Acta Oncologica, 2013; 52: 1076–1085

informa
healthcare

ORIGINAL ARTICLE

A longitudinal assessment of work situation, sick leave, and household income of mothers and fathers of children with cancer in Sweden

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Abstract

Background. The diagnosis of childhood cancer often results in an altered life situation for the parents, characterized by difficulties regarding work, family and household demands. Previous research shows that parents' work situation and income are impacted, yet, few studies have explored the issue from a longitudinal perspective. This study sought to increase the knowledge about the socio-economic conditions of parents of children with cancer in Sweden by means of a longitudinal assessment of work situation, sick leave, and household income. *Material and methods.* The sample consisted of mothers (n = 139) and fathers (n = 138) of children with cancer recruited from 2002 to 2004. Data was collected by telephone interviews at six time points, ranging from the time of diagnosis to one year after the end of treatment. *Results*. Findings showed that parents' work situation was most evidently impacted during the child's treatment, when the greatest proportions of non-working and sick-listed parents were found. Compared with the time of diagnosis, fewer mothers worked up to three months after the end of treatment, and more mothers were on sick leave one year after the end of treatment. Although the extent of sick leave among fathers did not differ compared with the time of diagnosis, fewer fathers worked one year after the end of treatment. Household income was significantly reduced during the child's treatment and months thereafter, while income was at an equal level as before the diagnosis for most families one year after the end of treatment. *Conclusion*. The results offer a unique understanding of how mothers' and fathers' work situation and income are impacted in the short- and long-term, and give guidance on how to improve the comprehensive support given to parents of children with cancer. Socio-economical issues should be emphasized as these may provide targets for policy interventions aiming to reduce parental strain related to work and finances.

The diagnosis of childhood cancer and subsequent treatment are potential sources of parental distress, resulting in an altered life situation for all family members. Parents care for their sick child, whilst also trying to juggle everyday domestic and caring responsibilities [1,2]. As a result of the difficulties that may arise from balancing care of the child with work commitments some parents reduce working hours or change employment [3]. Parents' work ability may be affected by lingering psychological stress [4,5], possibly leading to sick leave [6,7]. Thus, a child's cancer diagnosis can have an important impact on parents' employment pattern and household income [8–10]. Loss of earnings may be especially burdensome since the treatment of childhood cancer often is associated with additional expenses, e.g. for travel, overnight accommodation, and food [11]. For parents, concerns related to work and loss of earnings often cause additional stress in an already demanding situation. This economical stress can be buffered by the social security system, which is quite different between different countries. Sweden is known to be a country that guarantees a certain economic basic security for its citizens, including, e.g. sickness benefit and parental benefit for the care of children. However, these compensations cover only part of the income loss and are temporary.

Work-related and economical consequences of parenting a child with cancer have been addressed in recent studies [1,3,7,11–15]. However, little attention has been paid to the issue from a longitudinal perspective [11]. Findings from cross-sectional studies indicate that childhood cancer has a short-term impact on parents' employment and income,

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(Received 21 September 2012; accepted 15 December 2012)

ISSN 0284-186X print/ISSN 1651-226X online © 2013 Informa Healthcare
DOI: 10.3109/0284186X.2012.760846

and that the expenses are highest during the first six months of treatment, regardless of diagnosis [3,14]. Mothers' and fathers' work situation and income are impacted in different ways, mothers being particularly affected [3,7,15–17]. This points to the importance of addressing both mothers' and fathers' experiences for a complete evaluation of the impact of childhood cancer on parents' work- and financial situation.

The purpose of the current study was to increase the knowledge about the socio-economic conditions of families of children with cancer in Sweden by means of a longitudinal assessment of work situation, sick leave, and household income of mothers and fathers, respectively. Specifically, the study aims to answer the following research questions according to parents' reports at six assessments during the child's illness trajectory, ranging from the time of diagnosis to one year after the end of treatment: 1) Does the number of working mothers and fathers change over time? 2) Does the number of mothers and fathers on sick leave change over time? 3) Does the household income change over time? 4) Do demographic and illness-related factors have an impact on parents' work situation, sick leave and the household income after the end of treatment? 5) Are there any differences between mothers and fathers regarding work situation and extent of sick leave during and after treatment?

Material and methods

Participants and procedures

This study is based on data collected within an ongoing project aiming at investigating psychosocial and economic consequences of parenting a child with cancer (first report [18]). The project has a longitudinal design with seven assessments (T1–T7). The first three (T1–T3) are related to the time of the child's diagnosis, the following to end of treatment (T4–T7)/the child's death (T5–T7). Data collected at T1–T6 are reported in the present study: T1 = one week, T2 = two months, and T3 = four months after the diagnosis. T4 = one week after the end of treatment/six months after bone marrow, stem cell or organ transplantation, T5 = three months after the end of treatment/nine months after transplantation, and T6 = one year after the end of treatment/18 months after transplantation.

Parents of children treated for cancer at four of the six pediatric oncology centers in Sweden (Gothenburg, Linköping, Umeå, and Uppsala) were consecutively recruited from 2002 to 2004, during 18 continuous months at each center. Specifically, parents of children treated at Linköping, Umeå, and Uppsala were recruited from April 2002 to September 2003, whereas the recruitment period of parents with children treated at Gothenburg was September 2002 to February 2004. To be eligible the following criteria had to be met: Swedish and/or English speaking parents (including step-parents) of ≤ 18 years old children, diagnosed with cancer for the first time (≤ 14 days ago), scheduled for chemotherapy and/or radiotherapy (not applied in case of a CNS tumor), and with access to a telephone. Ethical approval was obtained from the local ethics committees at the respective faculties of medicine. Eligible parents received written and oral information about the study from a coordinating nurse at the respective center within two weeks after the child's diagnosis (M = 4 days after diagnosis). Thereafter oral informed consent was asked for over the telephone by one of two interviewers (M = 7 days after diagnosis). Permission to contact the parent at the next data collection was obtained at the end of each interview.

In total, 371 parents were invited to participate, of whom 81 refused participation, yielding a response rate of 78% at T1. The main reasons for refusal were: 'Not able to prioritize study participation during circumstances', 'Not interested', 'Preferred written questionnaire', and 'Doesn't feel representative'. The present study includes all parents who participated at T1 and at least one additional assessment, 139 mothers and 138 fathers of 149 children (excluding 13 parents who participated at T1 only). Moreover, in this study, parents of children who died were excluded from analyses from the time of the child's death. See Table I for a presentation of parent and child characteristics. Reasons for attrition are presented in Table II. One hundred and eighty-nine parents (51% of the invited parents) participated at all assessments. The interviews were conducted over the telephone on an average of eight (T1), 61 (T2), and 120 days (T3) after the diagnosis, and an average of 13 days after the end of treatment/188 days after transplantation (T4), 94 days after the end of treatment/276 days after transplantation (T5), and 371 days after the end of treatment/554 days after transplantation (T6).

Assessments

Demographic and socio-economic data were collected via telephone interviews. The data covered information about parents' education, age, marital status, number of children in the family, distance to hospital, child age, and sex. Data about parents' status with regard to work, sick leave and household income were gathered at all assessments. Questions about type of work, working hours, and reasons

Table I. Parent and child characteristics.

		Parents	
	Children n = 149	Mothers n = 139	Fathers n = 138
Parent characteristics			
Marital status[a] – no. (%)			
Married/cohabiting	–	120 (86.3)	121 (87.7)
Partner	–	6 (4.3)	5 (3.6)
Single	–	12 (8.6)	12 (8.7)
Other	–	1 (0.7)	–
Custody[a] – no. (%)	–		
Joint	–	129 (92.8)	125 (90.6)
Single	–	5 (3.6)	–
Stepparent	–	5 (3.6)	12 (8.7)
Not stated	–	–	1 (0.7)
Education[a] – no. (%)	–		
Nine years	–	14 (10.1)	28 (20.3)
Upper secondary	–	67 (48.2)	73 (52.9)
University	–	55 (39.6)	35 (25.4)
Not stated	–	3 (2.2)	2 (1.4)
Work status[a] – no. (%)	–		
In work	–	111 (79.9)	131 (94.9)
Full-time [b]	–	52 (46.8)	124 (94.7)
Part-time [b]	–	54 (48.6)	7 (5.3)
Not stated	–	5 (4.5)	–
Annual household income, €[a]	–		
11 000–22 000	–	11 (7.9)	3 (2.2)
22 110–33 000	–	17 (12.2)	20 (14.5)
33 110–44 000	–	24 (17.3)	25 (18.1)
44 110–55 000	–	50 (36.0)	55 (39.9)
> 55 000	–	29 (20.9)	32 (23.2)
Not stated	–	8 (5.8)	3 (2.2)
Age of parent[a], years			
Mean (SD)	–	37.2 (6.6)	39.8 (6.8)
No. (%)			
< 30	–	20 (14.4)	10 (7.2)
31–39	–	72 (51.8)	68 (49.3)
≥ 40	–	47 (33.8)	60 (43.5)
Siblings[a] – no. (%)			
0		12 (8.6)	14 (10.1)
1–2		99 (71.2)	102 (73.9)
≥ 3		28 (20.1)	22 (15.9)
Distance to pediatric oncology center, km			
Mean (SD)	–	140.0 (110.5)	175 (344.6)
Child characteristics			
Sex – no. (%)			
Boy	72 (48.2)	69 (49.6)	69 (50.0)
Girl	77 (51.7)	70 (50.4)	69 (50.0)
Age of child[a], years			
Mean (SD)	8.2 (5.2)	8.3 (5.2)	8.0 (5.2)
No. (%)			
0–3	40 (26.8)	36 (25.9)	39 (28.3)
4–7	36 (24.2)	38 (27.3)	34 (24.6)
8–12	42 (28.2)	35 (25.2)	39 (28.3)
13–18	31 (20.8)	30 (21.6)	26 (18.8)
Diagnosis – no. (%)			
Leukemia	54 (36.2)	49 (35.3)	51 (37.0)
CNS tumors	31 (20.8)	29 (20.9)	29 (21.0)
Other solid tumors	64 (43.0)	61 (43.9)	58 (42.0)
Prognosis[c] – no. (%)			
≥ 75%	82 (55.0)	75 (54.0)	73 (52.9)
< 75%	67 (45.0)	64 (46.0)	65 (47.1)

(*Continued*)

Table I. (*Continued*).

		Parents	
	Children n = 149	Mothers n = 139	Fathers n = 138
Length of treatment, months			
Mean (SD)	15.4 (11.7)	16.2 (11.8)	15.9 (11.9)
Range	0.7–64.3	2.3–59.6	0.7–64.3
No. (%)			
< 6 months	36 (24.2)	29 (20.9)	28 (20.3)
6–12 months	38 (25.5)	36 (25.9)	36 (26.1)
> 12–24 months	27 (18.1)	27 (19.4)	28 (20.3)
> 24 months	40 (26.8)	40 (28.8)	37 (26.8)
Not stated	8 (5.4)	7 (5.0)	9 (6.5)
Treatment intensity[d] – no. (%)			
Not high intensity	80 (53.7)	73 (52.5)	74 (53.6)
High intensity	69 (46.3)	66 (47.5)	64 (46.4)
Relapse during the entire study period – no. (%)			
No	113 (75.8)	105 (75.5)	103 (74.6)
Yes	36 (24.2)	34 (24.5)	35 (25.4)

[a] At T1 = one week after child's diagnosis.

[b] Percentages based on the number of parents in work.

[c] Five-year probability of survival based on childhood cancer survival in the Nordic countries [25].

[d] Treatment intensity was estimated as high intensity vs. not high intensity. High intensity included the following diagnoses and protocols: AML (all protocols); ALL (extra intensive/very intensive protocols and Philadelphia positive); Ewing sarcoma (all protocols); Osteosarcoma (all protocols); B-cell lymphoma; Neuroblastoma (high risk); HIT (Hirntumor)-protocol; SIOP 4 PNET-protocol; BMT/SCT; and other treatments for high-risk groups. All other treatments were assigned to the category not high intensity.

for not working or working part-time were posed. Parents who were employed, self-employed, students or worked from home were categorized as working, regardless if working part- or full-time. Non-working or part-time working parents were asked to specify reasons for not working full-time. Reasons for not working or working part-time were categorized as: own choice, unemployment, receiving (temporary) parental benefit for staying at home taking care of the child, sickness absence, or being pensioned from work due to age or sickness. Information about annual household income was collected at all assessments. At each assessment parents were asked whether their work situation, sick leave status and/or annual household income had changed from the preceding assessment, and if so specify the change. Clinical information on the children (e.g. diagnosis, time of diagnosis, treatment intensity, prognosis) was obtained from the medical records.

Analyses

At T1, data about work situation, sick leave, and household income were gathered for the period immediately preceding the diagnosis. Parents who lost their child during the time of the study were excluded from the analysis following that event. For example, parents who were bereaved between T4 and T5 were included in analyses of T1–T4 but excluded from analyses including T5 or T6. Parents' work status was dichotomized into 'working (full- or part-time)'/'not working'. Parents' sick leave status was dichotomized into 'on sick leave (fully/partly)'/ 'not on sick leave'.

Table II. Attrition among parents who participated at T1 and at least one additional assessment (n = 277).

Attrition	T2 (137 mothers; 135 fathers)	T3 (120 mothers; 121 fathers)	T4 (122 mothers; 116 fathers)	T5 (121 mothers; 113 fathers)	T6 (109 mothers; 105 fathers)
Temporarily excluded[a]	1	25	2	2	–
Excluded from further participation[b]	–	1	6	6	8
Lost their child	2	4	24	28	45
Temporarily withdrawal	2	2	1	1	–
Withdrawal	–	4	6	6	8
Administrative reasons	–	–	–	–	2

[a] Exclusion related to, e.g. a short treatment.

[b] Exclusion related to, e.g. assignment to a non-included hospital/pediatric oncology center, parent's death.

Cochran's Q tests were conducted to evaluate change over time with regard to work situation and sick leave status. Changes in the proportion of parents who worked and who were on sick leave between two assessments were analyzed with McNemar's Significance Test. Friedman test was used to identify potential differences over time with regard to annual household income, and Wilcoxon test was used to identify potential differences between two assessments. In addition to significance testing of changes in annual household income, descriptive data of differences in income level between T1 and follow-up assessments (T2–T6) were considered. A change was recorded if parents reported the annual income to be within a different income category as described in Table I. Accordingly, three categories were established; unchanged, less income, or more income compared with T1. χ^2-tests were conducted to identify potential associations between on one hand parent gender and on the other hand work- and sick leave status, including the extent and length of sick leave.

Univariate analyses were performed to assess the associations of demographic and/or illness-related variables and parents' work situation, sick leave status and annual household income at T4 and T6. Each of the following factors was evaluated as a potential influential factor in the univariate analyses: sex (parent and child), age (parent and child), marital status, number of siblings, parent education, household income at T1, length of treatment, intensity of treatment, prognosis, relapse history, and distance to hospital. χ^2-tests were applied in the univariate analyses, and the categorizations of variables shown in Table I were used in analyses. Binary logistic regression models were used to determine the final association factors on parents' work situation, sick leave status and annual household income at T4 and/or T6. All significant factors in the univariate analyses were entered into the binary logistic regression models as independent factors.

Two-tailed testing was applied, and an alpha level of $p < 0.05$ was chosen to indicate statistical significance. All analyses were performed using SPSS version 20.0 for Windows (SPSS Inc., Chicago, IL, USA).

Results

Work situation

The number of parents in work changed over time (Cochran's test: $p < 0.001$ for mothers and fathers, respectively; Figure 1). Compared with T1, a drop of working mothers and fathers was found at T2 (McNemar's test: $p < 0.001$ for mothers and fathers, respectively). Of the parents working at T1, 91 mothers (83%) and 77 fathers (60%) had either stopped working or reduced their working hours at T2. The majority of these reported sick leave as the cause (86 mothers, 67 fathers).

Fewer parents were in work during the child's treatment and after the end of treatment compared with at T1 (Figure 1). Among parents who were in work at T1, 51 mothers (52%) and 45 fathers (41%) had reduced their working hours by working part-time or by not working at T4, 46 mothers (47%) and 23 fathers (21%) at T5, and 25 mothers (28%) and 17 fathers (17%) at T6. The most common reasons for reduced working hours or for not working after the end of treatment are presented in Table III. At T6, the proportion of working fathers was lower compared with T1, while the proportion of mothers in work was not different at T6 in comparison with T1 (Figure 1).

Compared with fathers, fewer mothers were in work part- or full-time at T1–T5 (χ^2-tests: $p < 0.001$) (Figure 1). However, no difference between the sexes was found at T6.

Results of the binary logistic regression analysis indicated that being female, and having a child with a shorter treatment (up to 24 months) were associated with not working at T4 (Table IV). As to

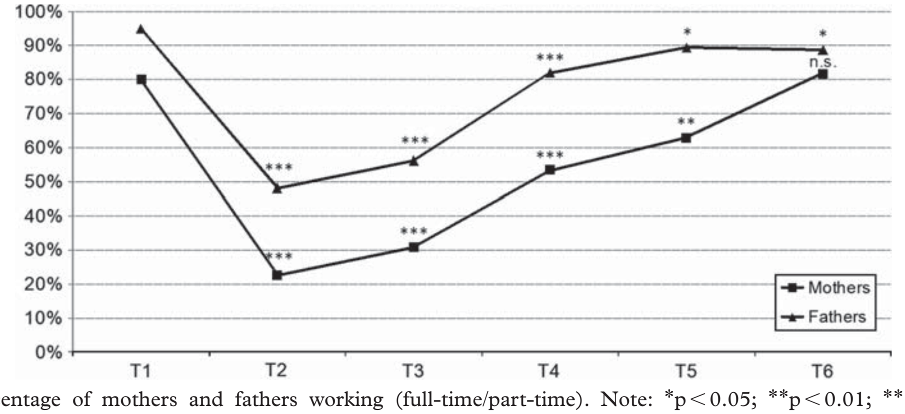

Figure 1. The percentage of mothers and fathers working (full-time/part-time). Note: $^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$; n.s. not significant. Statistically significant differences to T1 by McNemar's Significance Test.

Table III. The most common reasons among parents who, in comparison to T1, had reduced their working hours or stopped working after the end of treatment.

	Sick leave n (%)			Parental benefit n (%)			Unemployment n (%)			Own choice n (%)			Other n (%)		
	T4	T5	T6	T4	T5	T6	T4	T5	T6	T4	T5	T6	T4	T5	T6
Mothers	42 (82.4)	34 (73.9)	12 (48.0)	5 (9.8)	4 (8.7)	7 (28.0)	3 (5.9)	2 (4.3)	2 (8.0)	–	1 (2.2)	3 (12.0)	1 (2.0)	5 (10.9)	1 (4.0)
Fathers	28 (62.2)	13 (56.5)	5 (29.4)	9 (20.0)	4 (17.4)	4 (23.5)	2 (4.4)	1 (4.3)	3 (17.6)	4 (8.8)	5 (21.7)	4 (23.5)	2 (4.4)	–	1 (5.9)

parents' work situation at T6, parents of children with a poorer prognosis, and who had three or more siblings were more likely to not work at T6 (Table IV).

Sick leave

The number of parents on sick leave (full- or part-time) changed over time (Cochran's test: $p < 0.001$ for mothers and fathers, respectively; Figure 2). Compared with at T1, more parents were on sick leave during the child's treatment phase – the period when the greatest proportion of parents on sick leave was found (Figure 2).

The number of mothers on sick leave after the end of treatment differed between T1 and all subsequent assessments (Figure 2). Compared with at T1, more fathers were on sick leave at T4 and T5, but not at T6 (Figure 2).

More mothers than fathers were on sick leave at T1–T6 (χ^2-tests: T1: $p < 0.05$; T2–T5: $p < 0.001$; T6: $p < 0.01$; Figure 2). Additionally, mothers had longer periods of sick leave compared with fathers (Table V). The length of parents' sick leave is presented in Table V.

Outcomes of the binary logistic regression analysis indicated that being female, and having a child with a more intensive treatment were associated with being on sick leave at T4 (Table IV). As to parents' sick leave status at T6, mothers were found to be more likely to be on sick leave than fathers (Table IV).

Household income

The families' annual household income at T1 is presented in Table I. Reported household income changed over time (McNemar's test: $p < 0.001$). Compared with T1, household income was reduced at T2–T5 (Friedman test: $p < 0.001$ for mothers and fathers, respectively), but no difference was found at T6. Changes in household income in relation to T1 are presented in Table VI.

Results of the binary logistic regression analysis indicated that parents of boys were more likely than parents of girls to report poorer annual household income at T4 (Table IV). Regarding parents' household income at T6, no demographic or illness-related factors were found to be associated with changes in annual household income (Table IV).

Discussion

The current study is one of the first to evaluate the impact of childhood cancer on parents' work situation, sick leave, and household income from a longitudinal perspective. A longitudinal approach is necessary to capture a change over the child's illness trajectory. Findings showed that the parents' work situation, extent of sick leave, and household income changed over time. Analysis by gender showed a long-term impact on both mothers' and fathers' work situation. Although no difference was found between mothers' work situation (in work or not) at the time of the diagnosis and one year after the end of treatment, more mothers were on sick leave at T6 than at T1. A different pattern was found for the fathers. Compared with the time of diagnosis, fewer fathers were in work at T6, but no difference was found with regard to the number on sick leave. Household income was negatively impacted following the time of diagnosis up to three months after the end of treatment.

Having a child with cancer may impact parents' employment and economy [1,3,12]. Still, due to the cross-sectional designs of prior studies there is a lack of knowledge on how parents' work situation is impacted over time. As expected, the results of the present study showed that parents' work status was most evidently impacted during active treatment. Corresponding to prior findings [7,8], both mothers' and fathers' work situation was affected during the child's treatment. The effects were, however, somewhat more pronounced for the mothers. This could relate to that mothers generally assume primary caretaking responsibilities for the sick child during treatment and spend more time in the hospital [9], thus resulting in greater difficulty in fulfilling work commitments. Moreover, parents' work situation continued to be impacted even when the child's treatment was completed. Sickness absence was the most common reason for not working or for working

Table IV. Factors associated with parents' work situation (in work or not), sick leave status (on sick leave or not), and household income (less than at T1 or not) one week (T4) and one year (T6) after the end of treatment.

	Odds Ratio[b] (95% Confidence Intervals)					
	Work situation		Sick leave		Household income	
Factors[a]	T4	T6	T4	T6	T4	T6
Parent sex						
Mothers (fathers)	4.78 (2.52–9.04)***	–	3.89 (2.21–6.84)***	3.95 (1.62–9.63)**	–	–
Child prognosis						
Prognosis < 75% (≥ 75%)	1.51 (0.74–3.13)	4.08 (1.39–12.00)*	1.45 (0.80–2.62)	–	–	2.04 (0.94–4.45)
Treatment length						
< 6 months (> 24 months)	7.81 (3.06–19.96)***	2.45 (0.72–8.36)	–	–	–	1.74 (0.65–4.63)
6–12 months (> 24 months)	3.73 (1.36–10.20)*	0.89 (0.22–3.57)	–	–	–	2.56 (0.94–6.98)
12–24 months (> 24 months)	2.92 (1.03–8.34)*	0.41 (0.80–2.12)	–	–	–	1.62 (0.54–4.84)
Number of healthy siblings						
No siblings (≥ 3 siblings)	–	0.91 (0.19–4.29)	–	–	–	–
1–2 siblings (≥ 3 siblings)	–	0.28 (0.11–0.71)**	–	–	–	–
Household income at T1, €						
< 33 000 (> 55 000)	–	1.47 (0.47–4.61)	–	–	–	–
33 110–55 000 (> 55 000)	–	0.43 (0.16–1.20)	–	–	–	–
Intensity of treatment						
Not high (high intensity)	–	–	0.46 (0.26–0.83)*	–	–	–
Child sex						
Girl (boy)	–	–	–	–	0.43 (0.23–0.81)**	–

[a] Factors found significant in univariate analyses were included in the regression models. Reference group is in parentheses.

[b] Odds of not working, being on sick leave, and having less income.

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$. Significant factors by binary logistic regression models.

fewer hours during and after the child's treatment. The increased sick listing may relate to parents experiencing symptoms of burnout after the end of treatment that affect their work ability [6]. Reducing working hours could be a way to help parents to cope with stress in the aftermath of a life-threatening disease in one's child, and/or related to any permanent health deficits for the child. The observed shifts in work together with increased sick listing during and following the often long period of treatment need to be taken into consideration, as unemployment and sick listing may negatively affect parents' psychological health, career opportunities, and work ability [19,20]. Reduced working hours often corresponds to income losses and could lead to economical burden for these families. On the other hand, parents' work situation may be impacted by a reappraisal of life values and priorities as a consequence of the cancer experience [6]. A shift of priorities often include contemplating the work- and family situation which for some parents results in reduced working hours to spend more time with the family.

The participants reported poorer income during the child's treatment and months thereafter.

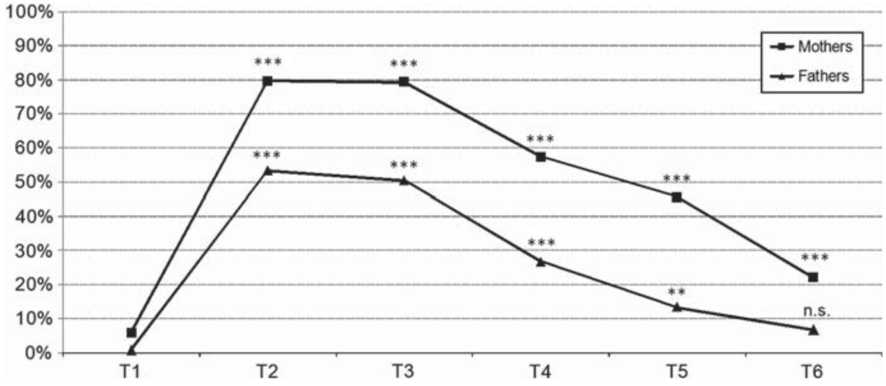

Figure 2. The percentage of mothers and fathers being on sick leave (full-time/part-time). Note: *$p < 0.05$; **$p < 0.01$; ***$p < 0.001$; n.s. not significant. Statistically significant differences to T1 by McNemar's Significance Test.

Table V. Length of sick leave among parents who reported being on sick leave at T2 ($n = 181$)[a].

Length of sick leave	All n (%)	Mothers n (%)	Fathers n (%)
T2–T3	153 (86.4)	96 (88.9)	57 (82.6)**
T2–T4	97 (61.4)	69 (70.4)	28 (46.7)**
T2–T5	61 (39.6)	48 (50.0)	13 (22.4)**
T2–T6	22 (15.1)	20 (20.0)	2 (3.6)**

[a] Parents who were on and off sick leave are not included in the presented figures.

**$p < 0.01$. Significant differences between mothers and fathers by χ^2-tests.

In parallel with this the expenses generally increase during the same period, e.g. due to transport to and from the hospital, medicines, and special food [10]. Such expenses are to some degree compensated for in Sweden. One year after the end of treatment income was at an equal level as before the diagnosis for the majority of the families. Considering the time-span from diagnosis to the end of treatment for most families, we may speculate that this signifies a delay in expected wage development. However, the study design do not allow for such conclusions.

A negative impact on working conditions has been identified as a risk factor for distress among fathers of children with cancer [2]. Accordingly, the impact on fathers' work status, with unemployment reported by about one fifth who had reduced working hours or stopped working at T6, needs further study as to its possible causes and consequences. The long-term impact on fathers' work situation contradicts findings of a recent Norwegian register-based study [15], and studies indicating that mothers are particularly affected [3,7,16]. Compared with our study, the Norwegian study covers a greater proportion of parents for whom a longer time had elapsed since diagnosis, which may account for the differing findings. Nevertheless, in the present study, fathers' work status did not significantly improve between the last two assessments (results not shown). Another possible explanation for contrasting findings relates to earlier studies' cross-sectional design [3,7,16,21]. If studying parents' work situation only at a single time point, results may indicate that mothers and fathers respond differently to the child's illness, although it may actually reflect sex differences in the general population [22]. Indeed, findings showed that mothers' and fathers' work situation differed already at the time before the child's diagnosis.

Table VI. Descriptive data on household income change from T1 reported by mothers and fathers, respectively.

Income change from T1	Mothers n (%)	Fathers n (%)
At T2		
Unchanged	110 (83.3)	106 (80.3)
More	–	–
Less	22 (16.7)	26 (19.7)
At T3		
Unchanged	90 (76.3)	91 (75.8)
More	2 (1.7)	1 (0.8)
Less	26 (22.0)	28 (23.3)
At T4		
Unchanged	90 (73.8)	80 (70.2)
More	6 (4.9)	5 (4.4)
Less	26 (21.3)	29 (25.4)
At T5		
Unchanged	77 (64.7)	77 (68.8)
More	7 (5.9)	6 (5.4)
Less	35 (29.4)	29 (25.9)
At T6		
Unchanged	60 (56.1)	61 (58.1)
More	18 (16.8)	17 (16.2)
Less	29 (27.1)	27 (25.7)

A substantial number of parents were found to be on long-term sick leave. Long-term sick listing (> 6 months) is associated with various negative consequences for the individual, relating to career and salary development [19]. Particularly mothers were on long-term sick leave and may accordingly experience such consequences to a greater extent than fathers. Trends towards increased psychological distress in mothers and more frequent use of emotion-focused coping may help explain the increased risk for long-term sick leave among mothers [16]. Still, given the gender differences in sickness absence found in the current study and in prior research [22], mothers in Sweden may have additional needs of support from society and health care in general, as means of reducing sick leave. The non-existing lasting impact on fathers' sick leave suggests that other sources than solely sickness absence account for the greater proportion of non-working fathers found one year post-treatment, presumably parental benefit and unemployment.

Factors such as a poor prognosis, intensive treatment, and relapse may act as additional stressors for the parents that could influence their work ability. Specifically, such factors may result in demanding caring responsibilities, including frequent hospital visits, and ongoing worry that aggravates the possibilities to balance care of the child with work commitments. In this study we evaluated the significance of such factors in determining parents' work status. Parents of children who underwent a longer treatment were more likely to be in work and less likely to be on sick leave soon after the end of treatment. One explanation may be that a longer treatment period offers the parents time to adapt to the situation emotionally and practically, which possibly facilitates the return to work when treatment ends.

On the other hand, parents of children with longer treatment regimens not have the opportunity to stay at home once treatment ends, even if a need exists. Furthermore, the finding that parents of children with more intensive treatment regimens were more likely to be on sick leave soon after the end of treatment may indicate that a more intensive treatment may in itself act as an additional stressor for the parents, possibly affecting their psychological health and work ability. Moreover, a significantly elevated work probability one year after the end of treatment was found for parents who had a child with a favorable prognosis. This contrasts earlier findings of the importance of the cancer prognosis on parents' work and income [15]. Although a poor prognosis may be associated with greater uncertainty regarding child outcomes, the statistical survival prognosis per se has not been found to systematically influence parental distress levels [2,23]. An alternative explanation to the relationship between a less favorable prognosis and parental work status may instead relate to permanently poorer health and increased caregiving needs among some of those children [24].

Strengths of the current study relate to its longitudinal approach, the high response rate, the inclusion of both mothers and fathers, and the possibility of addressing differences in work status and sick leave in relation to illness-related factors and socio-demographic information on parents. The longitudinal design of the study makes it possible to follow the families through the dynamic illness trajectory and point to specific landmark disease stages important for examining parents' adjustment. Study limitations relate to the lack of individual data on income, and the lack of a comparison group. The use of a comparison group of parents of the general population with comparable demographic characteristics as our study group would have contributed with information of the work situation of parents in general, and thus enabling us to better target the specific impact a child's cancer may have. Furthermore, the study findings should be understood in light of the current working conditions and national regulations in Sweden. All individuals living in Sweden are covered by the Swedish national sickness insurance. The requisite for compensation is impaired ability to work by at least 25% due to illness or injury. In addition, the Swedish system is relatively 'family-friendly' as it comprises state-funded childcare, generous parental insurance, and child allowance. The Swedish welfare state policies and social insurance system thus provides parents with opportunities of paid leave that may ease the economic burden on the families and facilitate the return to work after the end of treatment. Accordingly, as Sweden is a welfare state the findings of the current study may only apply to countries with similar health- and welfare systems.

Forthcoming studies are warranted for increased understanding of the observed findings of differing outcomes for mothers and fathers, of the relationship found between household impact and child sex, and for determining parents' perceived work ability. For example, the relationship between the child's caregiving needs and health status over time including possible late effects and parents' need and use of financial support, and their perceived work ability over the child's illness trajectory are interesting targets for forthcoming studies. The economic and work situations of bereaved parents are furthermore an important target for future studies. Such studies could focus on bereavement support following the death of their child, including support related to work and income of the family. Also, how mothers and fathers experience their alternatives and preferences with regard to work would facilitate the identification of possible interventions to reduce the adverse impact a child's cancer can have on employment.

Conclusions and implications

The diagnosis of childhood cancer is associated with both short- and long-term impact on parents' work status. During the period of active treatment the greatest proportions of non-working and sick-listed parents were found. Although the economic and working situation seems to normalize with time, fewer fathers were in work and a greater proportion of mothers were on sick leave one year after the end of treatment when compared with the time of diagnosis. Reductions in household income were evident during the course of the child's treatment and months thereafter.

Combined, findings of the current study contribute with deepened understanding of how parents' work situation is affected over the child's illness trajectory. Both mothers and fathers signal a need for social work services, during and after the child's cancer treatment. From a societal perspective, findings of a possible adverse impact on parents' work situation and household income are valuable topics for research in public health as well as childhood chronic illnesses. Moreover, this study could be of importance in the development of policy interventions that aim to reduce the influence of stressors related to work situation and finances on parents' well-being, and to assure equalities in provided social work services. Increased knowledge of how a child's cancer may impact parents' work and economy is furthermore important for the provision of quality family-centred care, and for enhancing the quality of the clinical encounters between families and health care providers, such as oncology social workers.

Acknowledgments

The authors gratefully acknowledge the time and energy contributed by the parents participating in this study and by RN, research assistant Susanne Lorenz who interviewed most parents.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

This work was supported by The Swedish Cancer Society (grant numbers 02 0274 and 03 0228 to LvE), the Swedish Research Council (grant number K2008-70X-20836-01-3 to LvE), and The Swedish Childhood Cancer Foundation (grant numbers 02/004 and 05/030 to LvE). The study sponsors had no involvement in the study design; in the collection, analysis and/or interpretation of data; in the writing of the manuscript; or in the decision to submit the manuscript for publication.

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