

# Parents of Children Surviving a Brain Tumor: Burnout and the Perceived Disease-related Influence on Everyday Life

Annika Lindahl Norberg, PhD

**Summary:** Parents of children diagnosed with a brain tumor often report distress, even after successfully completed cancer treatment. The aim of this study was to examine predictors of burnout (ie stress-induced exhaustion) in parents of children who have had a brain tumor. Twenty-four mothers and 20 fathers completed self-report questionnaires on 2 occasions at an interval of 7 months. Controlling for generic stress, parents' perception of the influence of the disease on everyday life-predicted burnout symptoms. Moreover, parents' appraisal of a disease-related influence on everyday life showed stability, implying that parental stress may be chronic. The findings encourage furthermore investigation of chronic stress among parents of children diagnosed with cancer.

**Key Words:** childhood brain tumor survivors, parents, stress, burnout, psychosocial

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It is now well documented that the diagnosis of cancer in a child is a devastating experience for the parents.<sup>1,2</sup> Furthermore, parents often report distress related to the child's cancer even after successfully completed treatment.<sup>3,4</sup> This distress may involve various types of psychologic outcome. Long-term parental reactions have been suggested as indicating the processing of a past trauma, experienced during active treatment.<sup>3</sup> Alternatively, such reactions may reflect the influence of present stressors.<sup>4,5</sup> Indeed, parental stressors do not necessarily cease even though the child's cancer treatment has been successfully completed. This particularly applies to parents of brain tumor survivors, as primary and secondary effects of remaining sequelae have an impact on the everyday life of the entire family.<sup>6,7</sup> Moreover, parenting a child with cancer may lead to changes in employment with negative financial consequences, thus adding to the stressors.<sup>8</sup> Possibly such influence on employment may also hamper career opportunities and leave parents in demanding or less stimulating work environment. Furthermore examination of chronic stress among those parents is justified as the possible effects of long-term stressors may entail psychologic and physical exhaustion.<sup>9</sup> In brief, when a situation involves stressors—the individual experiences stress, and if the stressors persist-exhaustion may be the consequence.

One of the most widely studied aspects of stress-related psychologic exhaustion is burnout, defined as

symptoms of physical, emotional, and cognitive exhaustion relating to a longstanding stress exposure.<sup>10,11</sup> Originally regarded as exclusively an effect of work stress, it is now assumed that burnout may follow chronic stress irrespective of its source.<sup>12</sup> In addition to stressors at work, economic stressors are known to amplify chronic stress.<sup>13</sup> Certain demographic factors—lower education and female gender—are often mentioned as risk factors for stress.<sup>14</sup>

In an earlier study, the first study investigating burnout in this population, symptoms of burnout were found to be more frequent among parents of children who had been treated for brain tumor than among parents of healthy children.<sup>15</sup> The aim of the present study was to examine disease-related and generic factors as predictors of burnout in the same sample of parents of children who have had a brain tumor. This aim included a preliminary investigation of the extent to which disease-related predictors impact parental burnout over and above generic factors. The disease-related risk variables chosen for analysis were broad and general. As this study was the first to explore burnout in this context, it was considered most fruitful to analyze variables covering disease-specific stress in general, rather than trying to pinpoint specific stressors; this may rather be a task for further studies. The 5 disease-related factors in focus related to the general status of the child, the time period of possible disease-related stressor exposure, and the subjective perceptions of the experience, and were specifically: sequelae severity, time elapsed since the cancer diagnosis, time off treatment perception of the treatment period as taxing, and general perception of a disease-related influence on everyday life. The 5 generic factors were: the parent's gender, education, work stressors, economic stressors, and global stress. A further aim was to examine the parents' perception of disease-related influence for stability over time, to get a brief indication of any chronic disease-related stress. Burnout is operationalized according to Shirom, Melamed et al<sup>10,11</sup> that is, as in the symptoms covered by the Shirom-Melamed Burnout Questionnaire (described further below). The term *stress* used in the definition that is commonly accepted in stress research<sup>16</sup>: a collective term describing the process (involving stimulus and response).

## MATERIALS AND METHODS

Self-report questionnaires were used in a longitudinal design including an initial assessment (T1) and a follow-up assessment (T2) approximately 7 months later. The rationale for this interval was that stress has been considered chronic if the stressors are of more than 6 months duration.<sup>12,17</sup> An estimation of sequelae at T2 was made by a pediatric oncologist and a pediatric oncology nurse.

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From the Childhood Cancer Research Unit, Department of Woman and Child Health, Karolinska Institutet, Stockholm, Sweden.  
Supported by the Swedish Childhood Cancer Foundation (RKT05/006).  
Reprints: Annika Lindahl Norberg, PhD, Childhood Cancer Research Unit, Astrid Lindgren Children's Hospital Q6:05, SE-171 76 Stockholm, Sweden (e-mail: annika.lindahl.norberg@ki.se).  
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## Sample

This report includes data from 44 parents (24 mothers and 20 fathers, of whom 19 were couples, whereas from 1 family only the father participated, and from 5 families only the mothers participated). The inclusion criteria for invitation were: a malignant brain tumor; treatment completed; the child under 19 years old; the parent should have sufficient knowledge of the Swedish language to complete the questionnaire. According to these criteria, we invited both the mothers and fathers of all the children who were diagnosed with a malignant brain tumor 2000–2004 at the pediatric cancer unit at Astrid Lindgren's Children's Hospital/Karolinska University Hospital in Stockholm, Sweden. A total of 59 (86%) out of the 69 parents invited, completed the T1 questionnaires. At T2, 6 parents were not included owing to a relapse of the child's disease. Of the 53 eligible at T2, 44 (83%) participated. Thus, the study sample includes 64% of the parents originally invited.

At T2 the sample had these characteristics. Fifty-five per cent of the parents ( $n = 24$ ) had children diagnosed with low-grade astrocytoma, 18% ( $n = 8$ ) medulloblastoma, 11% ( $n = 5$ ) optic glioma, and 16% ( $n = 7$ ) other (teratoma, oligodendromatosis, chranioopharyngeoma, and dysgerminoma). The age of the children ranged from 5 to 18 years old. Forty percent of the nonresponding/excluded parents were parents of children with medulloblastoma; this large number was partly explained by the fact that most of the parents excluded at T2 owing to a relapse of the child's disease had children with medulloblastoma. The small numbers in each subgroup did not permit a statistical analysis. The time elapsed since the diagnosis did not differ between responders and nonresponders.

## Procedures

The parents were invited by telephone by a contact nurse, obtaining informed consent. Those who agreed to participate received a letter with written information, the questionnaire, and a prepaid reply envelope. Individuals who had questions about the study or the questionnaire were able to contact the investigator by e-mail or telephone. T2-questionnaires were sent out approximately 7 months later. Reminders were sent by mail 2 and 4 weeks after the T1 and T2 distributions. The study was approved by the local Ethics Committee and carried out in accordance with the ethical standards of the recent version of the 1964 Declaration of Helsinki.

## Assessments

- The Shirom–Melamed Burnout Questionnaire (SMBQ, 22 items assessing: emotional exhaustion/physical fatigue, listlessness, tension, and cognitive difficulties)<sup>10,11</sup> gives scores ranging from 1 to 7, a higher score reflecting more burnout symptoms. High correlation with the Pines Burnout Measure and subscales of the Maslach Burnout Inventory indicates good construct validity.<sup>18</sup> Cronbach's  $\alpha$  0.98 in this study showed good internal consistency.
- A perception of the treatment period was obtained through the questionnaires at T1. On a 4-point scale parents reported whether they perceived the treatment period in general as: "Very taxing," "Quite taxing," "Not very taxing," or "Not taxing at all."
- Similarly, a general perception of disease-related influence on everyday life was estimated through the question: "Is your family and your everyday life today affected by experiences or problems associated with the illness and

the treatment?" with the response alternatives: "The family is very much affected," "—quite affected," "—not very much affected," and "—not affected at all." The estimation at T1, closest to the end of treatment, was used.

- The parents reported their educational level: elementary school only, high school, or university.
- Economic stressors: a 4-point scale from "Not at all" to "All the time," with a question regarding how often the respondent worried about how to make ends meet.
- Work stressors: parents estimated their work situation based on 6 items: demanding, stressful, stimulating, interesting, manageable, gives you opportunity to develop (the 4 latter reversed) on a 4-point scale from 0 = "Not at all" to 3 = "All the time." Higher mean scores indicated more intense stressors. For the 6 parents who were not working, the work stressors were regarded to be "Not at all." In a sample of 215 parents of healthy children, this measure of work stressors showed a significant relationship with burnout assessed with the SMBQ (Spearman  $\rho$  0.44,  $P < 0.001$ ).
- Global (ie, nonspecified) stress at T1 was assessed with the 14-item Perceived Stress Scale (PSS),<sup>19</sup> declared to be suitable to examine the role of appraised stress in the aetiology of disease and behavioral disorders. It covered the previous week. Results are sum scores between 0 and 56, a higher score reflecting more stress. Psychometric properties of the scale are adequate.<sup>19</sup>  $\alpha$  in this study was 0.84. Explicitly, the PSS is a measure of perceived load of stressors, as opposed to the SMBQ, which assesses symptoms of burnout.
- An estimation of long-term clinical and/or neuro-psychologic sequelae was based on an earlier established categorization,<sup>20</sup> including 3 categories:
  - no or minor sequelae (no limitation of daily activity, requires no special medical attention, no cosmetic differences apparent);
  - a certain extent of sequelae, although not severe (mild restriction of activity, and/or mild cosmetic changes, and/or some medical attention or equipment needed);
  - severe sequelae (significant restriction of daily activity, and/or significant cosmetic changes, and/or significant medical attention or equipment needed). A pediatric oncologist and a pediatric oncology nurse blind for the study outcome independently made estimations of sequelae at the time of T2. Subsequently, any divergences between the 2 sets of estimations were examined, and 1 set was established.

## Data Management and Statistics

Unanswered items in the SMBQ were replaced with the respondent's mean score of the subscale in question for 5 respondents who had omitted 1 item each. Regarding predictor variables, 1 answer was missing concerning economic stressors, and was treated as "Not at all."

No systematic dependence in burnout scores caused by the shared experiences of the 2 parents in a family was indicated when comparing mother and father from the 19 couples in which both parents participated: Pearson  $r = 0.25$ ,  $P = 0.303$ , and paired samples  $t = 2.87$ ,  $P = 0.010$  for a significant difference.

The stability of the parents' perceived disease-related influence on daily life was explored with Wilcoxon signed-ranks test. The association between perceived influence and time was also examined cross-sectionally, through Spearman

correlations involving the perceived influence at T1 and T2, respectively, and the time elapsed since end of treatment.

Univariate tests (2-tailed Spearman correlations) were used to identify any associations between burnout and each of the predictor variables (except sequelae). To minimize the risk of Type I error in the correlation involving 9 tests, results significant at  $P=0.006$  or less were considered according to Bonferroni adjustment. Any association between burnout and sequelae was examined with 1-way analysis of variance (ANOVA).

The impact of disease-related predictors over and above generic factors was calculated through hierarchical regression analysis with forced entry at each step, including factors that were significantly associated with burnout. First, the variance explained by generic factors was removed by forced first-block entry. Subsequently, the disease-related factors were entered.

## RESULTS

### Descriptive Statistics

#### Disease-related Factors

- Seventeen (39%) were parents of children with no/minor sequelae, 22 (50%) had children with a certain extent of sequelae, and 5 (11%) severe sequelae.
- The time off treatment ranged from 8 to 70 months (mean 34 mo, SD 21).
- Seventeen to 71 months had elapsed since diagnosis (mean 42 mo, SD 18).
- Thirty-three parents (75%) felt that the treatment period had been “Very taxing,” 17 (23%) “Quite taxing,” and 1 (2%) “Not very taxing.” None of the parents considered the treatment period as “Not taxing at all.”
- The parents’ general perception of the disease-related influence on everyday life at T1 was reported as: 16 parents (36%) felt that the family has been very much affected, 17 (39%) the family has been quite affected, 11 (25%) the family has not been very much affected, whereas no one felt that the family has not been affected at all.

The parents’ general perception of the disease-related influence on everyday life at T1 was highly correlated ( $\rho = 0.79$ ,  $P < 0.001$ ) with the estimation at T2 7 months later. Wilcoxon signed-ranks test further showed stability in the parents’ appraisal of disease-related influence ( $P = 0.564$ ). Moreover, weak associations between the time elapsed as the end of treatment, and the disease-related influence (T1  $\rho = 0.20$ ,  $P = 0.188$ ; T2  $\rho = 0.03$ ,  $P = 0.840$ ) indicated that the experience of influence was equally prevalent at various points in time after the end of treatment. In other words, the perceived influence of the disease on everyday life was not generally lower in parents for whom a longer time had elapsed since the end of treatment.

#### Generic Factors

- Twenty-four (55%) of the parents were mothers, and 20 (45%) were fathers.
- Fourteen (32%) had an education at a university level, and 29 (66%) had been to high school. As only 1 parent had no higher education than elementary school, this category was merged with the high-school category.
- Work stressors ranged from 0 to 2.33 (mean 1.45, 0.46).
- Economic stressors were reported: “All the time” for 5 parents (11%), “Often” for 17 (39%), “A little/

**TABLE 1.** Correlations Between Predictor Variables and Burnout in Parents of Children With Cancer (n=44)

	Spearman $\rho$	P (2-tailed)
Disease-related factors		
Time off treatment†	-0.11	0.470
Time since diagnosis†	-0.15	0.330
Treatment perceived as taxing*	0.20	0.183
Disease-related influence*	0.40	0.006
Generic factors		
Sex	0.31	0.038
Education†	-0.28	0.069
Economic strain†	0.16	0.299
Work strain*	-0.06	0.731
Global stress (PSS)*	0.74	< 0.001

\*Assessed at T1, 7 months before T2.

†Status at T2.

sometimes” for 17 (39%), and “Not at all” for 4 parents (9%).

- One nonresponse regarding economic stressors was treated as “Not at all.” Global stress, assessed as a PSS score, ranged from 8 to 47 (mean 24.3, SD 8.7).

### Associations Between Predictors and Burnout

Only 1 variable in each predictor category was significantly correlated with burnout (Table 1). Thus, parents who reported that their families were more seriously affected by cancer-related matters and those with a higher level of global stress reported more burnout symptoms 7 months later. ANOVA revealed no systematic variation in burnout between the 3 sequelae groups (comparison of Groups I and II  $P = 0.853$ ; II and III  $P = 0.682$ ; I and III  $P = 0.606$ ).

Subsequently, a 2-step hierarchical regression analysis was made. Collinearity between the 2 independent variables was found to be unproblematic ( $\rho = 0.18$ ,  $P = 0.233$ ). According to the results of the hierarchical regression analysis, 61% of the variance in burnout was accounted for by global stress, and an additional 6% was explained by the parents’ perceptions of the disease-related influence (Table 2).

## DISCUSSION

Several researchers have assumed that parenting a child with cancer entails chronic stress. This assumption was supported by the present findings, in which burnout symptoms experienced by parents of childhood brain tumor survivors suggest a long-term stress exposure. However, it has been presumed that the cancer treatment phase is the period that entails chronic parental stress,<sup>2,21</sup> implying that any posttreatment burnout basically should be lingering effects of this phase. Yet, these findings suggest that neither the perceived demands of treatment nor the passing of time

**TABLE 2.** Prediction of Burnout in Parents of Children With Cancer Using Hierarchical Regression Analysis

Steps/Predictors	R <sup>2</sup>	R <sup>2</sup> change	$\beta$	t	P
1. Global stress (PSS)	0.61		0.78	8.13	< 0.001
2. Disease-related influence		0.06	0.26	2.82	0.007

was systematically associated with burnout symptoms. According to this cross-sectional study, burnout symptoms may be present at any point in time during the first 6 years posttreatment. In addition, results indicated that parents' subjective perception of the everyday influence from the disease is associated with burnout symptoms 7 months later.

The perceived disease-related influence explained an additional small part of the variation in burnout, over and above global stress including stress of any kind, whether disease-related or not. The relationship between stress and burnout in the parents of childhood cancer survivors should be furthermore examined with an approach that better identifies the various sources of stress, and using larger samples.

It should be observed that the perceived influence was not assessed as an objective measure of effect on the family. Rather, it was intended to reflect the parents' subjective experiences. Although the single question constituted a rough measure, the responses indicate that many parents perceived that their lives were markedly affected by matters associated with the child's brain tumor. Moreover, the parents' responses to this question were fairly stable over time, which may alert to experiences of prolonged stressors.

The imprecision of this single-item measure prompts a consequential question regarding which types of disease-related stressors are specifically associated with parental burnout. We know from earlier research that an increased overall parenting burden seems to persist when treatment has been completed.<sup>22,23</sup> In the case of long-term late effects in general, and neurocognitive sequelae in particular, survivor needs relate to all kinds of everyday life activities, in which parents invest a large amount of time and commitment.<sup>6</sup> Moreover, the situation also influences family functioning and marital roles, and balancing sibling needs. For the parent as an individual, routine and the view of life often change, which can be perceived as stressful. Thus, parents of brain tumor survivors often experience combinations of tangible stressors and existential challenges.<sup>6,24</sup> For example, changes in parenting routines are triggered by the child's actual needs, but also by uncertainty about the future and by the cancer experience per se.

Consequently, long-term late effects in survivors of childhood brain tumor are likely to cause stress in parents. Yet, more severe sequelae did not systematically imply higher level of burnout symptoms in this study. This is in line with earlier findings that the objective severity of a child's disability does not seem to systematically have an impact on parent well-being in the same way as subjectively perceived stressors do.<sup>25</sup> The explanation may converge with the general stress theory, in which the psychologic outcome seems to be dependent on the subjective experience of the event rather than its objective features. In addition, the mere fact that the child has changed can be stressful.<sup>26</sup> Adapting to even a minor sequel, eg, nutrition problems or minor attention difficulties, typically influences the entire life of the family.<sup>6</sup>

Perceived work stressors did not show any association with burnout in this sample. This furthermore supports the suggestion that burnout in the study group may be related to nonwork stressors. A possible explanation may also be traced to the fact that parents of childhood cancer survivors often report a more relaxed attitude to work and career.<sup>6,23</sup>

Burnout in parents of childhood cancer survivors is not only a problem for the parents themselves. A parent suffering from the emotional and cognitive symptoms of burnout may perceive a reduced capacity for parenting. Moreover, any deterioration in the ability to take in medical information may affect the quality of care. In addition to regular crisis support and counseling, components from methods developed for the prevention and treatment of work-related burnout may be useful in pediatric psycho-oncology care.<sup>27</sup> Indeed, preliminary findings indicate that coached involvement in the child's rehabilitation may alleviate parents' chronic stress.<sup>28</sup>

Some obvious methodologic limitations of the study need to be mentioned. The first is the relatively small sample, preventing us from reliably drawing generalized conclusions based on the findings, and reducing the power of statistical tests. In addition, although the use of comparison groups is complicated in the study of context-specific stressors, the lack of a comparison group is a limitation of the study. Second, the measure of stress and burnout was based only on self report. Physiologic measures relevant to the chronic stress process would have added more weight to the study. Moreover, the use of stress appraisal to predict stress outcome is challenging, owing to possible reciprocity. Besides, burnout can be stable, and may well have been present already at T1, blurring the possibility to interpret the direction of causality. In addition, as burnout was measured only at T2, we cannot tell if the predictor variables were associated with a change in burnout levels. In addition, our rating of sequelae severity did not include measures of behavior or psychosocial problems, which may be demanding for the parent. Furthermore, the estimations of the parents' perception of the disease-related influence and the perception of treatment were simple and may not capture the concept accurately. Single items have a questionable validity, and the latter was retrospectively estimated, which is always less than optimal. Nevertheless, single items are efficient in the preliminary screening of general phenomena, without overloading already burdened respondents. The fact that the perception of the disease-related influence showed an association with burnout encourages furthermore examination. However, it should be borne in mind that the findings of this study relate to parents of children surviving a brain tumor, and cannot be generalized to parents of children with other diagnoses. Furthermore, the cross-sectional nature of the study group as regards time elapsed since the end of treatment may be a limitation. However, the influence can be regarded as minor as the data were analyzed longitudinally, and the preliminary analysis revealed no association between the time elapsed since the end of treatment and the outcome measure of burnout. The range of time between time of diagnosis is very large to draw conclusions from. In addition, no baseline scores of parental stress before the child's illness could be obtained. Finally, in addition to the generic stressors addressed in this report, further studies could investigate the impact of the experience of other disease, bereavement, or interpersonal conflict.

The findings imply that the appraised stressors of parenting a brain tumor survivor may contribute to burnout symptoms. If that is the case, intervention programs may target chronic stress early in the psychosocial follow-up of these families to prevent negative consequences. The findings that parental burnout indeed

is related to a child's disease and that the stress levels do not seem to change in relation to the time since the end of treatment are interesting and encourage furthermore investigation of chronic stress among parents, by using a more elaborated assessment approach to identify critical stressors and by using multicentre approach to accumulate larger samples. Furthermore, the parents' subjective statements of disease-related burden and general stress may well reflect a risk of serious consequences. Consequently, findings also highlight the importance of paying attention to the parents' subjective perceptions of the situation. Clinicians in pediatric oncology and researchers in the field should recognize the significance of the parents' own reports of stress.

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#### REFERENCES

- Vrijmoet-Wiersma CM, van Klink JM, Kolk AM, et al. Assessment of parental psychological stress in pediatric cancer: a review. *J Pediatr Psychol*. 2008;33:694–706.
- Barrera M, D'Agostino NM, Gibson J, et al. Predictors and mediators of psychological adjustment in mothers of children newly diagnosed with cancer. *Psychooncology*. 2004;13:630–641.
- Kazak AE, Alderfer M, Rourke MT, et al. Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. *J Pediatr Psychol*. 2004;29:211–219.
- Lindahl Norberg A, Lindblad F, Boman KK. Parental traumatic stress during and after paediatric cancer treatment. *Acta Oncologica*. 2005;44:382–388.
- Phipps S, Long A, Hudson M, et al. Symptoms of post-traumatic stress in children with cancer and their parents: effects of informant and time from diagnosis. *Pediatr Blood Cancer*. 2005;45:952–959.
- Lindahl Norberg A, Steneby S. Experiences of parents of children surviving brain tumour: a happy ending and a rough beginning. *Eur J Cancer Care (Engl)*. 2009;18:371–380.
- Mulhern RK, Merchant TE, Gajjar A, et al. Late neurocognitive sequelae in survivors of brain tumours in childhood. *Lancet Oncol*. 2004;5:399–408.
- Eiser C, Upton P. Costs of caring for a child with cancer: a questionnaire survey. *Child Care Health Dev*. 2007;33:455–459.
- Orth-Gomer K, Leineweber C. Multiple stressors and coronary disease in women. The Stockholm Female Coronary Risk Study. *Biol Psychol*. 2005;69:57–66.
- Melamed S, Kushnir T, Shirom A. Burnout and risk factors for cardiovascular diseases. *Behav Med*. 1992;18:53–60.
- Melamed S, Ugarten U, Shirom A, et al. Chronic burnout, somatic arousal and elevated salivary cortisol levels. *J Psychosom Res*. 1999;46:591–598.
- Swedish National Board of Health and Welfare. [Syndrome of Exhaustion. Stress Related Psychological Ill-health] Swedish. Stockholm, Sweden: Swedish National Board of Health and Welfare; 2003.
- MacFadyen AJ, MacFadyen HW, Prince NJ. Economic stress and psychological well-being: an economic psychology framework. *J Econ Psychol*. 1996;17:291–311.
- Hallman T, Perski A, Burell G, et al. Perspectives on differences in perceived external stress: a study of women and men with coronary heart disease. *Stress Health*. 2002;18:105–118.
- Lindahl Norberg A. Burnout in parents of children surviving brain tumour. *J Clin Psychol Med Settings*. 2007;14:130–137.
- Lazarus RS. *Psychological Stress and the Coping process*. New York: McGraw-Hill; 1966.
- Bennett EJ, Tennant CC, Piesse C, et al. Level of chronic life stress predicts clinical outcome in irritable bowel syndrome. *Gut*. 1998;43:256–261.
- Grossi G, Perski A, Evengard B, et al. Physiological correlates of burnout among women. *J Psychosom Res*. 2003;55:309–316.
- Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. *J Health Soc Behav*. 1983;24:385–396.
- Kazak AE, Stuber ML, Barakat LP, et al. Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancers. *J Am Acad Child Adolesc Psychiatry*. 1998;37:823–831.
- Miller GE, Cohen S, Ritchey AK. Chronic psychological stress and the regulation of pro-inflammatory cytokines: a glucocorticoid-resistance model. *Health Psychol*. 2002;21:531–541.
- Hillman KA. Comparing child-rearing practices in parents of children with cancer and parents of healthy children. *J Pediatr Oncol Nurs*. 1997;14:53–67.
- Quin S. The long-term psychosocial effects of cancer diagnosis and treatment on children and their families. *Soc Work Health Care*. 2004;39:129–149.
- Forinder U, Lindahl Norberg A. 'Now we have to cope with the rest of our lives'. Existential issues related to parenting a child surviving a brain tumour. *Support Care Cancer*. 2010;18:543–551.
- Skok A, Harvey D, Reddihough D. Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy. *J Intellect Dev Disabil*. 2006;31:53–57.
- Young B, Dixon-Woods M, Heney D. Identity and role in parenting a child with cancer. *Pediatr Rehabil*. 2002;5:209–214.
- Perski A, Grossi G. [Treatment of patients on long-term sick leave because of stress-related problems. Results from an intervention study] Swedish. *Läkartidningen*. 2004;101:1295–1298.
- van't Hooft I, Lindahl Norberg A. SMART cognitive training combined with a parental coaching programme for three children treated for medulloblastoma. *NeuroRehabilitation*. 2010;26:105–113.