

ORIGINAL ARTICLE

Sick leave among parents of children with cancer – a national cohort study

Sofia Hjelmstedt^a, Annika Lindahl Norberg^{a,b}, Scott Montgomery^{c,d,e}, Ida Hed Myrberg^a and Emma Hovén^a

^aDepartment of Women's and Children's Health, Karolinska Institutet, Stockholm, Sweden; ^bCentre for Occupational and Environmental Medicine, Stockholm County Council, Stockholm, Sweden; ^cDepartment of Medicine, Karolinska Institutet, Stockholm, Sweden; ^dDepartment of Clinical Epidemiology and Biostatistics, Örebro University, Örebro, Sweden; ^eDepartment of Epidemiology and Public Health, University College London, London, UK

ABSTRACT

Background: Due to psychological distress and an increased care burden, parents of children diagnosed with cancer may face a higher risk of sickness absence from work. The objective of this study was to examine the association of childhood cancer with parents' sick leave.

Material and methods: The sample comprised 3626 parents of 1899 children diagnosed with cancer in Sweden during 2004–2009, and a matched control group of parents ($n = 34\,874$). Sick leave was measured as number of days with sickness benefit, retrieved from national registries. Logistic and negative binomial regression models were used to compare outcomes with parents from the control cohort.

Results: The risk of sick leave was statistically significantly higher up to six years following a child's cancer diagnosis. The increase in number of days with sickness benefit was most pronounced the year after diagnosis. Although mothers' sick leave prevalence was higher, the increase in risk relative to control parents was similar for mothers and fathers. Bereavement was associated with a heightened risk of sick leave, especially on the year of the child's death.

Conclusions: Findings confirm that mothers and fathers of children diagnosed with cancer are at higher risk of sickness absence from work, with particularly pronounced risk among bereaved parents. Acquisition of further knowledge is warranted regarding possibilities and constraints of parents trying to combine their work life with caring for both their child and themselves.

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Childhood cancer has a large impact on the life of the affected children and their families. For the parents, the diagnosis is associated with caring for a child with increased care needs, while continuing to balance everyday responsibilities of work and family [1]. The emotional strain of parents is often most evident in the initial stages of diagnosis and treatment, but due to the unpredictable course of treatment and possible late sequelae, cancer in one's child may also cause long-lasting psychological effects [2]. Previous studies show that mothers report more psychological distress than fathers [2–4], and that parents who have lost their child to cancer are at particular risk of adverse psychological health [4,5]. Increased caregiving demands and psychological stress may lead to a decreased ability to work [6]. Previous studies suggest that parents reduce working hours or quit their job, mothers to a larger extent than fathers [7–9]. Work disruptions may be accounted for by the parents staying at home to care for their child, which in Sweden is compensated for by temporary parental benefits. Another potential reason for work disruptions is parents being on sick leave due to their own ill health [7,8]. Knowledge of how childhood cancer impacts the risk of sick leave among mothers and fathers is scarce.

When studied, results indicate parents' sick leave to increase after the diagnosis, with a higher prevalence among mothers [7,8] and among bereaved parents [10].

Although socioeconomic characteristics such as income, employment status, and occupation might affect the risk of sick leave [11], sick leave per se might also influence social and economic conditions [12], social life situation [13], and predict future low work ability [14]. The lack of population-based studies of sick leave among parents of children with cancer hampers the ability to draw firm conclusions of the risk of sick leave, as well as possible consequences of sick leave.

This study utilized a cohort of Swedish parents of children diagnosed with cancer and a matched general population cohort to examine the risk of sick leave among parents following a child's cancer diagnosis. The following research questions were addressed: (1) Does childhood cancer increase the risk of sick leave among parents? (2) Are there any differences in risk of sick leave between mothers and fathers? (3) Are sociodemographic characteristics associated with the risk of sick leave? (4) Does bereavement increase the risk of sick leave?

Material and methods

Study sample

Children ($n = 1918$) who were 18 years of age or younger, diagnosed with a primary cancer diagnosis during the years 2004–2009, were identified via the Swedish Childhood Cancer Registry (SCCR). Statistics Sweden used the children's personal identification number to identify the parents. After the exclusion of 19 children without complete child/parental information, the study cohort consisted of 1899 families (1881 mothers; 1745 fathers).

A matched control cohort design was used. The control parents ($n = 34\ 874$) were individually matched on the following factors evaluated two years before year of diagnosis: child's year of birth, family status, family disposable income, number of children living at home, area of residence, and parental age. Table 1 presents sociodemographic characteristics of the study sample.

Of the children, 54% ($n = 1024$) were boys. Forty percent ($n = 761$) were diagnosed between the ages 0–4 years, 20% ($n = 373$) between the ages of 5–9 years, 24% ($n = 461$) between the ages of 10–14 years, and 16% ($n = 304$) at age 15 or older. The most frequent diagnoses were central

nervous system tumors (28%; $n = 527$) and leukemia (27%; $n = 512$).

Measures

Sick leave was measured using annual individual data on number of reimbursed days with full or partial sickness benefit. In Sweden, sickness benefit may be granted after a period of, most often, 14 days with sick pay. In order to receive sickness benefits, it is necessary to fulfill an income criterion and provide a medical certificate to the Swedish Social Insurance Agency ensuring reduced work ability by at least 25%. The work ability is considered in relation to occupational status, for instance individuals on parental leave or unemployed also have access to sickness benefit. The work ability has to be reduced due to own illness; having to care for another person does not allow access to sickness benefit [15]. Parents who are not sick themselves, but who are unable to work due to their child's ill health, may in Sweden receive temporary parental benefits [16].

Data on days with sickness benefit and sociodemographic information were extracted from the Longitudinal Integration Database for Health Insurance and Labor Market Studies

Table 1. Sociodemographic characteristics of the study sample at baseline (one year before diagnosis).

Characteristics	Parents of children with cancer ($n = 1899$ families)				Control parents ($n = 18\ 192$ families)			
	Mothers ($n = 1881$)		Fathers ($n = 1745$)		Mothers ($n = 18\ 116$)		Fathers ($n = 16\ 758$)	
	No.	%	No.	%	No.	%	No.	%
Age, years								
Mean	36.8		39.5		36.6		39.5	
Median	37.0		39.0		37.0		39.0	
SD	7.0		7.6		7.0		7.6	
Income from employment, 1000 SEK								
Mean	157.7		284.3		153.2		258.6	
Median	151.1		275.9		151.5		271.7	
SD	140.0		198.5		134.9		225.5	
Area of residence								
Intermediate/densely populated	1286	68.4	1193	68.4	12 514	69.1	11 487	68.5
Thinly populated	560	29.8	525	30.1	5555	30.7	5176	30.9
Missing	35	1.9	27	1.5	47	0.3	95	0.6
Education								
Basic/secondary	1352	71.9	1351	77.4	13 204	72.9	13 056	77.9
Post-secondary	475	25.3	356	20.4	4495	24.8	3416	20.4
Missing	54	2.9	38	2.2	417	2.3	286	1.7
Living arrangement								
Cohabiting	1470	78.1	1438	82.4	14 571	80.4	14 075	84.0
Not living with another adult	376	20.0	280	16.0	3498	19.3	2588	15.4
Missing	35	1.9	27	1.5	47	0.3	95	0.6
Employment status								
Employed	1471	78.2	1521	87.2	14 082	77.7	14 642	87.4
Not employed	375	19.9	197	11.3	3987	22.0	2021	12.1
Missing	35	1.9	27	1.5	47	0.3	95	0.6
Number of children living at home								
0	94	5.0	233	13.4	889	4.9	2078	12.4
≥ 1	1752	93.1	1485	85.1	17 180	94.8	14 585	87.0
Missing	35	1.9	27	1.5	47	0.3	95	0.6
Country of birth								
Sweden	1536	81.7	1438	82.4	14 566	80.4	13 642	81.4
Other	344	18.3	306	17.5	3539	19.5	3109	18.6
Missing	1	<0.1	1	<0.1	11	<0.1	7	<0.1

SD: standard deviation.

(LISA by Swedish acronym). The children's medical data were gathered from SCCR.

Analysis

Characteristics of parents of children with cancer and control parents were compared two years before diagnosis using Pearson's χ^2 -test.

The proportions receiving any sickness benefit (>0 days) were modeled using logistic regression. The expected number of days with sickness benefit was modeled using negative binomial regression. The analyses were conducted separately for mothers and fathers, and pooled together to test for differences between them. An indicator variable for being a parent to a child with cancer or a control parent, years since diagnosis, and the associated interaction were included in all models. A variable for bereavement was included in separate models. A Wald χ^2 -test for the three-way interaction of case, years since diagnosis, and parent's sex was applied when comparing incidence rate ratios (IRR) between mothers and fathers.

The analyses were adjusted for the following sociodemographic characteristics, specified in the results section, measured at baseline (one year pre-diagnosis): income, living arrangement, education, employment status, country of birth, area of residence, number of children living at home, parental age, and calendar year. Stratified analyses were conducted for specific sociodemographic groups. To investigate whether changes in employment status affected the outcomes, employment status was included as a time-dependent covariate in separate sensitivity analyses. Adjusting for days with sickness benefit one year pre-diagnosis did not reduce the statistical significance; however, since it resulted in non-convergence of the regression models and numerically unstable estimates, it was omitted from the analyses.

Additional analyses were conducted for bereaved parents, taking into account the year of the child's death. As the study sample was small for those whose child passed away three or more years post-diagnosis ($n < 30$ for each year), significance tests were only conducted for those whose child passed away within two years from diagnosis.

Observations between matched groups were assumed to be independent. The within-subject and within-group dependence was accounted for using cluster robust standard errors. Estimates with p values < 0.05 were considered statistically significant. Pearson's χ^2 -tests were performed using STATA version 14 (StataCorp, College Station, TX, USA). Regression models were fitted, and Wald χ^2 -tests were performed using R version 3.2.5 (R Foundation for Statistical Computing).

Ethics

This study was approved by the regional Ethical Review Board in Stockholm, Sweden.

Results

There were no differences between parents of children with cancer and control parents at two years pre-diagnosis

regarding living arrangement, parental age, number of children living at home, county of residence, disposable income, and education ($p > 0.10$).

Sick leave

At the year of diagnosis, the proportions receiving any sickness benefit among parents of children with cancer were 42.4% of mothers and 32.8% of fathers, while the corresponding proportions were 16.9% of control mothers and 8.8% of control fathers. The proportions were statistically significantly higher compared to control parents up to four years post-diagnosis among mothers and three years post-diagnosis among fathers ($p < 0.01$).

Unadjusted and adjusted IRRs for number of days with sickness benefit are presented in Table 2. When adjusted for sociodemographic characteristics, the number of days with sickness benefit was significantly higher compared to control parents from the year of diagnosis to five years post-diagnosis among mothers of children with cancer, and six years post-diagnosis among fathers (Table 2). The effect was most pronounced one year post-diagnosis, when the numbers of days were 4.50 times higher for mothers, and 6.29 times higher for fathers, respectively (Table 2, Figure 1(A,B)).

Sensitivity analysis including employment status as a time-dependent covariate did not change the outcomes significantly (results not shown).

Differences between mothers and fathers

Mothers had 1.96 times higher expected number of days with sickness benefit than fathers (95% CI 1.84–2.09, $p < 0.0001$). This effect reflects differences between mothers and fathers among both parents of children with cancer and control parents. When comparing the number of days with sickness benefit in relation to control

Table 2. Incidence rate ratios for expected number of days with sickness benefit among parents of children with cancer compared to control parents.

Years from diagnosis	Unadjusted			Adjusted		
	IRR	95% CI	p	IRR	95% CI	p
Mothers						
–1	1.03	0.88–1.21	0.6824	1.08	0.91–1.27	0.3866
0	3.18	2.89–3.50	< 0.0001	3.35	3.02–3.72	< 0.0001
1	4.51	4.06–5.00	< 0.0001	4.50	4.02–5.04	< 0.0001
2	2.98	2.63–3.37	< 0.0001	3.08	2.69–3.53	< 0.0001
3	2.08	1.76–2.46	< 0.0001	2.14	1.79–2.56	< 0.0001
4	1.46	1.18–1.81	0.0005	1.50	1.19–1.88	0.0005
5	1.21	0.93–1.57	0.1572	1.33	1.00–1.77	0.0497
6	1.14	0.81–1.62	0.4545	1.26	0.86–1.84	0.2409
7	0.98	0.62–1.55	0.9406	0.93	0.59–1.45	0.7510
Fathers						
–1	1.08	0.85–1.37	0.5313	1.11	0.86–1.43	0.4136
0	3.85	3.38–4.39	< 0.0001	5.42	4.63–6.35	< 0.0001
1	4.60	3.95–5.35	< 0.0001	6.29	5.24–7.54	< 0.0001
2	2.65	2.20–3.21	< 0.0001	3.48	2.75–4.40	< 0.0001
3	1.88	1.46–2.43	< 0.0001	2.09	1.56–2.81	< 0.0001
4	1.54	1.11–2.12	0.0089	1.66	1.15–2.39	0.0064
5	1.44	1.01–2.07	0.0460	1.72	1.12–2.66	0.0142
6	1.51	0.97–2.37	0.0688	1.70	1.05–2.77	0.0308
7	1.74	0.99–3.07	0.0551	1.74	0.96–3.13	0.0662

IRR: incidence rate ratios. Year '0': year of diagnosis.

mothers and fathers, no statistically significant differences between mothers and fathers of children with cancer were found.

Sociodemographic characteristics

Table 3 presents the expected number of days with sickness benefit at one year post-diagnosis among mothers and fathers of children with cancer compared to control parents, stratified by sociodemographic characteristics. Table 1 in the Supplemental information presents these outcomes for all years.

Sick leave following bereavement

Losing a child to cancer was associated with an increased risk of sick leave (Figure 1(C,D)). At the year of the child's death, 76.3% of bereaved mothers and 66.5% of bereaved fathers received sickness benefit. The association of being a bereaved parent with the number of days with sickness benefit had an IRR of 2.24 (95% CI 1.88–2.66, $p < 0.0001$) among mothers, and 2.66 (95% CI 2.03–3.48, $p < 0.0001$) among fathers. Separate analyses conducted for parents whose child passed away within two years from diagnosis showed that the effect was most pronounced the year of

the child's death. Uptake of sickness benefit remained significantly higher compared to control parents 1–3 years after the child's death, depending on parents' sex and on how many years from diagnosis the child passed away (Figure 1(C,D)).

Discussion

Findings from this population-based matched cohort study provide insight into how childhood cancer is associated with sick leave among parents in Sweden. When compared to parents in a general population cohort, a higher risk of sick leave was evident at the year of diagnosis and up to six years subsequently, with particularly pronounced effects following bereavement.

It should be borne in mind that sick leave is granted due to parents' own ill health, not increased caregiving responsibilities or the child's health, for which temporary parental benefits may be granted in Sweden [16]. Our results show that despite having access to such benefits, a large share of parents have a reduced work ability due to their own ill health for several years following the child's cancer diagnosis.

Being able to be on sick leave and receive compensation might be crucial for a parent when coping with a child's illness. However, sick leave per se is also associated with

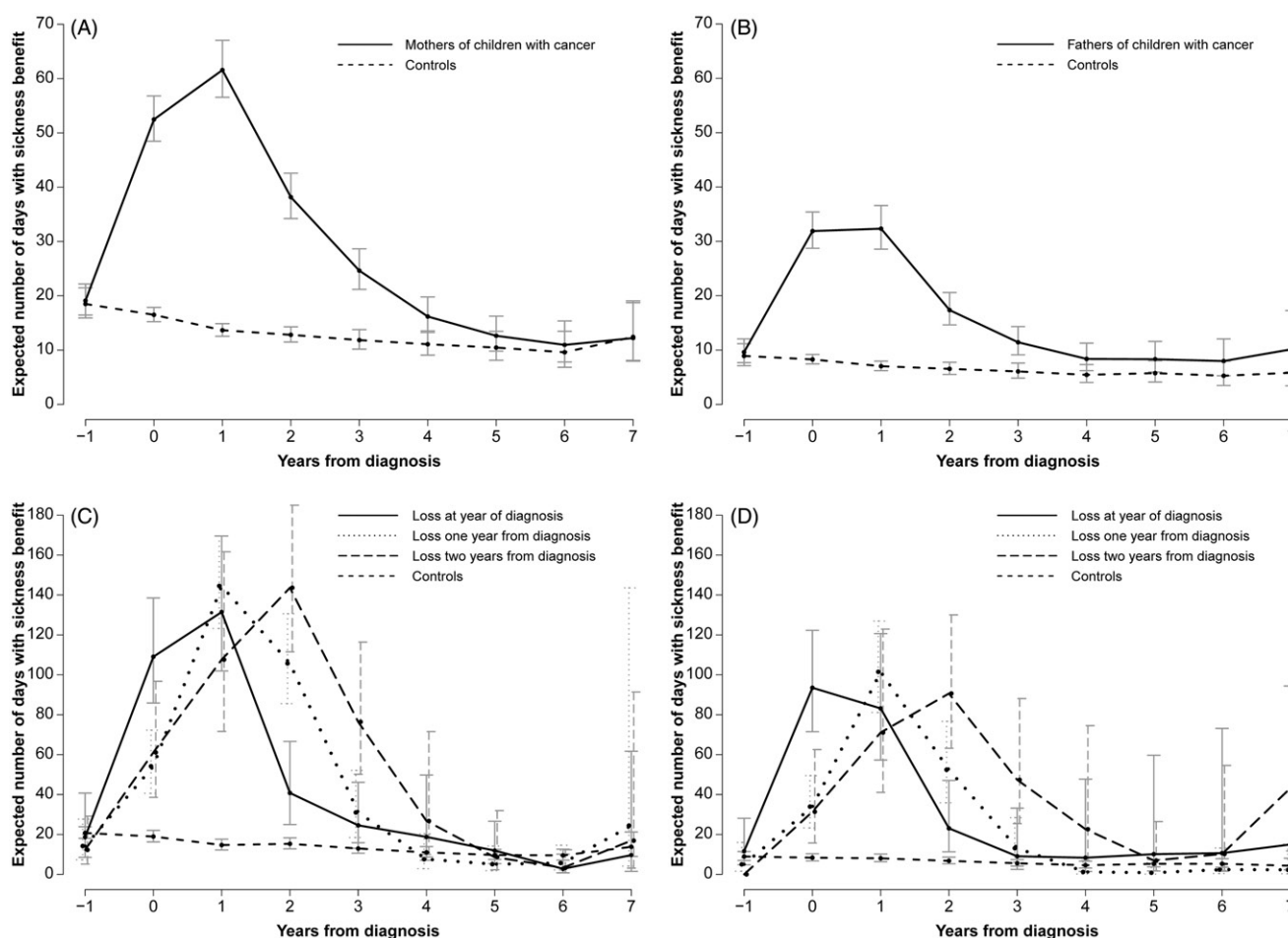


Figure 1. Expected number of days with sickness benefit and 95% confidence intervals. (A) All mothers; (B) all fathers; (C) bereaved mothers; (D) bereaved fathers.

Table 3. Stratified incidence rate ratios for expected number of days with sickness benefit at one year post-diagnosis among parents of children with cancer compared to control parents^a.

	Mothers		Fathers	
	IRR ^b	95% CI	IRR ^c	95% CI
Income				
Below median	3.68	3.15–4.31	4.22	3.43–5.20
Above median	5.37	4.60–6.27	8.37	6.41–10.92
Living arrangement				
Cohabiting	4.73	4.17–5.36	6.66	5.45–8.15
Not living with another adult	3.56	2.69–4.70	4.90	3.23–7.45
Education				
Basic/Secondary	4.31	3.81–4.88	4.90	4.08–5.89
Post-secondary	4.98	3.91–6.33	16.17	10.29–25.39
Employment status				
Unemployed	3.05	2.26–4.11	3.30	1.73–6.30
Employed	4.85	4.30–5.48	6.94	5.73–8.40
Country of birth				
Sweden	4.54	4.02–5.13	7.51	6.16–9.15
Other	4.45	3.29–6.02	2.34	1.47–3.75
Area of residence				
Thinly populated	3.77	3.10–4.58	6.33	4.65–8.62
Intermediate/densely populated	4.86	4.25–5.57	6.32	5.05–7.92
Number of children living at home				
0	5.31	2.55–11.07	7.04	4.40–11.27
≥1	4.49	4.0–5.04	6.28	5.15–7.65
Age				
Below median	4.59	3.90–5.41	8.97	6.85–11.75
Above median	4.62	3.95–5.41	4.49	3.48–5.80

^aAll covariates were evaluated the year before diagnosis.^bAll *p* values <0.0001.^cAll *p* values <0.0001, except for 'Unemployed' (*p* = 0.0003) and 'Other country of birth' (*p* = 0.0004).

IRR: incidence rate ratios.

adverse effects on a person's social, economic, and work situation [12–14]. The high number of days on sick leave found in this study implies significant work disruptions. Absence from work to care for a child has in Sweden been found to have a negative effect on upward career moves among women [17], and on wage levels among men [18]. Correspondingly, stalled career prospects and slower wage growth might also affect parents of children with cancer with significant absence from work due to sick leave.

In contrast to previous studies on self-report data and without control group data [7,8], our findings show that despite a higher prevalence of sick leave among mothers, the increase in risk relative to control parents was similar for mothers and fathers. This finding is explained by the higher prevalence of sick leave among mothers than fathers in the control group, thus providing different reference measures.

Low income, low educational attainment, older age, unemployment, living in a thinly populated area, and being born outside Sweden have been associated with a higher sick leave prevalence in the general Swedish population [11]. Among fathers of children with cancer, however, a tendency for higher risk was seen among fathers born in Sweden and with, at baseline, higher income, higher educational attainment, younger age, and who were employed. These results indicate that cultural and economic factors influence both possibilities and difficulties in being on sick leave among fathers of children with cancer.

The study is strengthened by the use of a closely matched control group, allowing us to take into account preexisting

characteristics of mothers and fathers, and the use of prospectively recorded registry data. This enabled us to investigate previously indicated patterns found in studies using self-reported data [7,8], which contrary to registry-based studies are subject to recall bias and bias of men being less inclined to report ill health than women [19]. A potential limitation of registry-based data concerns information bias such as over- or under coverage and incomplete or inaccurately recorded data. Importantly, the data from LISA could be regarded as comprehensive and reliable, with no indication of systematic errors. Another study limitation is that we do not have information on sick leave diagnoses; it is merely hypothesized that the increased risk of sick leave reflects illness that occurs as a result of having a child diagnosed with cancer. Adjusting for existing morbidity and use of medications would have provided a more comprehensive understanding of the effect of a child's cancer on parents' sick leave, and should preferably be addressed in future studies. Besides bereavement, the risk of sick leave was not studied in relation to child medical factors. Further studies are called for on how disease- and treatment-related factors may influence parents' work ability and risk of sick leave. Being employed is not a prerequisite for sickness benefit in Sweden. However, the income criterion necessary to be entitled sickness benefit might be more difficult to fulfill when not employed. Our sensitivity analysis including time-varying work status did not, however, reveal different outcomes. Another potential study limitation is that the legislation on sick leave and temporary parental leave has changed in Sweden during the study period [20]. To limit the effect of legislation changes, outcomes were adjusted for calendar year.

Conclusions

Childhood cancer is associated with a heightened risk of sick leave among parents. Although the prevalence of sick leave is higher among mothers, both mothers and fathers are likely to experience a similar increase relative to mothers and fathers in the general population. Bereavement is associated with an even higher risk of sick leave.

This study contributes to an understanding of work disruptions among parents of a child with cancer, but may also be generalized to parents of children with other illnesses. The findings may particularly apply to welfare states with a similar sickness insurance system, such as other Nordic countries; however, it provides important insights on the adverse effects on parents' work ability due to own ill health following a child's cancer, irrespective of the possibilities of receiving sickness benefit.

Considering the risks of adverse effects of sick leave on parents' socioeconomic situation, future studies should build on the present study and explore the possibilities and constraints of parents trying to combine their work life with caring for their child.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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