

ORIGINAL ARTICLE

## Parent distress in childhood cancer: A comparative evaluation of posttraumatic stress symptoms, depression and anxiety

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### Abstract

The aim was to assess symptoms consistent with posttraumatic stress (PTS; cognitive intrusions, avoidance, arousal) related to the child's illness, and generic distress (anxiety, depression) in parents of childhood cancer patients. Outcomes were compared to normative and relevant reference data, and analysed for their dependence on time passed since diagnosis. Swedish parents (266 mothers, 208 fathers) were recruited at two centres. Data from a clinical sample of posttraumatic stress disorder (PTSD) patients and parents of healthy children were used for comparison. The Impact of Events Scale (IES-R) was used for assessing PTS symptoms, and self-report scales for anxiety and depression. Elevated stress and generic distress varied as a function of time from diagnosis. Up to 12% of parents for whom >5 years had passed since diagnosis still reported equally, or more intrusive thoughts, avoidance and arousal when contrasted to patients suffering from PTSD. Parents of recently diagnosed children had more cancer-related intrusive thoughts than those of long-term survivors. Heightened anxiety and depression was most prominent in mothers and fathers up to 2.5 years after diagnosis. In conclusion, severe generic distress characterises the first years after diagnosis, and initially common PTS symptoms are found in a considerable portion of parents years after diagnosis. Clinically, attention should be paid to continuous parent support needs. Individual variation vis-à-vis distress vulnerability should be acknowledged, and presupposed gender differences avoided. When treatment situation asks the most of parents' collaboration, many are under pressure of severe stress.

Parents are recognized as one of the main sources of emotional support for children with cancer. However, parents ability to provide care during their child's illness and treatment is known to be dependent on how they manage to cope with the diagnosis and its consequences [1]. The disclosure of the cancer diagnosis together with the knowledge of the fatality of the disease constitutes a potentially traumatic stressor stated as a diagnostic causal criterion for the diagnosis of posttraumatic stress disorder (PTSD; [2]). Furthermore, parenting a child in treatment for cancer involves an array of potentially stressful events (e.g. [3]). Therefore, symptoms of acute stress and posttraumatic stress may evolve in parents at any phase in the course of their child's disease and its' treatment, and interfere with their ability to care for themselves and their children.

Elevated levels of anxiety and depression are found in parents close after the disclosure of

diagnosis [4,5], and may not drop to normal until a few years after diagnosis [6]. Moreover, parental distress has been observed many years after successfully completed treatment [7,8]. Posttraumatic stress (PTS) symptoms, including the clinical diagnosis of PTSD, has been suggested to be a useful model for understanding long-term distress in parents of children with cancer [9], and the characteristic symptoms intrusion, avoidance and hyperarousal have been observed in parents of children who survive (e.g. [10]). On the basis of an extensive review, Smith et al. [11] note that the estimated rates of PTS and PTSD are often even higher in parents of children with cancer than in pediatric and adult cancer patients themselves. The incidence of pronounced posttraumatic stress symptomatology among parents is estimated to be between about 10 and 40% [12–14]. Reported rates vary, probably due to varying methods of

assessment, and different criteria for the estimation of PTS. Comparisons of findings are further complicated by the fact that previous studies often have included mothers only. At the same time, in one of the rare studies systematically surveying PTS symptoms at various points in time after the child's cancer diagnosis, Phipps and colleagues [15] question the appropriateness of using the posttraumatic stress disorder concept, derived from psychiatric pathology, as a model for understanding long-term adjustment to childhood cancer. Apparently further research is needed to clarify the nature of parental stress, and the significance of time elapsed since diagnosis.

To date studies examining the traumatic aspects of stressors, and studies investigating symptoms of posttraumatic stress in parents of children with cancer have predominantly emanated from North America [12–14,16], despite single exceptions involving restricted samples [17]. However, a precise understanding of disease-related stress in parents has yet to be fully established by empirical investigation of populations emanating from various national contexts. Routines relating to, for example, care, support, and follow-up may vary widely from one country to another, influencing the situation of parents. Furthermore, fathers are generally being underrepresented in this research, as several studies have focused on mothers only. In parts of Western society today parenting roles are shifting towards both parents equally sharing the responsibility for the care of the child. This justifies the inclusion of both parents when evaluating the psychosocial family consequences of a child's cancer, as a basis for developing family support interventions. The fact that many studies of parental distress have involved rather small study groups ( $n < 100$ ), also tends to reduce the reliability of findings.

To complement previous research, the present study aimed to describe psychological symptomatology in a relatively large Swedish sample including both mothers and fathers of childhood cancer patients. The specific aims were to, in relation to relevant normative and comparison data, examine symptoms of disease-related distress (characteristic posttraumatic stress symptoms) and generic distress (anxiety and depression) among parents at different points in time after the child's cancer diagnosis. To this aim, a cross-sectional sample of parents of children in and off cancer treatment was compared with data from patients diagnosed with PTSD after being the victims of assault (reference group for PTS symptoms), and with parents of healthy children (reference group for anxiety and depression).

## Method

### *Subjects and data sources*

The study group consisted of 474 parents of children with cancer (266 mothers and 208 fathers). Both parents of 190 families participated, while from 76 families only the mother participated, and from 18 families only the father took part in the study. Forty-seven percent of the parents had a child in active cancer treatment, while 53% had a child who had successfully completed treatment. The study sample represented various subtypes of cancer: 45% were parents of children with leukaemia, while the corresponding rates were for lymphoma 9%, CNS tumour 16%, neuroblastoma 7%, Wilms' tumour 7%, bone tumour 6%, soft-tissue sarcoma 4%, germ-cell neoplasm 4%, and other/unspecified solid tumours 2% of the parents. Children's age at diagnosis ranged from newborn to 21 years (mean 6 years 9 months). Time elapsed from disclosure of the child's diagnosis to study assessment ranged from one week up to 14 years 6 months (mean 2 years 5 months). Table I shows the distribution of parents as regards time elapsed since the child's diagnosis. The total number of children in the families ranged from one to eight children (mean 2.5). Data regarding the parent's age was available only for 375 of the study parents, for whom age ranged from 21 to 64 years, with a mean age of 41 years.

Since the experience of a psychological trauma is a core criterion of posttraumatic stress, the subjects in the reference sample for PTS symptoms was required to have experienced a traumatic event. For this purpose, we used historical data from 20 traumatized assault victims with the clinical diagnosis of PTSD. These data were collected in an a Swedish study described elsewhere [18].

One hundred and seventy-six parents (100 mothers and 76 fathers) from the community constituted a reference sample for generic distress (anxiety, depression). All were parents of at least one child 0–16 years. In the reference families, no children had any chronic or serious diseases at the time of assessment. The reference group comprised the parents of one to five children, mean 2.2, and the

Table I. Proportions of parents of children in and off cancer treatment, respectively.

Time elapsed since diagnosis	n	mothers, %	in/off treatment, n
0–3 months	133	57%	128/5
3–12 months	78	54%	51/27
1–2½ years	99	56%	27/72
2½–5 years	108	56%	12/96
5–14 years	56	59%	3/53

ages of the reference parents at the time of the study ranged from 20 to 56 year, mean 39 years.

### *Procedures*

The participants were recruited at two Swedish childhood cancer centres; at Astrid Lindgren Children's Hospital (ALCH) in Stockholm, and Linköping University Hospital. Non-Swedish-speaking parents were not included, since questionnaires were available in Swedish only. The invited families had an ongoing contact with either the in-patient unit or follow-up clinic. Parents were invited to participate in the study when visiting the hospital, or by phone or by mail. All parents received an invitation letter, including written information about the project, and informed consent was obtained. They were instructed to complete the questionnaires independently, without consulting the other parent. After completion of the questionnaires, parents returned them by mail in a pre-paid return envelope. The response rate was 73%. Data collection was carried out between November 2000 and December 2002. The study has been reviewed and approved by the local ethics committee and performed in accordance with the ethical standards laid down in the appropriate recent version of the 1964 Declaration of Helsinki. Informed consent was thus obtained from participants prior to inclusion.

For the reference group of parents of healthy children, 200 mothers were randomly selected from the population of mothers of children 0–16 years of age, in the catchment area of the largest of the two centres, the one at ALCH. In a letter of invitation, both parents were asked to participate. Out of all returned questionnaires, 205 contained sufficient information for data analyses. Twenty-one of these were excluded from the present analyses, since at least one child in the family suffered from chronic and/or severe illness. The remaining 176 parents constituted the final control group, of which 57% were mothers and 43% were fathers.

### *Measures*

The outcome variables were assessed with three self-report questionnaires, used previously to assess psychological symptoms in parents of childhood cancer patients. Higher scores reflected the presence of more symptoms.

*PTS symptoms.* Symptoms, typically consistent with post-traumatic stress were assessed using the Impact of Event Scale – Revised (IES-R) [19]. The IES-R was designed to assess stress responses in the dimensions of intrusion, avoidance, and arousal,

respectively. The three symptom clusters correspond with the B-, C-, and D-criteria of PTSD, according to DSM-IV [2]. The IES-R consists of 22 items (intrusion 8, avoidance 8, and arousal 6 items), relating to a specific event experienced by the respondent. By marking their response along a 5-point scale, scored 0–4, respondents report the extent to which they have experienced symptoms of traumatic stress during the past week. Individual results are expressed by sum scores. In the present study, parents were asked to answer the questionnaire with their child's illness as the explicit reference, according to the common practice in studies addressing PTS and PTSD in parents of children with cancer. In the study sample, Cronbach's  $\alpha$  coefficients indicated satisfactory to good internal consistency for the total score and the three subscales: total IES-R score had an  $\alpha$ -value of 0.93, intrusion 0.90, avoidance 0.83, and arousal 0.85.

*State anxiety.* A 17-items version of the STAI anxiety scale [20], adapted by Van Dongen-Melman et al., 1995 [21], was used for assessing anxiety. Response alternatives follow a 4-point Likert scale format, and an individual score is computed by dividing the total of the individual values by the total number of answered items. In the present study, Cronbach's  $\alpha$  of the anxiety scale was 0.96 in the study sample, and 0.91 in the reference group of parents of healthy children.

*Depression.* Depression was assessed using an adapted version of the Zung Self-Rating Depression Scale developed by Van Dongen-Melman et al. [22]. The scale comprises 10 items, rated by respondents on a 4-point Likert scale. Respondents are asked to consider questions in the past week perspective. A mean value of the item answers represent the individual score. The Cronbach's  $\alpha$  coefficient for the depression scale was 0.85 (study sample) and 0.73 (reference group).

### *Data management and statistical analyses*

Respondents who had left more than 25% items of any of the three scales unanswered were excluded from the analyses. In the final study group of 474 parents, missing values were replaced with the individual mean score of the scale in question. Such imputations were most often made for the anxiety and the depression scales (42 and 30 respondents, respectively). Imputations for missing answers in the intrusion subscale were made for 15 respondents, while the corresponding numbers for the avoidance and arousal subscales were 11 and 5

respondents. In the reference group imputations were made in the anxiety scale for 8 respondents and in the depression scale for 3 respondents.

In the analyses, scale scores were treated as continuous variables. Initially, zero-order correlations were calculated for the outcome measures – anxiety, depression and the three subscales of the IES-R.

In order to evaluate the effect of time since diagnosis, parents were categorized into five groups according to time elapsed since the child's diagnosis. These were A) one week up to and including 3 months, B) more than 3 months up to and including 12 months, C) more than 1 year up to and including 2½ years, D) more than 2½ years up to and including 5 years, and E) more than 5 years up to and including 14 years after the child's diagnosis.

Due to the context-specific quality of PTS, the effect of time elapsed since diagnosis was examined through comparisons within the group of parents of children with cancer. Accordingly, each of the four first time-groups (A–D) was compared with the group most distant in time from diagnosis (group E). To this end, one-way analysis of variance (ANOVA), contrast tests, was used. Time-group constituted the grouping factors, and the intrusion, avoidance, and arousal symptom categories constituted the dependent variables.

T-tests were used to compare scores of the IES-R between parents and PTSD patients. Subsequently, we calculated the proportions of parents, whose IES-R scores exceeded the mean scores of PTSD patients. This was done separately for mothers and fathers of each time group.

ANOVA was performed for comparing level of anxiety and depression between reference parents and study parents in the five time-groups. Through contrast tests, each of the time-groups was compared with the reference group. As standard deviations for anxiety and depression scores were narrow in this relatively large sample, additional guidance for evaluating the clinical significance of found differences was given by subsequent calculations of effects sizes using Cohen's *d*. Cohen's tentative guidelines for interpretation were followed, meaning that  $d \geq 0.2$ ,  $d \geq 0.5$ , and  $d \geq 0.8$ , were interpreted as indicating small, medium, and large difference, respectively [23]. Separate tests were performed for mothers and fathers throughout the analyses. As multiple statistical tests were performed (each series of contrasts involved five tests), the alpha level was modified to fend off the risk of Type I error. Thus, differences at  $p < 0.01$  were considered statistically significant. Two-sided tests were conducted throughout the statistical analyses.

## Results

All the aspects of distress reported by parents of the childhood cancer (CC) patients were moderately to highly correlated, with avoidance showing the weakest associations (Table II). The associations were similar for mothers and fathers, and for the five time-groups (not presented here).

Scores of PTS symptoms (intrusion, avoidance and arousal), anxiety and depression among mothers and fathers of children with cancer are presented in Table III. At visual examination most of the aspects of distress appeared to be more frequent in parents who were assessed close in time after their children's diagnosis, compared with parents who had responded to the questionnaires after a longer period of time. This impression was tested in the subsequent analyses (see presentation below).

### PTS symptoms

Comparisons of intrusion, avoidance and arousal in patient parents were done with the reference group data for the intrusion, avoidance and arousal subscales of the IES-R [18]. In this reference sample of assault victims diagnosed with clinical PTSD, the mean score of intrusions was 18.8 (SD 6.6), avoidance 17.3 (6.3), and arousal 15.1 (4.9). Group mean scores of PTSD patients significantly exceeded those of CC parents. However, several parents presented levels of symptoms equal to or higher than the mean values of PTSD patients. Table IV presents the proportions of mothers and fathers of each time group, whose IES-R scores exceeded the mean scores of PTSD patients. Intrusion seemed to be the most prominent of the three symptom categories, with 30.3% of the mothers and 22.8% of the fathers 0–3 months after the child's diagnosis exceeding the mean scores of PTSD patients.

Comparisons within the study group revealed significantly higher levels of intrusion and arousal among mothers close after the child's diagnosis, compared with the group of mothers more than five years after the diagnosis. A similar pattern applied for fathers, although statistically significant only for intrusion. More specifically, 0–3 months

Table II. Posttraumatic stress and generic distress co-morbidity correlation coefficients for parents of children with cancer,  $n = 474$ .

	Intrusion	Avoidance	Arousal	Anxiety
Avoidance	0.55***			
Arousal	0.83***	0.56***		
Anxiety	0.64***	0.42***	0.68***	
Depression	0.61***	0.40***	0.70***	0.80***

\*\*\* $p < 0.001$  (2-tailed).

Table III. Posttraumatic stress, anxiety and depression in parents of children with cancer at different points in time after the child's diagnosis.

Time elapsed since diagnosis	Intrusion, mean (SD)	Avoidance, mean (SD)	Arousal, mean (SD)	Anxiety, mean (SD)	Depression, mean (SD)
<b>Mothers</b>					
A. 0-3 mos, n = 76	15.2 (7.24)	6.0 (5.71)	8.5 (5.57)	2.9 (.59)	2.4 (.57)
B. >3-12 mos, n = 42	12.8 (7.65)	5.2 (4.84)	7.1 (6.15)	2.7 (.75)	2.3 (.50)
C. >1-2½ yrs, n = 55	12.2 (8.18)	5.6 (6.1)	6.5 (6.36)	2.5 (.69)	2.2 (.68)
D. >2½-5 yrs n = 60	9.6 (7.41)	3.9 (5.33)	4.9 (5.32)	2.3 (.73)	2.0 (.59)
E. >5-14 yrs, n = 33	8.4 (6.75)	4.4 (5.90)	3.6 (4.90)	2.1 (.60)	2.0 (.53)
<b>Fathers</b>					
A. 0-3 mos, n = 57	11.8 (7.28)	5.2 (3.87)	6.1 (4.72)	2.7 (.55)	2.2 (.48)
B. >3-12 mos, n = 36	11.4 (9.02)	6.8 (5.72)	6.6 (5.59)	2.6 (.64)	2.2 (.57)
C. >1-2½ yrs, n = 44	8.6 (6.06)	5.5 (5.70)	4.5 (4.79)	2.3 (.67)	2.0 (.51)
D. >2½-5 yrs, n = 48	7.4 (6.20)	5.4 (5.47)	3.8 (4.58)	2.2 (.63)	1.9 (.52)
E. >5-14 yrs, n = 23	6.8 (6.51)	4.8 (6.19)	3.6 (4.68)	2.0 (.46)	1.7 (.35)

after diagnosis intrusion was more prominent in mothers ( $t = 4.4, p < 0.001$ ) and fathers ( $t = 3.0, p = 0.005$ ), compared with the group 5-14 years after diagnosis. Mothers reported higher levels of arousal in the time-groups 0-3 months ( $t = 4.1, p < 0.001$ ) and 3-12 months ( $t = 2.6, p = 0.009$ ) after diagnosis.

*Anxiety and depression*

Symptom levels of anxiety and depression in patient parents generally exceeded those of parents of healthy children, except for parents who were most distant in time from the child's diagnosis (Figure 1). Mean score of depression for reference mothers ( $n = 100$ ) was 1.88, SD 0.43, and for reference fathers ( $n = 76$ ) 1.71, SD 0.35. Regarding anxiety, the mean score for reference mothers was 2.01, SD 0.45, and for reference fathers 1.88, SD 0.40. Compared with reference mothers, CC mothers at 0-3 months post-diagnosis reported significantly more anxiety ( $t = 11.2, p < 0.001$ ,

Cohen's  $d = 1.7$  "large") and depression ( $t = 7.0, p < 0.001$ , Cohen's  $d = 1.1$  "large"), as did mothers at 3-12 months (anxiety  $t = 5.7, p < 0.001$ , Cohen's  $d = 1.2$  "large"; depression  $t = 4.3, p < 0.001$ , Cohen's  $d = 0.93$  "large"), and at 1-2½ years (anxiety  $t = 5.1, p < 0.001$ , Cohen's  $d = 0.9$  "large"; depression  $t = 3.4, p < 0.001$ , Cohen's  $d = 0.6$  "medium"). Similarly, fathers reported significantly higher levels of distress 0-3 months (anxiety  $t = 9.0, p < 0.001$ , Cohen's  $d = 1.7$  "large"); depression  $t = 6.0, p < 0.001$ , Cohen's  $d = 1.2$  "large"), 3-12 months, (anxiety  $t = 6.3, p < 0.001$ , Cohen's  $d = 1.5$  "large"; depression  $t = 4.7, p < 0.001$ , Cohen's  $d = 1.1$  "large"), and 1-2½ years (anxiety  $t = 4.1, p < 0.001$ , Cohen's  $d = 0.8$  "large"; depression  $t = 3.1, p = 0.003$ , Cohen's  $d = 0.7$  "medium") after their children's cancer diagnosis, compared with fathers of healthy children. In addition, anxiety in fathers in the fourth time-group (2½-5 years) was significantly higher than the anxiety reported by reference fathers ( $t = 3.2, p = 0.002$ , Cohen's  $d = 0.6$  "medium").

**Discussion**

In this cross-sectional study, findings overall indicated considerable vulnerability of parents to develop symptoms of intrusion, avoidance and arousal, typically considered to express posttraumatic stress, and heightened, above normal, levels of generic distress symptoms (anxiety and depression). Also, parent distress proved to vary as a function of time from diagnosis, with parents of more recently diagnosed patients presenting higher levels of symptoms than parents of long-term survivors. Moreover, findings show that a subgroup of parents experience distress related to the child's cancer years after the diagnosis. The threatening potential of parents' life-situation was confirmed by the co-morbidity, expressed by the substantial correlation between the

Table IV. Proportions of parents of children with cancer exceeding mean posttraumatic symptom levels of PTSD-diagnosed comparison patients.

Time elapsed since diagnosis	Intrusion	Avoidance	Arousal
<b>Mothers</b>			
A. 0-3 mos, n = 76	30.3%	7.9%	7.9%
B. >3-12 mos, n = 42	21.4%	2.4%	14.3%
C. >1-2½ yrs, n = 55	25.5%	7.3%	12.7%
D. >2½-5 yrs n = 60	15.0%	5.0%	6.7%
E. >5-14 yrs, n = 33	12.1%	9.1%	6.1%
<b>Fathers</b>			
A. 0-3 mos, n = 57	22.8%	0	3.5%
B. >3-12 mos, n = 36	25.0%	2.8%	5.6%
C. >1-2½ yrs, n = 44	6.8%	6.8%	4.5%
D. >2½-5 yrs, n = 48	10.4%	2.1%	4.2%
E. >5-14 yrs, n = 23	8.7%	8.7%	4.3%

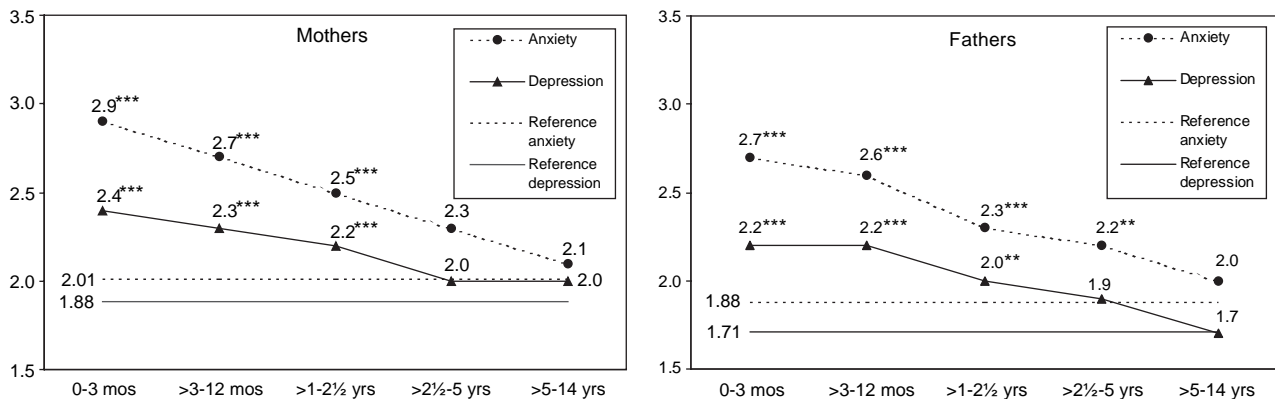


Figure 1. Anxiety and depression in mothers and fathers of children with cancer at different points in time after the child's diagnosis, and anxiety and depression in reference mothers and fathers of healthy children.

most significant aspects of distress: intrusion, anxiety and depression.

The outcome of our study corresponds to previous findings of an initially intense stress in many mothers and fathers [15,17], and a vulnerability for long-term PTSD symptoms in a small subgroup [12–14,24]. The incidence and severity of intrusion, avoidance and arousal in the study group were – at an entire group level – less pronounced compared to assault victims diagnosed with a current PTSD. Nevertheless, a portion of the parents exhibited symptoms above mean levels of PTSD patients. In particular, this was found regarding intrusive cancer-related thoughts. About one fourth of the parents within the first year after diagnosis were bothered by intrusive thoughts about the child's illness as much as the PTSD patients were troubled by intrusions about their trauma. This may reflect an expected reaction in this early stage of illness and treatment, considering the exposure to a broad array of potentially stressful disease-related events during this period [3]. Any expressions of posttraumatic stress during this phase may indeed be accompanied and intensified by reactions to current stressors. However, about 10% of parents for whom 5 years, or more, had passed since diagnosis were still bothered by intrusive thoughts about what they had experienced as much as PTSD-patients generally were. Findings can be interpreted as indicating that "normal" recovery with time can be expected for most parents, while a subgroup remains for which this does not happen – at least not without additional supportive measures, after identifying at an early stage which these vulnerable parents at risk might be.

Frequent cognitive intrusions and less frequent avoidance and hyperarousal is in line with the reports from previous studies [14,25], and suggest that intrusions among parents of children with cancer may not always reflect full-blown posttraumatic symptomatology. Phipps and colleagues (2005) raise

the notion that there is indeed little evidence that stress-response symptoms in relation to childhood cancer are truly "post-traumatic". It has rarely been studied to what extent parental intrusions, avoidance and arousal primarily relates to past experiences during the course of the illness, or whether they are caused by the current situation. And, indeed, addressing the question empirically is not easily done. Yet, the elevated level of parental distress is a concern, which warrants appropriate interventions. For the clinician, an individual assessment have to settle whether the suffering for which he or she is supposed to support a parent is predominantly posttraumatic or triggered by ongoing stressors.

Confirming the effect of time, the levels of anxiety and depression were higher among parents for whom a shorter time of illness and treatment had elapsed. In parents assessed during the first years after the diagnosis, anxiety and depression was consistently more prominent compared with parents of healthy children. This applied to mothers as well as fathers. Moreover, in fathers elevated levels of anxiety was seen up to 5 years post-diagnosis. This finding somewhat contradict the conclusions of previous studies reporting gender differences. Typically, those studies have merely compared the scores of mothers with those of fathers, and often found that mothers report more distress than fathers do (e.g., [4,6]), although other times no such gender differences are found (e.g., [10,26]). Relying on the approach used in the present study, we may conclude that the experience of the child's illness often is as stressful for fathers as for mothers. Although researchers and medical professionals today increasingly address both mother and father as significant caregivers, it is important to continue paying attention to the risk of discrimination and exclusion of fathers in medical care and research in case of childhood illness.

Some methodological limitations of this study need to be recognized. Firstly, the parents were

assessed cross-sectionally, and, consequently, assumptions about individual processes over time cannot be drawn. Secondly, the sample in this study was somewhat skewed with respect to time elapsed since diagnosis, with most of the parents assessed during the first years. Due to this skewness, the time-group most distant from diagnosis had to be extended over 9 years. Furthermore, we used previously collected reference data for the comparisons of intrusion, avoidance and arousal. Although an acceptable approach, it is admittedly less rigorous than concurrent assessment of a control sample. Moreover, as the study did not cover parents of children with malignancies known to be incurable, and children in palliative treatment, results cannot be generalized to parents of children under these circumstances. Parents of children under these medical conditions can be expected to present more severe symptoms of situational distress, and should be addressed in forthcoming research. Finally, parents' distress was not analysed on the basis of whether the child was in or off treatment. Instead the influence of time passed since diagnosis was evaluated in detail. A reason for that decision was that, in a mixed group of malignancies as this one, the in-treatment and off-treatment categorization does not tell about how close in time parents are to the initial experience of learning about the child's cancer diagnosis.

In conclusion, reactions of severe stress can be expected in several parents during the first years after a cancer diagnosis of a child. Although not necessarily resulting in enduring reactions such as posttraumatic stress in the majority of parents, disease-related strain may accompany parents for an extended time. The clinical significance of the findings refers to their signalling the call for continuous attention to the psychosocial needs of parents following a child's cancer diagnosis, and not only immediately at the first hospital referral. Health care professionals meeting the families should bear in mind that parents may be particularly vulnerable to situational distress during the period when the medical care system demands the most of their collaboration. Furthermore, many parents may struggle with the consequences of severe stress, even if the child was diagnosed years ago. Indeed, a few parents may be more or less permanently affected by stress reactions related to the child's disease. In addition, professionals should be encouraged to consider individual variation rather than to presuppose the existence of gender differences, as the latter may lead to erroneous assumptions about distress, reactions and needs.

Parents of children where treatment is less successful are expectedly even more psychologically

vulnerable. The need of studies particularly addressing them was indicated above. Other suggestions for future study include the thorough examination of the strains of the life situation of parents at different stages after a child's cancer diagnosis. This may shed further light on the nature of parental stress: whether posttraumatic or mainly caused by concurrent stressors. Along these lines, future studies should address the relative significance of the experience of learning the diagnosis, on one hand, and experiences during the child's cancer treatment, on the other. As long as this question remains unclarified, the term "post-traumatic stress" should be used with caution in characterizing this parent population.

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