

Surviving a brain tumor in childhood: impact on family functioning in adolescence

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Abstract

Objective: To investigate family functioning in families with an adolescent survivor of a pediatric brain tumor. We explored whether adolescent, parent, disease and treatment factors, and demographic characteristics predicted family functioning.

Methods: In this cross-sectional study, 45 adolescent survivors of pediatric brain tumors and their parents completed self-report questionnaires on family functioning, and emotional and behavioral problems. Parents completed questionnaires on their own mental health and the burden of treatment.

Results: Compared to general population norms, adolescents reported higher levels of cohesion, expressiveness, organization, control, family values and social orientation, and absence of conflict. Parents reported higher levels of social orientation and lower levels of conflict and family values. The only predictor of family functioning was current age of the adolescent; older adolescents reported less family conflict. No relation was found between family functioning and emotional and behavioral problems, disease- or treatment factors, and demographic variables.

Conclusions: In this exploratory study, adolescent survivors of a pediatric brain tumor characterized their families by higher levels of cohesion, expressiveness, organization, control, family values and social orientation, and absence of conflict, which differs from the more normative view held by their parents. A higher adolescent age predicted less family conflict, which may indicate deviant autonomy development in these survivors. Because of limitations of this study, conclusions should be considered provisional; they provide clues for further research in this area.

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Introduction

A pediatric brain tumor and associated treatment have a profound impact on the psychosocial functioning of both child and family [1,2]. After treatment, children remain vulnerable to physical, social, and neuropsychological or psychological sequelae. These late effects can extend the impact of the disease and increase the risk of maladaptive family functioning [3,4], whilst family support is a vital resource for children in stressful circumstances [5].

Pediatric brain tumor survivors have been understudied because of the heterogeneity of diagnosis and treatment. Furthermore, the severe cognitive deficits of these children often prevent them from participating in scientific studies [6]. Due to the diversity of diagnosis and treatment in brain tumor survivors, related late effects also differ in nature and severity. The most late effects problems in this population are, beside severe cognitive deficits, limited educational attainments, emotional and behavioral problems, and social limitations [1,7].

Late effects of a pediatric brain tumor may affect family functioning. This is especially relevant in adolescence, since this is normally a developmental phase characterized by rapid

transitions in family functioning. In adolescent survivors of a pediatric brain tumor, family functioning may be influenced by late effects such as delayed autonomy development and individuation [8]. At the moment, literature about the relation between late effects of brain tumors specifically and family functioning is limited. However, studies on late effects of pediatric cancer in general have found that mothers of children with cancer were likely to report more family conflict and perceived the family system as less flexible and adaptable than mothers of healthy children [9,10]. It remains unclear whether such differences in family functioning between families of cancer survivors and families of healthy children are also present in adolescent survivors of a pediatric brain tumor.

Besides adolescent characteristics, parent characteristics also play a major role in family functioning. In particular, parenting stress has been investigated extensively and has been found to be elevated in parents during the diagnosis and treatment of a pediatric brain tumor [3]. For example, a recent study revealed that parents of children with a brain tumor may experience high parenting stress for a long period of time, up to as long 6 six years after diagnosis [11]. High levels of parenting stress may disrupt parents' abilities to meet their child's altered needs, which, in turn, may

lead to maladaptive family functioning [12]. Although the focus in pediatric patients is usually on disease-related factors (e.g. type of tumor or time since diagnosis), demographic characteristics (e.g. parent's marital status or level of education) also influence family functioning [12,13].

In this study, we explored family functioning in families with an adolescent survivor of a pediatric brain tumor. We expected that family functioning in these families would differ from that of families with a healthy adolescent. Furthermore, we hypothesized that family functioning would be related to adolescent emotional and behavioral functioning. Besides the influence of adolescent behavioral characteristics, we also explored the impact of disease and treatment factors and demographic variables on family functioning.

Methods

Participants and procedures

Adolescents (12–18 years old) and their parents were recruited from the complete cohort of pediatric brain tumor patients diagnosed and treated at the Wilhelmina Children's Hospital between 1995 and 2007. To be eligible for the study, adolescents had to be diagnosed at least 2 years ago and off treatment at the time of data collection.

The study protocol was approved by the Institutional Review Board. Parents and adolescents were approached separately for informed consent. Parents were asked to give consent for themselves and their child. Adolescents gave their own consent if they had the cognitive capacities to understand the informed consent procedure and were physically able to sign their own consent form. After consenting to participate, parents and adolescents were asked to complete the questionnaires independently of each other. In cases where this caused emotional distress or discomfort, participants were encouraged to contact the first author for psychological support.

Of the 60 eligible families contacted, 51 families (85%) gave their informed consent and returned the questionnaires (8 fathers, 42 mothers, and 45 adolescents). Parents of 8 adolescents reported that their children had cognitive disabilities and could not understand the informed consent procedure; 2 of these adolescents also had visual disabilities and could not sign their own consent form. Reasons for refusal to participate included: (a) completing the questionnaires was too great a burden ($n = 3$); (b) the adolescent did not know or understand he/she had a brain tumor ($n = 3$); (c) families had closed the disease chapter ($n = 1$); and (d) families were tired of taking part in scientific research ($n = 3$). There were no differences between consenting families ($n = 51$) and non-consenting families ($n = 9$), except for ethnicity. In the group who gave consent, all families were Dutch, while in the non-consenting group, one family was Turkish and one family was Moroccan. Descriptive statistics of the participants are

presented in Table 1. Demographic data was obtained from parents and therefore also available for non-consenting adolescents with consenting parents. Six months after inclusion, one adolescent participant contacted the first author for psychological support.

Measures

Family functioning

Family functioning was measured using the Dutch version of the Family Environment Scale (FES) [14]. The FES was completed by parents and adolescents and consists of 77 true–false questions that constitute 7 subscales, each containing 11 items (range of scores 0–11). These scales are: (a) *cohesion*, the emotional bonding between family members; (b) *expressiveness*, the open and direct expression of feelings and opinions; (c) *conflict*, the expression of anger and aggression; (d) *organization*, the rules, roles and duties within the family; (e) *control*, the restraints (i.e. discipline) family members impose upon each other;

Table 1. Characteristics of adolescent brain tumor survivors and their parents

| | Adolescents ($n = 51$) | |
|---------------------------------------|--------------------------|----|
| | <i>n</i> | % |
| Adolescent sex, male | 33 | 65 |
| Adolescent age, mean years (SD) | 14.8 (1.9) | |
| Time since diagnosis, mean years (SD) | 7.4 (3.3) | |
| Adolescent education | | |
| Primary education | 2 | 4 |
| Primary special education | 3 | 6 |
| Secondary education | 25 | 49 |
| Secondary special education | 21 | 41 |
| Adolescent living situation | | |
| With both parents | 44 | 87 |
| With one parent | 6 | 13 |
| Care home | 1 | 2 |
| Adolescent has siblings | 50 | 98 |
| Adolescent diagnosis | | |
| Gliomas | 27 | 53 |
| Ependymomas | 2 | 4 |
| Germ cell tumors | 8 | 16 |
| Craniopharyngiomas, prolactinomas | 3 | 6 |
| Other tumors | 11 | 21 |
| Treatment (%) | | |
| No treatment | 6 | 12 |
| Surgery | 35 | 69 |
| Radiotherapy (all focal) | 13 | 26 |
| Chemotherapy | 4 | 8 |
| | Parents ($n = 50$) | |
| Parental education | | |
| Low | 14 | 28 |
| Middle | 19 | 38 |
| High | 17 | 34 |
| Parent marital status | | |
| Married | 44 | 88 |
| Divorced | 3 | 6 |
| Living apart together | 1 | 2 |
| Single | 2 | 4 |

(f) *family values*, the values the family adheres to; and (g) *social orientation*, the involvement of family members in the social environment. Extreme scores on both the high and low end of these subscales are considered maladaptive. The FES general Dutch population norm group consists of 1707 parents and 551 adolescents. For this group, Cronbach's alpha as a measure of internal reliability varied between 0.63 and 0.82 for the subscales.

Adolescents' emotional and behavioral problems

Adolescent behavior was evaluated by the adolescents themselves using the Youth Self-Report (YSR), and by their parents using the Child Behavior Checklist (CBCL) [15]. These questionnaires provide parallel information on internalizing and externalizing problems and total problems. The higher the *T*-score, the more problematic the adolescents' behavior is perceived to be. The 2068 parents and 1016 adolescents of the general Dutch population norm group yielded an internal reliability with Cronbach's alpha between 0.85 and 0.92 for internal, external, and total problems [16,17].

Perceived parental mental health status

Parental mental health was assessed using the Dutch version of the General Health Questionnaire (GHQ-28), which is a screening tool to detect common mental health problems and domains of depression, anxiety, somatic symptoms, and social withdrawal among adults. Higher scores on the GHQ-28 indicate worse functioning. When applied to the general Dutch population, the GHQ-28 has a high reliability: Cronbach's alpha is 0.94, based on a norm group of 485 adults [18].

Demographic and medical information

Parents reported on adolescent education, living situation, and siblings, and on their own sex, level of education, and marital status. They were also asked to rate their perceived intensity of treatment on a 5-point Likert scale (1 = 'not intense'; 5 = 'very intense'). Information regarding adolescent birth date, sex, age at diagnosis, tumor type, and treatment was obtained from medical records.

Statistical analysis

Adolescent and parent FES *T*-scores were compared to general Dutch population data using one-sample *T*-tests. *P* values < .05 were considered significant. All analyses were two-tailed. As a measure of effect size, we calculated Cohen's *d* for all *T*-statistics [19]. Cohen's *d* was interpreted as *d* = 0.20: a small effect; *d* = 0.50: a medium effect; and *d* = 0.80: a large effect [20]. Relationships between FES subscales with adolescent emotional and behavioral problems, disease-related or treatment-related variables, parent mental health, and family demographic

characteristics were analyzed using MANCOVAs to adjust for multiple testing on the 7 FES subscales. For the effect size partial eta squared, $\eta^2 \geq 0.01$ was considered a small effect, $\eta^2 \geq 0.06$ a medium effect, and $\eta^2 \geq 0.14$ a large effect [20]. Statistical analyses were performed using IBM SPSS version 20.0.

Results

Characteristics of participants

The demographic and health-related characteristics of the adolescents and parents are presented in Table 1. Forty-seven percent of adolescents received some form of special education, indicating extensive educational problems in our sample compared to the general population where 4% receives special education [21]. This is in line with other studies that also report severe educational difficulties in pediatric brain tumor survivors [14]. Besides educational problems, the data in Table 2 show that total emotional and behavioral problems do not differ from the general population. The presence of differences with the general population in internalizing and externalizing problems is more ambiguous, dependent on whether the adolescent or parent completed the questionnaire. In particular, scores on some subscales (social problems, thought problems, attention problems) were significantly higher than population norms, although the mean score is not in the clinical range. This indicates that our sample is representative of a larger group of pediatric brain tumor survivors [6,22,23].

Family functioning

Table 3 presents the adolescent and parent mean *T*-scores on the FES subscales, and comparisons of these scores

Table 2. Adolescent YSR and CBCL *T*-scores and comparison with general Dutch population (population mean *T*-score = 50)

| | Adolescents Comparison adolescents and norm | | | |
|------------------------|---|-----------------------|----------|------|
| | Mean (SD) | <i>t</i> ^a | <i>P</i> | ES |
| YSR | (<i>n</i> = 45) | | | |
| Social problems | 56.5 (7.2) | 6.05 | <.001 | 1.82 |
| Thought problems | 55.0 (6.3) | 5.41 | <.001 | 1.63 |
| Attention problems | 54.3 (5.1) | 5.62 | <.001 | 1.69 |
| Internalizing problems | 52.2 (11.1) | 1.32 | .194 | 0.40 |
| Externalizing problems | 44.7 (8.2) | −4.32 | <.001 | 1.30 |
| Total problems | 48.9 (10.6) | −0.68 | .502 | 0.20 |
| CBCL | (<i>n</i> = 50) | | | |
| Social problems | 57.5 (8.3) | 6.34 | <.001 | 1.81 |
| Thought problems | 55.5 (7.1) | 5.49 | <.001 | 1.57 |
| Attention problems | 56.3 (6.4) | 6.88 | <.001 | 1.97 |
| Internalizing problems | 54.9 (10.4) | 3.35 | .002 | 0.96 |
| Externalizing problems | 47.6 (9.4) | −1.77 | .082 | 0.51 |
| Total problems | 51.9 (10.4) | 1.30 | .201 | 0.37 |

ES is Cohen's *d*.

YSR, Youth Self Report; CBCL, Child Behavior Checklist.

^aOne-sample *T*-tests used to compare adolescent scores to general Dutch population scores.

Table 3. FES adolescent and parent *T*-scores and comparison with general Dutch population (population mean *T*-score = 50)

| | Adolescent self-report (<i>n</i> = 42) | Parent-report (<i>n</i> = 48) | Comparison self-report and norm | | | Comparison parent-report and norm | | |
|--------------------|--|--------------------------------|------------------------------------|----------|------|--------------------------------------|----------|------|
| | Mean (SD) | Mean (SD) | <i>t</i> ^a | <i>P</i> | ES | <i>t</i> ^a | <i>P</i> | ES |
| Cohesion | 56.2 (4.3) | 50.2 (7.1) | 8.91 | <.001 | 2.89 | .22 | .824 | 0.07 |
| Expressiveness | 56.5 (9.1) | 52.2 (10.2) | 4.63 | <.001 | 1.45 | 1.47 | .148 | 0.43 |
| Conflict | 43.7 (9.1) | 45.5 (9.3) | −4.52 | <.001 | 1.41 | −3.36 | .002 | 0.98 |
| Organization | 56.6 (5.7) | 51.8 (7.2) | 7.48 | <.001 | 2.34 | 1.69 | .097 | 0.49 |
| Control | 57.2 (7.2) | 49.4 (8.2) | 6.48 | <.001 | 2.02 | −0.49 | .625 | 0.14 |
| Family values | 54.6 (4.9) | 47.1 (8.2) | 6.06 | <.001 | 1.89 | −2.44 | .019 | 0.71 |
| Social orientation | 54.2 (11.3) | 53.8 (8.1) | 2.42 | .020 | 0.76 | 3.22 | .002 | 0.95 |

ES is Cohen's *d*.

FES, Family Environment Scale.

^aOne-sample *T*-tests used to compare adolescent and parent scores to general Dutch population scores.

with general Dutch population scores. For our sample, Cronbach's alpha varied between 0.34 and 0.64 for the FES subscales reported by the adolescents, and between 0.32 and 0.72 for the subscales reported by the parents. Adolescents in our sample scored significantly higher than general population adolescents on all subscales ($T \geq 54$), except for *conflict* for which they scored significantly lower ($T = 43.7$). Parents presented a more mixed picture. Although they scored lower than general population parents on conflict ($T = 45.5$), just as the adolescents, they also scored lower than the general population on *family values* ($T = 47.1$). Parents scored, similar to the adolescents, higher on social orientation ($T = 53.8$). On all other scales, parents' scores did not differ from parents in the general population.

Adolescent emotional and behavioral problems and family functioning

We investigated whether adolescent emotional and behavioral problems predicted family functioning by conducting 2 MANOVAs: first using the YSR scales social problems, thought problems, attention problems, internalizing problems, and externalizing problems to predict adolescent-reported family functioning, and, second, using identical CBCL scales to predict parent-reported family functioning. Results of both multivariate analyses are presented in Table 4. Neither adolescent-reported emotional and behavioral problems nor parent-reported emotional and behavioral problems in the adolescent predicted family functioning.

Disease and treatment factors, parental mental health, family demographic characteristics, and family functioning

We investigated whether variables selected from the literature (current age of the adolescent, time since tumor diagnosis, whether or not the adolescent had received radiotherapy, whether or not the child was receiving special education, intensity of treatment reported by the parent, and parent mental health status) predicted family functioning as

Table 4. Multivariate analyses of YSR with adolescent-reported FES and CBCL with parent-reported FES

| | Prediction of adolescent-reported FES (<i>n</i> = 39) | | | Prediction of parent-reported FES (<i>n</i> = 47) | | |
|------------------------|--|----------|------------------|--|----------|------------------|
| | <i>F</i> | <i>P</i> | Partial η^2 | <i>F</i> | <i>P</i> | Partial η^2 |
| Social problems | 1.05 | .420 | 0.21 | 0.83 | .566 | 0.14 |
| Thought problems | 1.06 | .413 | 0.22 | 1.07 | .401 | 0.18 |
| Attention problems | 1.12 | .380 | 0.23 | 0.96 | .476 | 0.16 |
| Internalizing problems | 2.24 | .062 | 0.37 | 0.55 | .790 | 0.10 |
| Externalizing problems | 0.98 | .467 | 0.20 | 1.43 | .226 | 0.22 |

For adolescents, $df_1 = 7$, $df_2 = 27$. For parents, $df_1 = 7$, $df_2 = 35$.

reported by the adolescent and the parents. The reliability of our measure of parent mental health (GHQ-28) was Cronbach's alpha = 0.94. Multivariate analyses are presented in Table 5. For both adolescents and parents, current age of the adolescent was a multivariate predictor of family functioning, with a large effect size. In the univariate analyses, adolescent age significantly predicted adolescent-reported family conflict ($F_{(1,31)} = 7.51$, $P = .010$, partial $\eta^2 = 0.20$), with older adolescents reporting less conflict. For parent-reported family functioning, adolescent age was univariately a predictor of family conflict ($F_{(1,40)} = 6.24$, $P = .017$, partial $\eta^2 = 0.14$) and family expression ($F_{(1,40)} = 8.54$, $P = .006$, partial $\eta^2 = 0.18$). Thus, the older the adolescent, the lower the parent-reported family conflict and the parent-reported family expression.

Discussion

The aim of this exploratory study was to investigate family functioning in families with an adolescent survivor of pediatric brain tumor. We found significant differences in almost all areas of family functioning between our clinical group of families and the general population. This effect was most pronounced in the adolescents' assessment of family functioning. However, family functioning was not related to adolescent emotional and behavioral problems. Furthermore, of all disease-related and treatment-related variables

Table 5. Multivariate analyses of background variables with adolescent-reported and parent-reported FES

| | Prediction of adolescent-reported FES (<i>n</i> = 37) | | | Prediction of parent-reported FES (<i>n</i> = 46) | | |
|--|--|----------|------------------|--|----------|------------------|
| | <i>F</i> | <i>P</i> | Partial η^2 | <i>F</i> | <i>P</i> | Partial η^2 |
| Age of the adolescent | 2.53 | .041 | 0.42 | 3.03 | .014 | 0.38 |
| Adolescent attends special education | 1.36 | .267 | 0.28 | 2.15 | .065 | 0.31 |
| Time since diagnosis | 1.70 | .154 | 0.32 | 0.83 | .568 | 0.15 |
| Adolescent received radiotherapy | 0.79 | .603 | 0.18 | 0.74 | .639 | 0.13 |
| Parent-reported intensity of treatment | 1.11 | .389 | 0.24 | 0.88 | .534 | 0.15 |
| Parental mental health | 2.00 | .095 | 0.36 | 1.81 | .118 | 0.27 |

For adolescents, $df_1 = 7$, $df_2 = 25$. For parents, $df_1 = 7$, $df_2 = 34$.

and demographic characteristics included in our analyses, only current age of the adolescent was a significant predictor of family functioning. More specifically, as the adolescent grew older, family conflict and expressiveness decreased with adolescent's age.

Although discrepancies between child and parent reports are described in the literature [7], the magnitude of the difference between adolescent and parent evaluation of family functioning is remarkable. Adolescents reported their family functioning as being more positive than the general population for all aspects of family functioning, whilst parents' reports were generally in line with population norms. These findings seem to indicate that adolescent brain tumor survivors have a very positive perception of their families and experience limited family conflict. A possible explanation for this could be that the history of disease and treatment, in combination with neurocognitive sequelae and educational limitations, leads to an over-adaptive attitude and a delayed autonomy development of the adolescent. Research has shown that, because they perceive themselves as being more vulnerable due to their illness experience, adolescent survivors of pediatric cancer exhibit higher levels of socially desirable behavior compared to non-affected peers [24]. As a result of this socially desirable behavior, parents have to exert less control and discipline when rearing their adolescent, which may lead to stronger family bonding [25]. Another explanation could be that the adolescent's neurocognitive deficits require compensatory support and assistance from the family, which could be reflected in the adolescents' positive regard for their family [13].

Despite the presence of some social, thought, and attention problems in our sample, none of these specific problems or internalizing and externalizing behavior in general were predictive of family functioning. To our knowledge, this has not been described in the literature on brain tumor survivors, so far. A hypothetical explanation could be that the nature of the particular problems experienced by the adolescents in our sample may only interfere to a limited extent with family functioning. As most parents are aware of the (late effect-) neurocognitive difficulties, they provide a strong supportive family and educational climate. This cohesive climate may provide a protective factor in developing emotional and behavioral problems during adolescence. As a result, the

adolescents in our sample may behave not very different from their healthy peers. Furthermore, externalizing problems were not present in our sample, and in general these have a much more disruptive influence on family functioning than internalizing problems [26].

Unexpectedly, the only variable that predicted family functioning was age of the adolescent survivor, in that higher age of the adolescent predicted less family conflict. In normal adolescent development, the affective intensity of parent-child conflict increases from early to middle adolescence [27]. Looking closer at our data on the subscale conflict, we find no increase during early-to-middle adolescence. Indeed, the adolescents report lower conflict than their healthy peers which decreases even more during adolescence. Our finding therefore suggests that autonomy development may be delayed or deficient in our sample of adolescent survivors of a pediatric brain tumor. We had also expected radiotherapy to have an impact on family functioning, since some studies have found radiotherapy to have negative effects on social development, social competence, and social isolation [7,28].

Several limitations of the study must be noted. Regarding the measure of family functioning, the reliability of most subscales was low. This is probably due to our homogeneous and relatively small sample, which reduces variance in FES items. Therefore, eliminating subscale items did not improve reliability. However, several studies found that the FES has low reliability, even in large and diverse samples [29]. These results raise serious questions about use of the FES in future research. Furthermore, the cross-sectional design prevents conclusions being drawn about causality. Since family functioning is a dynamic process, longitudinal observations within the family are necessary for a complete understanding of the development of adolescent survivors [30]. In addition, the study lacks a control group. Because of the explorative nature of the data and the methodological limitations, the results should be interpreted with caution.

For future research, it would be interesting to investigate how family functioning is related to developmental milestones in adolescence, such as autonomy development. Such milestones seem to be more directly related to family functioning, and may act as mediators between disease-related and treatment-related variables.

For clinical practice, it is important to bear in mind that despite positive evaluations of family functioning and absence of behavioral disturbances in adolescence, survivors of pediatric brain tumor survivors seem to be vulnerable for later psychological and relational problems. Follow-up of these survivors in young adulthood, with specific attention to autonomy development, social relations, family functioning, and neurocognitive functioning (i.e. education, work) is therefore recommended. In practice, it may be adaptive to invite and involve family members in the late-effect consultations during early adulthood.

In conclusion, adolescent survivors of a pediatric brain tumor characterized their families by higher levels of cohesion, expressiveness, organization, control, family values and social orientation, and absence of conflict, which differs from the more normative view held by their

parents. Adolescent emotional and behavioral problems, important disease and treatment variables such as type of tumor and radiotherapy, and demographic characteristics did not predict family functioning. However, higher adolescent age did predict less family conflict, and this might indicate deviant autonomy development in adolescent brain tumor survivors.

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Conflict of interest

The authors declare that they have no competing interests.

References

- Fuemmeler BF, Mullins LL, Marx BP. Post-traumatic stress and general distress among parents of children surviving a brain tumor. *Child Health Care* 2001;**30**:169–182.
- Stam H, Grootenhuis MA, Caron HN, Last BF. Quality of life and current coping in young adult survivors of childhood cancer: Positive expectations about the further course of the disease were correlated with better quality of life. *Psycho-Oncology* 2006;**15**:31–43.
- Hutchinson KC, Willard VW, Hardy KK, Bonner MJ. Adjustment of caregivers of pediatric patients with brain tumors: a cross-sectional analysis. *Psycho-Oncology* 2009;**18**:515–523.
- Rolland JS. *Families, Illness, and Disability: An Integrative Treatment Model*. Basic Books: New York, 1994.
- Orbuch TL, Parry C, Chesler M, Fritz J, Repetto P. Parent-child relationships and quality of life: resilience among childhood cancer. *Fam Relat* 2005;**54**:171–183.
- Zebrack BJ, Gurney JG, Oeffinger K et al. Psychological outcomes in long-term survivors of childhood brain cancer: a report from the childhood cancer survivor study. *J Clin Oncol* 2004;**22**:999–1006.
- Carpentieri SC, Meyer EA, Delaney BL et al. Psychosocial and behavioral functioning among pediatric brain tumor survivors. *J Neurooncol* 2003;**63**:279–287.
- Freyer DR. Transition of care for young adult survivors of childhood and adolescent cancer: rationale and approaches. *J Clin Oncol* 2010;**28**:4810–4818.
- Pai ALH, Greenley RN, Lewandowski A et al. A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *J Fam Psychol* 2007;**21**:407–415.
- Kazak AE, Meadows AT. Families of young adolescents who have survived cancer: social-emotional adjustment, adaptability, and social support. *J Pediatr Psychol* 1989;**14**:175–191.
- Bennett E, English MW, Rennoldson M, Starza-Smith A. Predicting parenting stress in caregivers of children with brain tumours. *Psycho-Oncology* 2013;**22**:629–636.
- Kahalley LS, Wilson SJ, Tyc VL et al. Are the psychological needs of adolescent survivors of pediatric cancer adequately identified and treated? *Psycho-Oncology* 2013;**22**:447–458.
- Ach EA, Gerhardt CA, Barrera M et al. Family factors associated with academic achievement deficits in pediatric brain tumor survivors. *Psycho-Oncology* 2013;**22**:1731–1737.
- Jansma J, De Coole R. *GKS-II, Gezinsklimaatsschaal Handleiding*. Swets & Zeitlinger: Lisse, The Netherlands, 1996.
- Achenbach TM, Rescorla LA. *Manual for the ASEBA School-Age Forms and Profiles*. ASEBA: Burlington, VT, 2001.
- Verhulst FC, Van der Ende J, Koot HM. *Handleiding voor de CBCL/4-18*. Afdeling Kinder- en Jeugdpsychiatrie, Sophia Kinderziekenhuis/Academisch Ziekenhuis Rotterdam/Erasmus Universiteit Rotterdam: Rotterdam, The Netherlands, 1996.
- Verhulst FC, van der Ende J, Koot HM. *Handleiding voor de Youth Self-Report (YSR)*. Afdeling Kinder- en Jeugdpsychiatrie, Sophia Kinderziekenhuis/Academisch Ziekenhuis Rotterdam/Erasmus Universiteit Rotterdam: Rotterdam, The Netherlands, 1997.
- Koeter MWJ, Ormel J. *General Health Questionnaire: Dutch Edition*. Swets Test Services: Lisse, The Netherlands, 1991.
- Rosenthal R, Rosnow RL, Rubin DB. *Contrasts and Effect Sizes in Behavioral Research: A Correlational Approach*. Cambridge University Press: Cambridge, 2000.
- Cohen J. *Statistical Power Analysis for the Behavioral Sciences*. Lawrence Erlbaum: Hillsdale, NJ, 1988.
- National Institute of Public Health and the Environment, National Public Health Compass. <http://www.nationaalkompas.nl/participatie/onderwijsdeelname/onderwijsdeelname-samengevat> Searched September 2013.
- Poggi G, Liscio M, Galbiati S et al. Brain tumors in children and adolescents: Cognitive and psychological disorders at different ages. *Psycho-Oncology* 2005;**14**:386–395.
- Bhat SR, Goodwin TL, Burwinkle TM et al. Profile of daily life in children with brain tumors: An assessment of health-related quality of life. *J Clin Oncol* 2005;**23**:5493–5500.
- Madan-Swain A, Brown RT, Sexson SB et al. Adolescent cancer survivors. Psychosocial and familial adaptation. *Psychosomatics* 1994;**35**:453–459.
- Maurice-Stam H, Oort FJ, Last BF, Grootenhuis MA. Emotional functioning of parents of children with cancer: The first five years of continuous remission after the end of treatment. *Psycho-Oncology* 2008;**17**:448–459.
- Odell S, Sander E, Denson LA et al. The contributions of child behavioral functioning and parent distress to family functioning in pediatric inflammatory bowel disease. *J Clin Psychol Med Settings* 2011;**18**:39–45.
- Laursen B, Coy KC, Collins WA. Reconsidering changes in parent-child conflict across adolescence; A meta-analysis. *Child Dev* 1998;**69**:817–832.
- Stam H, Grootenhuis M, Last B. Social and emotional adjustment in young survivors of childhood cancer. *Support Care Cancer* 2001;**9**:489–513.
- Boyd CP, Gullone E, Needleman GL, Burt T. The Family Environment Scale: Reliability and normative data for an adolescent sample. *Fam Process* 1997;**36**:369–373.
- Treadgold CL, Kuperberg A. Been there, done that, wrote the blog: The choices and challenges of supporting adolescents and young adults with cancer. *J Clin Oncol* 2010;**28**:4842–4849.