and from 0.45 (thought problems) to 0.86 (anxiety/depression) for sons. These α values were comparable to those reported in the manual of the YSR.

Trait anxiety of the children was measured using the Dutch version of the trait anxiety subscale of the Spielberger State-Trait Anxiety for children (STAI-C) [30–32]. Children were asked how often a statement was applicable to them in general. They responded on a 3-point Likert scale, ranging from "almost never" to "often". Possible scores ranged from 20 to 60, with higher scores indicating more trait anxiety. Cronbach's α in the present study were 0.89 for daughters and 0.85 for sons

Children's perceptions of the seriousness of their parent's illnesses were assessed with a single item: How serious do you think your parent's illness is [18]? Adolescents responded on a 4-point Likert-scale, ranging from "not serious" to "very serious".

The following medical information was derived from the patients' medical records: time since diagnosis, treatment received and occurrence of recurrent disease.

2.4. Data-analyses

Descriptive statistics were used to examine the prevalence of stress response symptoms.

Independent t tests were conducted to investigate differences in means of stress response symptoms between sons and daughters, between sons and daughters of parents who had received intensive (compared with non-intensive) treatment, and between sons and daughters of parents with recurrent disease (compared with those of parents who did not suffer from a recurrence). One-way analyses of variance (ANOVA) and Post-Hoc tests (Dunnett T3) were used for comparison of stress response symptoms as a function of the gender of the child and that of the ill parent. ANOVA was also used to determine whether children's perceptions of the seriousness of their parents' illnesses had been affected by the presence of recurrent illness. Pearson's product-moment correlation coefficients were calculated to explore relationships between children's stress response symptoms and their age, trait anxiety, time since diagnosis, perceptions of the seriousness of their parent's illnesses, and the syndrome scales of the YSR. One-sample t tests were performed to compare the YSR-scores of adolescents having stress response symptoms below and above the cut-off score of the IES with those of adolescents from a norm population. All of the analyses performed were two-tailed.

3. Results

3.1. Prevalence of stress response symptoms

Twenty-five sons (21%) and 58 daughters (35%) had clinically elevated stress response symptoms (total score IES > 26). Twenty-one sons (18%) and 17 daughters (10%) reported no distress at all (IES-score = 0). Daughters had significantly higher mean scores on intrusion (t = -3.61, $P \le 0.001$), avoidance (t = -2.38, P = 0.017) and total distress (t = -3.22, t = 0.001) than sons did (Table 2).

Table 2
Descriptive statistics for the impact of event scale (IES)

	n	Intrusion			Avoidance			Total distress		
		Mean	SD	Range	Mean	SD	Range	Mean	SD	Range
Sons	120	6.5	6.5	0–27	8.4	8.0	0–30	14.9	13.4	0–47
Daughters	164	9.9***	8.8	0-35	11.0*	9.6	0-40	20.8*	16.8	0-73

SD, standard deviation.

^{*} $P \le 0.05$.

^{***} $P \le 0.001$ (comparison of sons versus daughters).

3.2. Relationships between stress response symptoms and study variables

3.2.1. Gender of child and parent

The gender of the child and that of the ill parent had significant effects on intrusion (F = 4.77, P = 0.003) and total distress (F = 3.32, P = 0.021), but not on avoidance. Daughters of ill mothers reported significantly higher mean scores on intrusion (P = 0.011) and total distress (P = 0.017) than did sons of ill mothers. No significant differences in stress response symptoms were found between daughters of ill mothers and daughters of ill fathers or between daughters of ill fathers and sons of ill fathers.

3.2.2. Age

There was no relationship between age and stress response symptoms, with the exception of a weak relationship between the age of daughters and intrusion (r = 0.17, P = 0.033).

3.2.3. Trait anxiety

Trait anxiety was positively related to stress response symptoms of both sons and daughters (intrusion: sons r = 0.42, $P \le 0.001$, daughters r = 0.65, $P \le 0.001$; avoidance: sons r = 0.36, $P \le 0.001$, daughters r = 0.55, $P \le 0.001$; total distress: sons r = 0.42, $P \le 0.001$, daughters r = 0.65, $P \le 0.001$).

3.2.4. Cancer-related variables

Daughters of a parent with recurrent disease had significantly higher mean scores on intrusion (t = -3.09, P = 0.004), avoidance (t = -2.27, P = 0.024), and total distress (t = -3.24, P = 0.001) than did daughters of parents who did not suffer from a recurrence. This effect was not found among sons. No significant differences were found in stress response symptoms between sons and daughters of parents who had received intensive treatment and those of parents who received non-intensive treatment. Time since diagnosis was not significantly related to reported stress response symptoms of sons and daughters.

3.2.5. Perception

Five sons (4%) and four daughters (2%) perceived their parent's cancer as not serious and 19 sons (16%) and 18 daughters (11%) perceived it as somewhat serious. More than half (55%) of the children (sons: n = 62; daughters: n = 95) perceived the illness as serious, and 28% as very serious (sons: n = 34; daughters: n = 45). Two daughters did not complete this question. ANOVA yielded significant effects of recurrent illness on the perception of the seriousness of the parent's illness (F = 4.113, P = 0.043). Both sons and daughters perceived the illness as more serious when the parent suffered from recurrent disease. When daughters per-

ceived the illness to be more serious, they reported higher scores on intrusion (r = 0.18, P = 0.024), avoidance (r = 0.22, P = 0.006), and total distress (r = 0.22, P = 0.006). No significant relationships between perception and stress response symptoms were found for sons.

3.3. Stress response symptoms and emotional/behavioural functioning

Analyses regarding the relationship between stress response symptoms and emotional/behavioural functioning were performed for children 18 years of age or younger, as the YSR was developed for children between 11 and 18 years of age. This subgroup consisted of 220 adolescents (97 sons, 123 daughters, mean age = 15.1 years, standard deviation (SD) = 2.3).

Significant associations were found between stress response symptoms and withdrawal (sons: r = 0.33, $P \le 0.001$; daughters r = 0.36, $P \le 0.001$), somatic complaints (sons: r = 0.25, P = 0.007; daughters: r = 0.34, $P \le 0.001$), anxiety/depression (sons: r = 0.38, $P \le 0.001$; daughters: r = 0.48, $P \le 0.001$), and attention problems (sons: r = 0.28, P = 0.003; daughters: r = 0.39, $P \le 0.001$). In addition, significant relationships were found between stress response symptoms and social problems (r = 0.19, P = 0.014), thought problems (r = .24, P = 0.002), and aggressive behaviour (r = 0.26, P = 0.001) for daughters. No significant associations were found between stress response symptoms and delinquent behaviour.

Sons with clinical stress response symptoms had significantly higher mean scores on anxiety/depression, thought problems and attention problems than did boys in a norm group, whereas, sons with non-clinical stress response symptoms did not differ significantly from boys in a norm group. Daughters with clinical stress response symptoms had significantly higher mean scores on withdrawal, somatic complaints, anxiety/depression, thought problems and attention problems than did girls in the norm group. Daughters with non-clinical stress response symptoms had significantly higher mean scores on somatic complaints and thought problems than did girls in the norm group (Table 3).

4. Discussion

The experience of parental cancer may lead to stress response symptoms in children. To date, limited research has been performed on stress response symptoms among the children of cancer patients. The primary goal of the present study was to examine the prevalence of stress response symptoms reported by adolescent and young adult children (aged 11–23 years) of cancer patients diagnosed 1–5 years before study entry. The results showed that 21% of the sons and 35% of the

Table 3
Descriptive statistics for the syndrome scales (YSR) of norm-group adolescents and adolescents with stress response symptoms below and above the cut-off score (IES)

Syndrome scales YSR	Norm group		Distress below	cut-off	Clinically elevated distress	
	Boys, $n = 560$ Mean (SD)	Girls, $n = 564$ Mean (SD)	Sons, $n = 78$ Mean (SD)	Daughters, $n = 81$ Mean (SD)	Sons, $n = 19$ Mean (SD)	Daughters, $n = 42$ Mean (SD)
Withdrawal	2.4 (2.1)	2.6 (2.2)	2.2 (1.8)	3.0 (2.3)	3.4 (2.5)	4.2***(2.8)
Somatic complaints	2.2 (2.1)	3.0 (2.6)	1.8 (2.1)	$3.7^*(3.0)$	3.3 (2.6)	4.7*** (3.0)
Anxiety/depression	4.2 (3.5)	5.4 (4.4)	3.8 (3.4)	5.1 (4.8)	7.4* (5.2)	9.2***(6.0)
Social problems	2.6 (2.1)	2.4 (2.1)	2.3 (1.9)	2.2 (1.9)	3.1 (2.6)	2.8 (2.2)
Thought problems	1.2 (1.6)	1.3 (1.6)	1.3 (1.3)	1.8*(1.9)	2.6* (1.7)	2.8***(2.0)
Attention problems	4.7 (2.7)	4.8 (3.0)	4.4 (2.4)	4.7 (3.2)	6.3* (2.6)	6.0^{**} (2.5)
Delinquent behaviour	3.8 (2.6)	3.0 (2.3)	3.4 (2.1)	3.4 (2.4)	4.7 (2.3)	3.4 (2.2)
Aggressive behaviour	7.7 (4.9)	7.0 (4.5)	6.8 (4.2)	6.9 (4.5)	8.6 (4.6)	8.1 (4.4)

^{*} $P \leq 0.05$.

daughters had reported clinically significant stress response symptoms in the form of intrusive thoughts and avoidance behaviour. These findings are consistent with a prior study of adolescent siblings of children who were, on average, five years post-cancer treatment. This study reported that 32% of the siblings suffered from moderate to severe post-traumatic stress [13]. The prevalence of post-traumatic stress symptoms reported by childhood cancer survivors, even many years after the end of treatment, across studies has been estimated to be between 2% and 20% [33]. Strikingly, the rate of clinically elevated stress response symptoms was actually higher among the children of parents with cancer and the siblings of children treated for cancer than among children who had experienced cancer themselves. This suggests that witnessing cancer in a family member may have a more profound impact on a child than being a cancer victim oneself.

A second goal was to gain insight into factors possibly related to the prevalence of stress response symptoms. Daughters reported more stress response symptoms than did sons. More specifically, daughters of ill mothers reported more stress response symptoms than did sons of ill mothers, while no such gender difference was found among children whose fathers were ill. One explanation may be that daughters took over household tasks and care responsibilities for siblings when the mother was ill, while the mother continued to fulfil these tasks when the father was ill. Another explanation may be that daughters have more empathic concern for and may therefore be more inclined to worry more about the ill parent than are sons, causing more distress [34]. It may also be that daughters worry more about their own chances of getting cancer. Two-thirds of the patients in the present study had female-specific cancer. It may be that daughters perceived themselves as having an increased risk of developing the same types of malignancies as their mothers.

Results revealed that the age of daughters was positively related to intrusive thoughts. This is in contrast to the results of an earlier study that found fewer intrusive thoughts with increasing age [21]. However, this specific study reported on children shortly after the parent's diagnosis and did not examine relationships for sons and daughters separately. It may be that the relationship between stress response symptoms and age changes when time moves further away from the initial, very distressing, period of diagnosis and treatment to later on in the course of illness.

Higher scores on trait anxiety seem to predispose children to increased stress response symptoms following a parent's cancer diagnosis. The positive relationship between this personality characteristic and the prevalence of PTSD in children faced with a cancer-related event has been previously described in studies of survivors of childhood cancer [10,23].

Time since diagnosis appeared to be unrelated to stress response symptoms. This suggests that witnessing a parent's cancer may be a traumatic stressor for children, both early in the course of disease and also in the longer term. This is consistent with the results of a recent review of post-traumatic stress symptoms following childhood cancer [33]. The present findings are also in line with the results of a study among children of cancer patients, assessed during the first weeks after the parent's diagnosis [18]. However, the current study, assessed children over a period of 1–5 years following the parent's diagnosis.

Extensive treatment consisting of surgery, chemotherapy, radiotherapy, or a combination supposedly results in more visible side-effects for children and more absence from home. Surprisingly, however, extensive treatment brought about no more stress response symptoms for children than did surgery alone. Daughters (but not sons) of parents who suffered from a recurrence of disease reported more stress response symptoms than

^{**} $P \leq 0.01$.

^{****} $P \le 0.001$ (comparison of norm-group adolescents with adolescents having scores below and above the IES cut-off).

did daughters of parents who did not experience a recurrence.

Most (83%) of the children perceived their parent's illnesses to be serious or very serious. Moreover, children of parents with recurrent illness perceived the illness to be more serious than did the children of parents who did not suffer from recurrent disease. These findings indicate that the children were aware of the potentially life-threatening nature of cancer and of the decreased chances for recovery following a recurrence. However, the perception of the seriousness of the parent's illness appeared to be related to the stress response symptoms of daughters, but seemed to be less important for the emotional responses of sons. A previous study among children of cancer patients also found that their stress response symptoms were related to children's perceptions of the seriousness of their parents' illnesses [18], but they did not examine relationships for sons and daughters separately. Further research is needed to examine why there is a relationship between recurrence, perception and stress response symptoms for daughters, but not for sons.

The third goal of this study was to examine relationships between adolescents' stress response symptoms and their emotional and behavioural functioning. This study showed that increased stress response symptoms were associated with more withdrawal, somatic complaints, anxiety/depression and attention problems for both sons and daughters. In addition, it led to more social problems, thought problems, and aggressive behaviour for daughters. The prevalence of stress response symptoms therefore coincided with problems in other areas. The association between stress response symptoms and problems in psychosocial functioning have been described previously [1,5]. However, it seems that children of cancer patients, when experiencing clinically elevated distress, also appear to suffer from internalising and cognitive problems. This is in contrast to children experiencing other types of traumatic events, e.g., children adopted from Romania and youngsters traumatised by sexual assault, witnessing trauma, and similar events, who appear to suffer from externalising problems as well [6,35]. It may be that children of cancer patients attempt to protect their parents by not showing their problems through externally maladaptive behaviour, but suffered instead from problems in ways that are less visible to their parents.

Compared with their norm-group peers, sons and daughters with clinically elevated distress reported more anxiety/depression, and problems with thought and attention. Daughters also showed more withdrawal and somatic complaints. The finding that adolescent children with clinically elevated distress reported more thought and attention problems than did their norm-group peers is consistent with other reports on the cognitive functioning of children with PTSD [6,35]. One

surprising finding was that daughters (but not sons) with non-clinical stress response symptoms reported more somatic complaints and thought problems than did girls in the norm group.

The present study is limited due to the low response rate. No differences were found between ill parents who consented to participate and those who did not in terms of gender, tumour type, or time since diagnosis. Various reasons for non-participation were mentioned, including the anticipation of negative emotional consequences of potential participation, the wish to move on, and the ignorance of children about their parents' health status. We can only speculate about the outcome had these families participated. A second issue is the low Cronbach's α of the thought problems subscale of the YSR (0.45 for boys and 0.54 for girls) which could indicate a certain amount of unreliability. However, the Dutch manual shows comparable α in the norm group (0.37–0.51). Addressing this problem in the manual the authors suggest the small number of items as an explanation. A satisfactory test-retest reliability of r = 0.71is reported for this scale [29] indicating a certain amount of stability. This is supported by the literature showing that high scores on thought problems are important predictors of psychological problems in the long run [36].

In conclusion, the findings of the present study make an important point for daily oncology practice: a considerable percentage of adolescent and young adult children, 35% of the daughters and 21% of the sons, suffered from clinically significant levels of intrusive thoughts and avoidance symptoms, combined with internalising and cognitive problems following a parent's diagnosis of cancer and its subsequent treatment. Such children may require professional help. It would benefit children if the clinicians were aware of the possibility that they too are suffering from problems due to the illness of their parent. Special attention should be given to children who are likely to react to stressful situations with anxiety, with particular attention for daughters whose parents suffer recurrent illness.

Conflict of interest statement

None declared.

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