ACTA ONCOLOGICA, 2017
VOL. 56, NO. 1, 93–100
http://dx.doi.org/10.1080/0284186X.2016.1250945

Taylor & Francis
Taylor & Francis Group

ORIGINAL ARTICLE

Impact of a child's cancer disease on parents' everyday life: a longitudinal study from Sweden

Emma Hovén[a], Helena Grönqvist[a], Ulrika Pöder[b], Louise von Essen[a] and Annika Lindahl Norberg[a,c]

[a]Clinical Psychology in Healthcare, Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden; [b]Caring Sciences, Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden; [c]Centre for Occupational and Environmental Medicine, Stockholm County Council, Stockholm, Sweden

ABSTRACT

Background: A child's cancer disease may disrupt the daily life of the affected family for a long period. The aim was to describe restrictions on parents' leisure activities and work/studies during and after the child's treatment.

Methods: This study used data from a cohort of mothers and fathers (n = 246) of children diagnosed with cancer. Data was collected five times from two months after diagnosis to one year after end of treatment. Reports of restrictions were evaluated over time, between mothers and fathers, and in relation to parent-reported child symptom burden (The Memorial Symptom Assessment Scale) and partial post-traumatic stress disorder (PTSD) (The PTSD Checklist-Civilian Version).

Results: Two (51%) and four (45%) months after diagnosis, about half reported that their leisure activities were restricted at least some of the time. Corresponding percentages for restrictions on work/studies were 84% and 77%. One year after end of treatment, the great majority reported that their leisure activities (91%) and/or work/studies (76%) were never/seldom restricted. During treatment, more mothers than fathers reported restrictions on work/studies all/most of the time. After end of treatment, gender was only related to reports of restrictions among parents not reporting partial PTSD. More parents who reported being restricted all/most of the time also reported partial PTSD and/or a greater symptom burden for the child.

Conclusion: Parents report frequent restrictions on everyday life during treatment. One year after end of treatment, parents report only a limited impact of the child's cancer on their leisure activities and work/studies. More parents who report restrictions also report partial PTSD and/or a greater child symptom burden. The effect of gender on restrictions varies depending on reports of partial PTSD. Future studies of gender differences regarding the impact of a child's cancer on parents' everyday life should thus consider mothers' and fathers' level of psychological distress.

ARTICLE HISTORY
Received 8 April 2016
Revised 14 October 2016
Accepted 15 October 2016

Every year, about 300 children in Sweden are diagnosed with cancer. In the developed countries today, a majority (~80%) will survive their primary malignancy [1]. Cure is nonetheless uncertain and treatment is typically intense, invasive and given for several months or years. Being a parent of a child diagnosed with cancer can challenge and disrupt the family's daily life, causing extensive psychological distress for parents [2,3]. Stressors associated with parenting a child diagnosed with cancer include taking care of the child through painful procedures and side effects of treatments, adaptation to a unpredictable treatment outcome, uncertainty regarding possible late effects, and financial and occupational concerns[2,4]. A subgroup reports psychological distress years after end of treatment [3]. Parents' adaptation after end of treatment is especially challenging if the child experiences late effects, which from a parent perspective often implies caregiving responsibilities.

Parents' involvement in a child's cancer care often entails absence from paid work. Even after the end of successful treatment, some parents need to reduce working hours [4]. The literature, still scarce, indicates that family income decreases and expenses increase in the wake of childhood cancer [5]. In a previous study, we concluded that childhood cancer affects parents', particularly mothers', possibility to maintain working hours up to one year after completion of treatment [6], however, only minor adverse effects were found five years after end of treatment [7].

Opportunities to engage in leisure activities, i.e. 'enjoyable free time activities', may play an important role in how parents cope with stressors associated with parenting a child during and after cancer treatment. Leisure activities buffer against stress-induced negative consequences, e.g. through distraction from negative life events and provision of social support, friendships and social acceptance [8]. The implica-

CONTACT Emma Hovén emma.hoven@pubcare.uu.se Clinical Psychology in Healthcare, Department of Public Health and Caring Science, Uppsala University, Box 564, 751 22 Uppsala, Sweden

Supplemental data for this article can be accessed here.

tions of leisure activities for the well-being of caregivers of children with special needs have rarely been studied. It has, however, been shown that leisure activities buffer against negative health effects of longer hours of care for informal caregivers [9]. It has also been reported that lack of own as well as couple-together leisure time is associated with burnout symptoms among parents of children with a chronic disease [10]. A systematic review has shown that disruptions of daily routines and daily life are common among parents of children diagnosed with cancer [11].

To the best of our knowledge, there is a gap in the literature regarding restrictions on leisure activities and work/studies among parents of children diagnosed with cancer. The aim of this study is to fill this gap by describing parents' reports of restrictions on leisure activities and work/studies during and after their child's cancer treatment. This was done by studying a cohort of mothers and fathers of children diagnosed with cancer during and after end of treatment. Restrictions were related to parents' reports of partial posttraumatic stress disorder (PTSD) and their child's symptom burden. Posttraumatic stress symptoms (PTSS) have been outlined as a useful framework for understanding parents' psychological response to childhood cancer [12]. If symptoms are not relieved, the reactions can develop into full or partial PTSD. Partial PTSD is a condition with clinically significant PTSD symptoms, which do not meet full criteria for PTSD [13]. The criteria for partial PTSD are at least one symptom of reexperiencing, avoidance and hyperarousal, respectively [14], and partial PTSD is associated with comorbid psychiatric symptoms almost to the same extent as full PTSD [13].

The research questions were:

1. How many parents report restrictions on leisure activities and/or work/studies all/most of the time, some of the time, and never/seldom during and after end of treatment?
2. Is there a difference over time with regard to the number of parents who report restrictions on leisure activities and/or work/studies all/most of the time, some of the time, and never/seldom?
3. Is there an association between parent-reported restrictions on leisure activities and/or work/studies and parent gender?
4. Is there an association between parent-reported restrictions on leisure activities and/or work/studies and parental partial PTSD?
5. Are there differences between parents by their reported restrictions on leisure activities and/or work/studies with regard to parent-reported child symptom burden?

Methods

The study is part of a project with the overall aim to investigate psychological and economic consequences of parenting a child diagnosed with cancer. The project involved (up to now) seven assessments via telephone: one week (T1), two (T2), and four months (T3) after diagnosis, one week after end of treatment or six months after end of stem cell transplantation (T4), three months after end of treatment or nine months after end of transplantation/child's death (T5), one year after end of treatment or 18 months after transplantation/child's death (T6), and five years after end of treatment or transplantation/child's death (T7). End of treatment is defined as the time when the child had completed treatment at the time considered successful by the responsible pediatric oncologist. Following discussions with pediatric oncologists, it was decided that six months after transplantation is considered equivalent to end of treatment. The data presented in this study was collected at T2–T6.

Sample

Parents (including step-parents) of children diagnosed with cancer at four Swedish pediatric oncology centers were consecutively recruited during 18 months between 2002 and 2004. Eligibility criteria at T1 included being a Swedish- and/or English-speaking parent of a child 0–18 years, diagnosed $\leq$14 days previously with a primary cancer diagnosis, scheduled for chemotherapy and/or radiotherapy (this criteria not applicable to children diagnosed with central nervous system tumors), and access to a telephone. Parents of children in palliative care and bereaved parents were not eligible at T2-T4. For a participant flow chart covering the entire study period see Ljungman et al. 2015 [15]. Of 325 eligible parents, 259 (130 mothers, 129 fathers) participated at T1 (80% response rate). In this study, parents who lost their child during the time of the study were excluded following that event. Table 1 presents the study sample (n = 246 parents of 133 children over the study period T2-T6) and reasons for exclusion or decline at each assessment.

Participants' mean age at T1 was 38 years (SD = 6.9). Most were well educated, 52% (n = 127) with upper secondary education, 33% (n = 81) with post-secondary education, and 14% (n = 34) with primary education (data on educational attainment was not available for four parents). At T2 about three quarters (73%; n = 180) had two or three children, 16% (n = 40) more than four children, and 11% (n = 26) no siblings to the child diagnosed with cancer. Most (87%, n = 215) were married/cohabiting, 7% (n = 18) single, 5% (n = 12) in partnership but not cohabiting, and 0.5% (n = 1) divorced. Diagnoses included leukaemia/lymphomas (58%, n = 77), solid tumors (30%, n = 40), and central nervous system tumors (12%, n = 16). The children were 0–18 years at diagnosis (M = 7.9, SD = 5.1).

Procedures

Eligible parents were provided written and oral information about the study by a nurse at the respective center within the first two weeks after diagnosis. The same nurse asked parents for verbal informed consent to participate and permission to be contacted over the telephone by a research assistant. At the end of each interview (T1–T5) verbal consent to contact the parent at the following assessment (T2–T6) was acquired. All data was collected via telephone. The structured interview guide used at T2–T6 is presented in

Table 1. Participants' (n = 246 over the study period) characteristics and reasons for exclusion or decline at each assessment (T2–T6).

	T2	T3	T4	T5	T6
Parents (children)	243 (132)	215 (115)	212 (116)	208 (114)	192 (107)
Mothers	122	107	109	108	98
Fathers	121	108	103	100	94
Eligible at each assessment[a]	259	244	241	213	213
Reeligible after previous decline/exclusion		1	26	1	3
Excluded					
Palliative care/child death	3	2	22	4	15
Child moved to a non-participating center	2	1	3		
Child ended successful treatment	1	24			
Parent death					2
Declined					
Not able to prioritize issues under circumstances	5			1	
Not interested	1	1	1		1
Prefers a written questionnaire	2		1		
Does not feel representative					
Too emotionally moved by last interview	2	1			1
Administrative failure			2		2

[a]The number of parents eligible at each assessment was based on the number of parents who had provided verbal consent to be contacted again and the number of parents who was reeligible after previous exclusion, e.g. 24 parents of a child who had ended successful treatment before T3 was excluded from the T3 assessment but reeligible at T4.

T2: two months after diagnosis; T3: four months after diagnosis; T4: one week after end of treatment or six months after end of transplantation; T5: three months after end of treatment or nine months post end of transplantation; T6: one year after end of treatment or 18 months after transplantation.

Supplementary Table S1 (available online at http://www.informahealthcare.com). The study was granted ethical approval by the local ethical committees at each participating center (Dnr: 02-006) and the Regional Ethical Review Board in Uppsala (Dnr: 2008/109).

Assessments

Demographic factors and medical data

Information pertaining to, for example marital status, annual household income and number of siblings of the child diagnosed with cancer were collected at each assessment. Parent educational attainment and age were recorded at T1. Child medical data was obtained from medical records.

Restrictions on leisure activities and work/studies

Parents first answered questions about whether their child's cancer disease had restricted (yes or no) their opportunities to engage in leisure activities and work/studies, respectively. Thereafter the following questions were posed: Have you been home from school/work because of your child's illness since the last interview? and Have you declined leisure activities due to your child's illness since the last interview? If restricted, parents were asked to specify frequency of restrictions with regard to leisure activities and work/studies, respectively, since the previous assessment on a four-point Likert scale as follows: all of the time; most of the time; some of the time; seldom.

Partial PTSD

Partial PTSD was assessed with the PTSD Checklist-Civilian Version (PCL-C), translated into Swedish by our research group using a forward-backward procedure. The PCL-C contains 17 items that parallel the DSM-IV symptom clusters of PTSD: reexperiencing, avoidance/numbing, and hyperarousal [16,17]. Parents were asked to rate the extent to which they had been bothered by each symptom during the previous month on a five-point Likert scale ranging from 'not at all' (1) to 'extremely' (5). Items were keyed to the child's cancer disease. The PCL-C has adequate internal consistency for the full scale, test-retest reliability, and good convergent and discriminant validity compared to other well established measures of PTSS [18]. In this study, the alpha coefficients of the total scale ranged from 0.90 to 0.94 at T2-T6. Based on the model used by Stein and colleagues [14], partial PTSD was defined as a score of $\geq$3 on at least one symptom of reexperiencing, avoidance and hyperarousal, respectively.

Child symptom burden

A modified version of The Memorial Symptom Assessment Scale (MSAS 10-18) [19] was used to assess parents' perceptions of their child's symptoms, translated into Swedish by our research group using a forward-backward procedure. The MSAS 10-18 was developed to be answered by children from approximately 10 years of age [19]. The instrument has adequate internal consistency, test-retest reliability, and construct and criterion validity [19]. The instrument used in this study includes two additional questions [19] about headache and hair loss, resulting in 32 items. For this study, the questions were modified to be answered by parents. For each symptom, parents were asked to assess whether it had been prevalent during the last week, and if so, to rate it according to frequency, intensity and distress for their child. Answers were provided on four- or five-point Likert scales: frequency, from almost never (1) to almost always (4); intensity, from slight (1) to very severe (4); and distress, from not at all (0) to very much (4). The total MSAS score was used to illustrate child symptom burden.

Analyses

With the aim to present the number of parents reporting a significant, some, or a minor impact of their child's cancer on their daily life, parents' reports of restrictions on leisure activities and work/studies, respectively, were collapsed into three categories: all or most of the time; some of the time; seldom or never. The latter category includes reports of no restrictions, i.e. a 'no' to the initial questions. The three categories were used in all analyses.

Descriptive statistics were used to present parent and child characteristics and the number reporting restrictions on leisure activities and work/studies all/most of the time, some of the time, and seldom/never [research question (RQ) 1]. Wilcoxon signed rank test was used to assess whether parent-reported restrictions differed between two time points (e.g. T2-T3; T3-T4) (RQ 2). χ^2-tests were performed to assess associations between parent-reported restrictions and gender and partial PTSD, respectively (RQs 3 and 4). As our previous work has shown that mothers report a higher level of PTSS than fathers [15], post hoc tests were conducted in which partial PTSD was included as a control variable. Effect sizes for χ^2-tests were measured by Cramer's V, with the reference values: 0 for no association, <0.2 for a weak association, 0.2–0.3 for a moderate association, and >0.3 for a strong association. Independent analysis of variance (ANOVA) was used to assess whether there were any differences between parents by their reported restrictions on leisure activities and/or work/studies and parent-reported child symptom burden (RQ5). Bonferroni post hoc test was used to evaluate potential differences between groups, by pairwise comparisons. Effect sizes for ANOVAs were measured by eta squared, with the reference values: small: 0.01, medium: 0.06, and large: 0.14.

All analyses were based on two-sided tests at $\alpha = 0.05$, performed using SPSS 22.0 for Windows (SPSS Inc., Chicago, IL, USA).

Results

Leisure activities

At T2 35% and at T3 24% reported that their leisure activities were restricted all/most of the time (Table 2). At the same assessments 49% (T2) and 55% (T3) reported that their activities were seldom/never restricted. Wilcoxon signed ranks test showed no difference between T2 and T3 and T5 and T6, respectively. However, differences were found between T3 and T4 ($Z = 2.446$, $p = .014$) and T4 and T5 ($Z = 6.507$, $p < 0.001$), indicating that the number reporting being restricted all/most of the time or some of the time decreased over time. One year after end of treatment, the great majority (91%, n = 174) reported being seldom/never restricted.

More mothers than fathers reported restrictions all/most of the time at T4 (Table 2). The post hoc analysis controlling for partial PTSD showed that the association between gender and restrictions remained for parents not reporting partial PTSD (χ^2=9.486, $p = .009$, Cramer's $V = 0.270$), but that the number reporting restrictions all/most of the time, some of the time, and never/seldom did not differ between mothers and fathers reporting partial PTSD (χ^2=2.429, $p = .297$, Cramer's $V = 0.172$).

Except for at T2, more parents reporting partial PTSD reported restrictions all/most of the time than parents not reporting partial PTSD (Table 3). One year after end of treatment, 13% (n = 4) reporting partial PTSD reported being restricted all/most of the time. The corresponding figure for parents not reporting partial PTSD was 3% (n = 4).

Table 2. Parents' reports of restrictions on daily activities and differences in reports between mothers and fathers.

	Leisure activities						Work/Studies					
	All or most of the time n (%)	Some of the time n (%)	Seldom or never n (%)	N/A n (%)	p-Value[a]	Effect size	All or most of the time n (%)	Some of the time n (%)	Seldom or never n (%)	N/A n (%)	p-Value[a]	Effect size
T2												
All	85 (35.0)	39 (16.0)	119 (49.0)				182 (74.9)	22 (9.1)	33 (13.9)	6 (2.5)		
Mothers	47 (38.5)	21 (17.2)	54 (44.3)				108 (88.5)	5 (4.1)	4 (3.3)	5 (4.1)		
Fathers	38 (31.4)	18 (14.9)	65 (53.7)		.333	0.095	74 (61.2)	17 (14.0)	29 (24.0)	1 (.8)	<.001	0.366
T3												
All	52 (24.2)	44 (20.5)	118 (54.9)	1 (0.5)			143 (66.5)	23 (10.7)	46 (21.4)	3 (1.4)		
Mothers	32 (29.9)	23 (21.5)	51 (47.7)	1 (0.9)			88 (82.2)	8 (7.5)	8 (7.5)	3 (2.8)		
Fathers	20 (18.5)	21 (19.4)	67 (62.0)		.082	0.153	55 (50.9)	15 (13.9)	38 (35.2)		<.001	0.371
T4												
All	35 (16.5)	50 (23.6)	127 (59.9)				99 (46.7)	48 (22.6)	59 (27.8)	6 (2.8)		
Mothers	26 (23.9)	27 (24.8)	56 (51.4)				64 (58.7)	24 (22.0)	16 (14.7)	5 (4.6)		
Fathers	9 (8.7)	23 (22.3)	71 (68.9)		.006	0.219	35 (34.0)	24 (23.3)	43 (41.7)	1 (0.9)	<.001	0.318
T5												
All	8 (3.8)	15 (7.2)	184 (88.5)	1 (0.5)			47 (22.6)	18 (8.7)	129 (62.0)	14 (6.8)		
Mothers	6 (5.6)	11 (10.2)	91 (84.3)				38 (35.2)	6 (5.6)	54 (50.0)	10 (0.9)		
Fathers	2 (2.0)	4 (4.0)	93 (93.0)	1 (1.0)	.086	0.154	9 (9.0)	12 (12.0)	75 (75.0)	4 (4.0)	<.001	0.347
T6												
All	8 (4.2)	9 (4.7)	174 (90.6)	1 (0.5)			12 (6.3)	18 (9.4)	145 (75.5)	17 (8.8)		
Mothers	7 (7.1)	4 (4.1)	87 (88.8)				9 (9.2)	13 (13.3)	65 (66.3)	11 (11.2)		
Fathers	1 (1.1)	5 (5.3)	87 (92.6)	1 (1.1)	.106	0.153	3 (3.2)	5 (5.3)	80 (85.1)	6 (6.4)	.017	0.215

[a]p-Value for differences in proportions between mothers and fathers as determined by χ^2-tests. Effect size measured by Cramer's V.
T2: two months after diagnosis; T3: four months after diagnosis; T4: one week after end of treatment or six months after end of transplantation; T5: three months after end of treatment or nine months after end of transplantation; T6: one year after the end of treatment or 18 months after transplantation.

Table 3. The association between parent-reported restrictions on daily activities and partial PTSD.

	Leisure activities				Work/Studies			
	No case[a] n (%)	Case[a] n (%)	p-Value[b]	Effect size	No case[a] n (%)	Case[a] n (%)	p-Value[b]	Effect size
T2								
All or most of the time	35 (29.7)	50 (40.0)			82 (71.3)	100 (82.0)		
Some of the time	17 (14.4)	22 (17.6)			12 (10.4)	10 (8.2)		
Seldom or never	66 (55.9)	53 (42.4)	.105	0.136	21 (18.3)	12 (9.8)	.122	0.133
T3								
All or most of the time	22 (17.7)	30 (33.3)			75 (61.0)	68 (76.4)		
Some of the time	23 (18.5)	21 (23.3)			12 (9.8)	11 (12.4)		
Seldom or never	79 (63.7)	39 (43.3)	.008	0.213	36 (29.3)	10 (11.2)	.007	0.216
T4								
All or most of the time	16 (12.3)	19 (23.2)			54 (42.9)	45 (56.3)		
Some of the time	28 (21.5)	22 (26.8)			27 (21.4)	21 (26.3)		
Seldom or never	86 (66.2)	41 (50.0)	.041	0.173	45 (35.7)	14 (17.5)	.018	0.197
T5								
All or most of the time	3 (1.9)	5 (10.9)			24 (15.9)	23 (53.5)		
Some of the time	6 (3.7)	9 (19.6)			13 (8.6)	5 (11.6)		
Seldom or never	152 (94.4)	32 (69.6)	<.001	0.329	114 (75.5)	15 (34.9)	<.001	0.381
T6								
All or most of the time	4 (2.5)	4 (13.3)			5 (3.4)	7 (24.1)		
Some of the time	4 (2.5)	5 (16.7)			13 (8.9)	5 (17.2)		
Seldom or never	153 (95.0)	21 (70.0)	<.001	0.321	128 (87.7)	17 (58.6)	<.001	0.332

[a]No case = parents not reporting partial PTSD; case = parents reporting partial PTSD.
[b]p-Value to denote significant relationship between parent-reported restrictions on daily activities and partial PTSD by χ^2-tests. Effect size measured by Cramer's V.
T2: two months after diagnosis; T3: four months after diagnosis; T4: one week after end of treatment or six months after end of transplantation; T5: three months after end of treatment or nine months after end of transplantation; T6: one year after the end of treatment or 18 months after transplantation.

Parents' reports of child symptom burden differed by reports of restrictions, at all assessments except T2 (Table 4). Bonferroni post hoc tests showed that at T3 and T4 parents who reported restrictions all/most of the time reported greater child symptom burden compared to parents who reported to be seldom/never restricted [T3: p = .038: 95% confidence interval (CI) 0.0074–0.3434; T4: p = .002: 95% CI 0.0765–0.4441]. At T5 and T6, post hoc tests showed that parents who reported restrictions some of the time reported greater child symptom burden compared to parents who reported to be seldom/never restricted (T5: p = .037: 95% CI 0.0071–0.3162; T6: p = .006: 95% CI 0.0488–0.3798).

Work/studies

At T2 75% and at T3 67% reported that their work/studies were restricted all/most of the time (Table 2). Wilcoxon signed ranks tests showed differences between assessments (T2 vs. T3: Z = 3.620, p < .001; T3 vs. T4: Z = 4.672, p < .001; T4 vs. T5: Z = 7.428, p < .001; T5 vs. T6: Z = 5.059, p < .001). The number reporting restrictions all/most of the time decreased over time whereas the number reporting being seldom/never restricted increased over time. One year after end of treatment, the majority (76%, n = 145) reported being seldom/never restricted.

At all assessments, more mothers than fathers reported restrictions all/most of the time (Table 2). Post hoc analysis controlling for partial PTSD showed that the result remained at T2 and T3. At T4–T6, the association between restrictions and gender was only present among parents who did not report partial PSTD (T4: χ^2=17.983, p < .001, Cramer's V = 0.378; T5: χ^2=16.120, p < .001, Cramer's V = 0.327; T6: χ^2=6.668, p = .036, Cramer's V = 0.214). At T4-T6, the number reporting restrictions all/most of the time, some of the time, and never/seldom did not differ between mothers and fathers reporting partial PTSD (T4: χ^2=2.084, p = .353, Cramer's V = 0.161; T5: χ^2=4.055, p = .132, Cramer's V = 0.307; T6: χ^2=1.983, p = .371, Cramer's V = 0.261).

At T3-T6, more parents reporting partial PTSD than not reporting partial PTSD reported restrictions all/most of the time (Table 3). One year after end of treatment, 24% (n = 7) reporting partial PTSD reported restrictions all/most of the time. The corresponding figure for parents not reporting partial PTSD was 3% (n = 5).

Parents' reports of child symptom burden differed by reported frequency of restrictions at T5 and T6 (Table 4). Bonferroni post hoc tests showed that at T5 parents reporting restrictions all/most of the time or some of the time reported greater child symptom burden compared to parents who reported to be less often restricted (some of the time vs. seldom/never: p = .025: 95% CI 0.0133–0.2645; all/most of the time vs. seldom/never: p = .007: 95% CI 0.0240–0.1944). At T6, post hoc tests showed that parents reporting restrictions all/most of the time reported greater child symptom burden compared to parents who reported being less often restricted (all/most of the time vs. some of the time: p = .010: 95% CI 0.0413–0.4031; all/most of the time vs. seldom/never: p < .001: 95% CI 0.1665–0.4513).

Discussion

This study followed a cohort of mothers and fathers of children diagnosed with cancer from the time of treatment up to one year after end of treatment, highlighting the impact

Table 4. Parents' report of child symptom burden by parent-reported restrictions on daily activities.

	Leisure activities				Work/Studies			
	Mean (SD)	95% CI	p-Value[a]	Effect size	Mean (SD)	95% CI	p-Value[a]	Effect size
T2								
All or most of the time	0.73 (0.52)	0.62–0.84			0.69 (0.47)	0.62–0.76		
Some of the time	0.70 (0.42)	0.57–0.84			0.62 (0.34)	0.47–0.78		
Seldom or never	0.61 (0.44)	0.53–0.69	.192	0.014	0.54 (0.48)	0.37–0.72	.233	0.012
T3								
All or most of the time	0.64 (0.50)	0.50–0.78			0.54 (0.44)	0.47–0.62		
Some of the time	0.50 (0.33)	0.40–0.60			0.51 (0.32)	0.37–0.65		
Seldom or never	0.47 (0.40)	0.39–0.54	.042	0.030	0.48 (0.47)	0.33–0.62	.669	0.004
T4								
All or most of the time	0.58 (0.58)	0.39–0.78			0.44 (0.48)	0.34–0.54		
Some of the time	0.38 (0.39)	0.27–0.49			0.33 (0.32)	0.24–0.43		
Seldom or never	0.32 (0.33)	0.26–0.49	.003	0.055	0.31 (0.32)	0.22–0.40	.122	0.021
T5								
All or most of the time	0.37 (0.27)	0.14–0.60			0.25 (0.29)	0.17–0.33		
Some of the time	0.34 (0.37)	0.14–0.54			0.28 (0.32)	0.12–0.44		
Seldom or never	0.18 (0.22)	0.14–0.21	.005	0.051	0.14 (0.14)	0.12–0.17	.001	0.070
T6								
All or most of the time	0.32 (0.35)	−0.01–0.64			0.44 (0.37)	0.21–0.68		
Some of the time	0.36 (0.37)	0.08–0–64			0.22 (0.38)	0.04–0.40		
Seldom or never	0.15 (0.18)	0.12–0.17	.001	0.072	0.13 (0.15)	0.11–0.16	<.001	0.149

[a]p-Value to denote significant relationship between parent-reported restrictions on daily activities and child symptom burden by ANOVA. Effect size measured by eta squared.

CI: confidence interval; T2: two months after diagnosis; T3: four months after diagnosis; T4: one week after end of treatment or six months after end of transplantation; T5: three months after end of treatment or nine months after end of transplantation; T6: one year after the end of treatment or 18 months after transplantation.

of a child's cancer disease on parents' everyday life. The findings show that the impact was most pronounced during treatment when the majority of mothers and fathers reported restrictions on leisure activities and/or work/studies all/most of the time. Over time, fewer parents reported being restricted all/most of the time. Parents' reports of restrictions on daily activities are related to parental cancer-related distress as well as perceived child symptom burden. More parents reporting partial PTSD and/or a greater child symptom burden reported restrictions all/most of the time. These findings were more pronounced after end of treatment. More mothers than fathers reported restrictions on work/studies all/most of the time over the study period, whereas more similar reports were found regarding leisure activities. After end of treatment, reports of restrictions differed between mothers and fathers not reporting partial PTSD but not between mothers and fathers reporting partial PTSD.

Expectedly, and in line with previous findings [6], the most pronounced impact on parents' leisure activities and working life/studies was found during treatment. In the context of pediatric care, parents have a prominent role being their child's primary source of support. One plausible explanation to the substantial impact found on leisure activities and/or working/study life is that parents in the wake of the child's cancer diagnosis need to adapt to increased caregiving tasks and responsibilities. Caregiving responsibilities during treatment include accompanying the child to the hospital, providing basic care, managing side effects, and providing adequate emotional support to the sick child as well as potential siblings. Moreover, in the Swedish context responsibilities include actively participating in treatment decisions.

Corresponding to previous findings [6,10], more mothers than fathers reported being restricted all/most of the time with regard to leisure activities and/or work/studies shortly after end of treatment. However, the effect of gender varied depending on parents' psychological distress, assessed as partial PTSD. Among parents not reporting partial PTSD more mothers than fathers reported restrictions, whereas more similar reports of restrictions were found among mothers and fathers reporting partial PTSD. Thus, future studies of gender differences regarding the impact of a child's cancer on parents' daily life should consider mothers' and fathers' level of psychological distress.

The association between restrictions on daily life and reports of partial PTSD warrants careful consideration. With the exception from the first assessment, findings show that more parents reporting partial PTSD than parents not reporting partial PTSD reported being restricted all/most of the time. The present study was not designed to draw conclusions about causality, and therefore we can only tentatively interpret the findings. However, the findings may be understood in view of the clinical profile of partial PTSD, including psychosocial dysfunction [13] with negative effects on one's ability and willingness to involve in social activities. Accordingly, parents with partial PTSD may be unable to fulfill work commitments and/or engage in leisure activities. Moreover, the associations between restrictions on daily activities and partial PTSD may well be reciprocal, with the risk of setting off a vicious circle. Specifically, absence of leisure activities may increase the risk of psychological distress and at the same time psychological distress may hamper behavior pertaining to social activities.

Corresponding to previous studies in which parents' reports of the child's illness severity have been shown to be related to adverse parental outcomes [10], our findings show that parents who reported being restricted all/most of the time also reported a greater symptom burden for their child than parents who reported less or no restrictions. This finding may be attributed to increased/lasting caregiving demands and/or worries of parents reporting a higher child symptom score, which limits their opportunities to have personal leisure time.

As indicated by this study, childhood cancer restricts parents' opportunities for leisure activities. This may be detrimental for the parents, as participation in leisure activities is beneficial for well-being. Studies on the implications of leisure activities for the well-being of parental caregivers of children with special needs are scarce. However, studies on family caregivers of adults show that leisure activities can reduce perceived care burden [20,21]. Moreover, leisure activities and leisure satisfaction mediate the relationship between caregiving stress and caregiver health in family caregivers of adult and elderly loved ones [21–23].

The main strengths of this study are the population-based sample, the inclusion of an equal number of mothers and fathers, and the longitudinal design covering five assessments during and after the children's cancer treatment. As we provide a rather crude measure of restrictions on parents' work situation, an interesting target for future studies would be to examine restrictions in relation to working arrangements, e.g. if having flexible working schedules, to see if the degree of impact on parents' working life vary by working arrangements.

In summary, this study demonstrates that parenting a child diagnosed with cancer is related to restrictions on leisure activities and work/studies. These restrictions may have adverse consequences for the parents, e.g. by constraining the potential benefits of leisure activities on well-being, as well as the entire family, e.g. by financial strain. Accordingly, recommendations to pediatric care include social worker advice on occupational issues and practical support and problem solving to facilitate parents' return to work, as well as encouraging continued participation in leisure activities;, making this part of the comprehensive psychosocial care provided to families. For early targeting of families in need of referral for occupational counseling and supportive resources, health care professionals working close to the families should be encouraged to being observant of parents whose daily life is hampered by frequent restrictions on their daily life.

Acknowledgments

We are grateful to all parents who took part in the study for their contribution. We also thank the nurses at the respective center who had the first contact with the potential participants and research assistant Susanne Lorenz who interviewed most parents.

Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

Funding

This work was supported by the Swedish Childhood Cancer Foundation [grant number PROJ08/010], the Swedish Research Council [grant numbers K2008-70X-20836-01-3, K2011-70X-20836-04-4, K2015-99X-20836-08-4], and the Swedish Cancer Society [grant numbers 2007/1015, 2010/726]. The funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript. The funders do not bear any responsibility for the analyses or interpretations presented here.

References

[1] Winther JF, Kenborg L, Byrne J, et al. Childhood cancer survivor cohorts in Europe. Acta Oncol. 2015;54:655–68.
[2] 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.
[3] Ljungman L, Cernvall M, Grönqvist H, et al. Long-term positive and negative psychological late effects for parents of childhood cancer survivors: a systematic review. PLOS One. 2014;9:e103340.
[4] Wakefield CE, McLoone JK, Evans NT, et al. It's more than dollars and cents: the impact of childhood cancer on parents' occupational and financial health. J Psychosoc Oncol. 2014;32:602–21.
[5] Pelletier W, Bona K. Assessment of financial burden as a standard of care in pediatric oncology. Pediatr Blood Cancer. 2015;62:S619–S31.
[6] Hovén E, von Essen L, Lindahl Norberg A. A longitudinal assessment of work situation, sick leave, and household income of mothers and fathers of children with cancer in Sweden. Acta Oncol. 2013;52:1076–85.
[7] Wikman A, Hovén E, Cernvall M, et al. Parents of children diagnosed with cancer: work situation and sick leave, a five-year post end-of-treatment or a child's death follow-up study. Acta Oncol. 2016;55:1152–7.
[8] Caldwell LL. Leisure and health: why is leisure therapeutic? Br J Guid Counc. 2005;33:7–26.
[9] Schryer E, Mock SE, Hilbrecht M, et al. Use of leisure facilities and wellbeing of adult caregivers. Leisure Sci. 2016;38:17–33.
[10] Lindström C, Åman J, Lindahl Norberg A. Parental burnout in relation to sociodemographic, psychosocial and personality factors as well as disease duration and glycaemic control in children with Type 1 diabetes mellitus. Acta Paediatr. 2011;100:1011.
[11] Long KA, Marsland AL. Family adjustment to childhood cancer: a systematic review. Clin Child Fam Psychol Rev. 2011;14:57–88.
[12] Bruce M. A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents. Clin Psychol Rev. 2006;26:233–56.
[13] Pietrzak RH, Goldstein RB, Southwick SM, et al. Prevalence and Axis I comorbidity of full and partial posttraumatic stress disorder in the United States: results from Wave 2 of the National Epidemiologic Survey on Alcohol and Related Conditions. J Anxiety Disord. 2011;25:456–65.
[14] Stein MB, Walker JR, Hazen AL, et al. Full and partial posttraumatic stress disorder: findings from a community survey. Am J Psychiatry. 1997;154:1114–19.
[15] Ljungman L, Hovén E, Ljungman G, et al. Does time heal all wounds? A longitudinal study of the development of posttraumatic stress symptoms in parents of survivors of childhood cancer and bereaved parents. Psychooncology. 2015;24:1792–8.
[16] American Psychiatric Association. Diagnostic and statistical manual of mental disorder. 4th ed. Washington (DC): American Psychiatric Association; 2000.
[17] Weathers FWLB, Herman DS, Huska JA, et al. The PTSD Checklist (PCL): reliability, validity, and diagnostic utility. Paper presented at the 9th Annual Conference of the ISTSS, San Antonio, TX. 1993.

[18] Ruggiero KJ, Del Ben K, Scotti JR, et al. Psychometric properties of the PTSD Checklist-Civilian Version. J Trauma Stress. 2003;16: 495–502.

[19] Collins JJ, Byrnes ME, Dunkel IJ, et al. The measurement of symptoms in children with cancer. J Pain Symptom Manage. 2000;19:363–77.

[20] Osaki T, Morikawa T, Kajita H, et al. Caregiver burden and fatigue in caregivers of people with dementia: Measuring human herpesvirus (HHV)-6 and -7 DNA levels in saliva. Arch Gerontol Geriatr. 2016;66:42–8.

[21] Schuz B, Czerniawski A, Davie N, et al. Leisure time activities and mental health in informal dementia caregivers. Appl Psychol Health Well Being. 2015;7:230–48.

[22] Ho JS, Bordon J, Wang V, et al. Reduced activity restriction buffers the relations between chronic stress and sympathetic nervous system Activation. J Gerontol B-Psychol. 2014;69:408–16.

[23] von Känel R, Mausbach BT, Millis PJ, et al. Longitudinal relationship of low leisure satisfaction but not depressive symptoms with systemic low-grade inflammation in dementia caregivers. J Gerontol B Psychol Sci Soc Sci. 2014;69:397–407.