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# Cancer Illness in Children and the Socioeconomic Resources of Parents

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## 1. Introduction

Cancer during childhood may have severe consequences for the children affected (1-5). It may, however, also influence entire families adversely: In order to care for a child with cancer, roles might be altered and family functioning may need to change for shorter or longer periods of time. Parents' work situations and/or relationships may thus be affected by increased psychological stress short- and long-term (6-8), but also by an increased parental care burden associated with chronic illness in children in general (9). As a consequence, the household's income may be reduced (10;11), and this may affect the family's welfare negatively. In addition, these factors alone or in combination may create strain on the family as a system. In line with this, a meta-analysis on the influence of pediatric cancer on parent and family functioning demonstrated that these mothers report a relatively small but significant increased level of family conflicts compared to healthy controls (12). This may negatively affect children's and parents' adjustment and thus affect various aspects of family life. This chapter will summarize existing research on how cancer illness in a child may impact on parental employment and earnings, and thus affect the economic situation of households affected by cancer. It will also present findings on how cancer in a child may affect parents' relationships and divorce rates. Empirical results from Norway on these matters will thereafter be presented (11;13). Knowledge of common outcomes may help families plan their lives, and serve as an important basis for societal attempts to assist.

There is also little knowledge about the impact of parental socioeconomic resources on childhood cancer survival in developed countries (14-19). As diagnostic procedures and treatment protocols for these diseases are largely standardized and centralized (20), childhood cancer survival is often assumed to be fairly equal across different social groups. For children with cancer and their families, it is important to ensure that treatment outcomes are maximized. If there are survival differences across social groups, clinical interventions ought to be targeted to ensure optimal care for all. The chapter will therefore also summarize and discuss research on the influence of parental resources or socioeconomic status more generally on mortality after childhood cancer in a society with presumably equal access to high quality cancer care. Empirical findings from a recent Norwegian study will then follow (21). Lastly, a summary of the current status of knowledge in this field is provided, and areas where further research is warranted are highlighted.

## **2. Childhood cancer and family effects**

Survival rates have improved substantially over the last decades for most childhood cancers (3). These cancers represent, however, diverse diseases treated differently and with dissimilar risks for poor outcomes such as death or long-term adverse effects (3;22-24). Also the burden associated with modern pediatric oncological treatment varies considerably, as certain cancers are treated by one modality for a short period of time while others involve active treatment for years in terms of multi-modal treatments often associated with potential life-threatening complications. The latter treatments also require prolonged and more frequent hospitalizations in which one of the parents generally accompanies the child. Treatment will therefore in varying degrees affect the family, and specifically the parents who will need to care for their child, care for other children, as well as maintain their jobs and personal relationship. Complicated childhood cancers (central nervous system (CNS) tumors, acute myeloid leukemia (AML) and bone tumors) have for instance a significantly more negative effect upon various aspects of parents' mental health than the less complicated acute lymphoblastic leukemia (ALL) (25). Psychologically, perceived uncertainties regarding outcomes have been demonstrated to be particularly stressful (8;25;26). More specific effects of cancer in a child on employment and earnings as well as possible effects on parents' relationship are presented below.

### **2.1 Existing research on economic consequences of having a child with cancer**

Cancer in a child may adversely affect parents' work opportunities due to enlarged care burdens and/or altered priorities: In order to care for a child with cancer, parental roles might be altered and family functioning may need to change for shorter or longer periods of time (6;27;28). Parents' work opportunities may thus be affected by increased psychological stress short- and long-term (6-8), but also by an increased parental care burden associated with chronic illness in children in general (9). In addition, parents' work priorities may change (26). As a consequence, households' incomes may be reduced. Few studies on parents' work force participation exist, however. No reviews on parental employment and/or earnings after cancer or other chronic illness in children could be identified. Published studies are relatively small and may reflect policies and labor markets in particular geographic areas (10;28-35), and only a few utilizes a comparison group (29-31). Existing studies suggest that parental employment and/or earnings are affected by a child's cancer, and that the households' reported incomes may be reduced, at least short-term (10;28;31;33;35). Mothers' employment and earnings appear particularly affected (33;34). The studies indicate that there may be country-specific or regional differences with regard to work opportunities and also that the various features of children's cancer may influence family employment and earnings. Population-based, longitudinal studies from different settings are needed on this topic.

### **2.2 Existing research on cancer in a child and parents' relationships and the risk of divorce**

It is likely a strong normative pressure not to leave a family in times of serious illness in a child, even in today's individualistic society. A low divorce rate could thus perhaps be expected shortly after diagnosis and during critical periods in which the child is hospitalized and/or very ill or there is great uncertainty about survival. Along the same

lines, elevated divorce rates could be expected as the child either has recovered fully or died. Also the age of the child at diagnosis could be hypothesized to influence parents' relationships to varying degrees, as parents of younger children may be hypothesized to experience the greatest care burdens (36). Few parental risk factors are known that are strongly associated with the development of cancer in a child (37). Over time, however, certain behaviors and environmental exposures that may be important for the incidence of various childhood cancers have changed, and there have also been socioeconomic and ideational changes with implications for marital stability. Calendar period might thus also influence divorce rates. Spouses' age affect their divorce rates, reflecting in part the link between current age, age at marriage, and duration of marriage, all of which are strong determinants of divorce (38). Educational attainment is an important factor with regards to divorce risk in general. The educational gradient in divorce rates has been found to be strong and negative in many countries, but there is variation in the effect of wives' education on divorce rates, depending on the welfare system and gender relations in countries (39-41). Further, cancer in a child may reduce incomes by interfering with work capabilities and opportunities (10). Lower incomes, especially among men, are likely to increase the chance of divorce (42). For women, it will depend on whether the relationship is tuned towards specialization or pooling of resources (43;44). When higher incomes are taken into account, one would expect that highly educated persons experience would lower divorce rates due to non-economic effects of education (40;41). The presence of siblings could be hypothesized to necessitate a division of parental care between sick and healthy child(ren), thus increasing parental strain and stress (45).

Most of the published studies on divorce are small and from the 1970s (46-48). Only one utilized a comparison group (46). Studies of couples with *disabled* children show, however, increased divorce rates (49;50). Reviews on parental stress and marital adjustment after cancer or other chronic illness in children conclude that population-based, longitudinal studies are needed (6;8;12;26;36;51), as existing myths about cancer in children resulting in increased divorce rates may add to the burden already experienced by couples with a (chronically) sick child (36).

### **3. Empirical findings on parents' income and divorce rates after cancer in children in Norway**

The findings presented here are described in more detail in two articles published in 2010 (11;13).

Detailed registry and census data on the entire Norwegian population with children was used in all analyses. The *Norwegian Population Register* provided information on date of birth, death or migration, dates of changes in marital status from 1974 onwards, and dates of birth of all children. Unique family numbers enabled us to link information on children and spouses. Educational levels were extracted from the *population censuses* of 1970, 1980, 1990, and 2001, and from the *Registry of Education*. The *Norwegian Directorate of Taxes* provided information on yearly gross labor earnings. The *Cause-of-Death Registry* provided information on cause of death for the children who died. Information on cancer in children was drawn from the *Cancer Registry of Norway*, which has registered all cancer diagnoses nationwide since 1953. Mandatory reporting from clinicians, pathologists, and death certificates ensures quality and completeness (52).

It was hypothesized that employment and earnings would be adversely affected by cancer, and that the most pronounced effects would be observed for cancers characterized by intense treatment over long time-periods and/or cancers that result in chronic health problems that persist after treatment is terminated. Similarly, it was hypothesized that the divorce rate would be elevated compared to that of the general population, and that the highest rates would be observed for the parents of children most adversely affected.

### **3.1 Parental employment and earnings after cancer in a child**

#### **3.1.1 Material and methods**

Data on the entire Norwegian population of working age (27-66 years old) with children under the age of 20 in 1990-2002 (N=1.2 million) was retrieved from national registries. *The Norwegian Directorate of Taxes* provided information on employment status (yes/no) and yearly gross labor earnings for all citizens, hereafter referred to as earnings. Public benefits (i.e. nursing and care allowances) due to chronic illness in children are limited to US \$45 000/year until 18 years of age and were not included in the earnings variable prior to 2002. Parents' first year sick leaves are similarly limited, but these benefits are included in the earnings variable. Employment rates for parents of 3263 children with cancer were compared to those of parents with children without cancer by means of logistic regression models. Log-linear regression models were used to explore childhood cancer's effect on annual parental earnings for the large majority who remained employed.

Employment probabilities in 2002 were assessed by means of logistic regression models. Altogether, 1644 mothers and 1619 fathers had children with cancer between 1991 and 2001. Around 92 % of the fathers and 87 % of the mothers were employed at the end of follow-up in 2002. How cancer in a child the preceding years affected their earnings was assessed by means of log-linear regression models. Overall effects and effects of different common childhood cancer forms, child death, the age of the child at diagnosis, and time elapsed from diagnosis were explored.

Parental age, the number of children, educational level, and prior employment status or earnings were included as covariates in all models. Additional models including interaction terms explored potential modifying effects of the covariates, with a particular focus on educational level, marital status, and presence of siblings. Only mothers' educational level and fathers' marital status appeared to have a modifying effect, and models stratified on these two variables were thus set up.

#### **3.1.2 Results**

Cancer in a child was in general *not* associated with a reduced risk of employment, although some exceptions exist among both mothers and fathers. For employed mothers, CNS cancers, germinal cell cancers, and unspecified leukemia were associated with significant reductions in earnings (10%, 21%, and 60%, respectively). Reductions were particularly pronounced for mothers with a young and alive child, and became more pronounced with time elapsed from diagnosis. Fathers' earnings were not affected significantly, and are thus not shown.



3.1.2.1 Overall effects and effects of specific cancer forms on employment

Descriptive characteristics of the population are shown in Tables 1 and 2. The overall adjusted odds ratio (OR) for being employed in 2002 was higher for both mothers and fathers of children with cancer compared to those of the control group, but not statistically significant.

	Mothers			Fathers		
	N	OR <sup>a</sup>	95 % CI <sup>b</sup>	N	OR	95 % CI
<b>Cancer status</b>						
Child without cancer	621439	1.00	(ref)	606469	1.00	(ref)
Child with cancer	1644	1.15	0.96-1.37	1619	1.12	0.90-1.39
<b>Parent's age<sup>c</sup></b>						
< 35 years	203692	1.19	1.16-1.21	133919	2.76	2.65-2.89
35-39 years	146102	1.00	(ref)	129381	1.00	(ref)
40-44 years	133280	1.06	1.03-1.09	132581	0.71	0.69-0.74
45-49 years	93233	1.04	1.01-1.07	113744	0.55	0.53-0.57
50-54 years	36911	0.82	0.79-0.85	64253	0.41	0.39-0.42
55-59 years	9162	0.58	0.55-0.61	25346	0.27	0.26-0.29
>= 60 years	703	0.43	0.36-0.53	8864	0.10	0.09-0.11
<b>Parent's education<sup>d</sup></b>						
Elementary school	193894	1.00	(ref)	163175	1.00	(ref)
High school	192797	5.12	5.01-5.22	169307	6.28	6.11-6.46
College education	225835	9.07	8.88-9.26	242818	14.97	14.55-15.41
Master degree	10557	13.67	12.75-14.67	32788	25.95	24.10-27.94
<b>Prior work status<sup>e</sup></b>						
Employed	455337	1.00	(ref)	523546	1.00	(ref)
Not employed	167746	0.25	0.24-0.25	84542	0.17	0.17-0.17
<b># of children</b>						
1 child	138201	0.86	0.84-0.88	129347	0.65	0.63-0.67
2 children	273062	1.00	(ref)	269180	1.00	(ref)
>= 3 children	211820	0.83	0.82-0.85	209561	1.08	1.05-1.11

<sup>a</sup>Odds Ratio. <sup>b</sup>Confidence interval. <sup>c</sup>Age at the end of follow-up. <sup>d</sup>Educational status 1990. <sup>e</sup>Work status 1990.

Table 1. Fully asjusted model of the effect of a child's cancer illnes on parent's employment probability

None of the common childhood cancer forms were associated with significantly reduced employment probabilities parents. The point estimates of employment varied somewhat across cancer sites, and tendencies of both increased and reduced probabilities were observed. No cancer form increased the employment probability among fathers.

3.1.2.2 Overall effects and effects of specific cancer forms on earnings

Median earnings for employed parents are shown in Figure 1. A child’s cancer did not impact on fathers' earnings overall, nor for any of the common cancer forms. It resulted in a non-significant 4 % reduction in mothers' earnings. The percentage change in earnings varied somewhat across cancer sites, and tendencies towards both increased and reduced earnings were observed. CNS tumors, germinal cell cancers, and unspecified leukemia were associated with significant reductions in mothers’ earnings of 10%, 21% and 60%, respectively.

	Mothers' employment			Mothers' earnings		Fathers' employment		
	N <sup>b</sup>	OR <sup>c</sup>	95 % CI <sup>d</sup>	% change <sup>e</sup>	95 % CI	N	OR	95 % CI
No cancer	621439	1.00	(ref)	(ref)	(ref)	606469	1.00	(ref)
<b>Cancer form</b>								
CNS cancer	459	1.07	0.77-1.49	-9.7	-18.2,-1.8	455	1.04	0.70-1.56
Leukemias (ALL, AML and nos <sup>f</sup> )	454	1.17	0.83-1.65	-3.2	-11.6,4.5	448	1.13	0.72-1.76
Lymphomas	173	1.45	0.82-2.56	0	-13.3,11.9	170	1.95	0.91-4.19
Germinal cell cancer	100	0.85	0.45-1.62	-20.8	-44.4,-1.8	98	0.90	0.41-1.97
Neuroblastoma	94	0.62	0.33-1.17	5.6	-12.6,21.1	93	1.19	0.40-3.51
Bone cancer	77	9.20	2.13-39.80	6.7	-12.1,22.4	76	1.27	0.51-3.15
Renal cancer <sup>g</sup>	67	1.21	0.49-2.99	1.6	-20.9,19.9	67	3.08	0.40-23.49
Soft tissue cancer	60	1.02	0.44-2.34	4.7	-18.5,23.6	59	0.87	0.33-2.35
Malignant melanoma	28	1.45	0.38-5.50	-34.7	-95.0,0.03	25	2.81	0.31-25.02
Endocrine cancer <sup>h</sup>	21	0.62	0.19-2.04	7.3	-38.1,38.4	20	0.99	0.27-3.64
Eye cancer <sup>i</sup>	12	1.62	0.20-13.25	-8.9	-55.8,38.8	12	>999.99	NA
<b>Vital status</b>								
Child with cancer, alive	1315	1.04	0.86-1.27	-5.7	-10.7,-0.9	1296	1.15	0.89-1.47
Child with cancer, dead	329	1.70	1.10-2.62	2.5	-6.8,10.9	323	1.01	0.63-1.62
<b>Time since diagnosis</b>								
Cancer 0-4 yrs prior	554	1.01	0.76-1.35	-0.3	-7.8,6.7	542	0.94	0.65-1.35
Cancer >=5 yrs prior	1090	0.80	0.64-1.00	-5.8	-11.2,-0.6	1077	0.87	0.66-1.15
<b>Age at diagnosis</b>								
Child 0-4 yrs	708	1.02	0.78-1.34	-4.7	-11.5,1.6	699	1.33	0.88-2.00
Child 5-9 yrs	352	1.14	0.77-1.69	-12.6	-23.2,-3.0	349	0.83	0.54-1.29
Child 10-14 yrs	307	1.24	0.84-1.83	0.5	-9.5,9.7	300	1.05	0.67-1.63
Child >= 15 yrs	277	1.38	0.90-2.12	3.1	-7.0,12.4	271	1.29	0.80-2.07

<sup>a</sup>Only the effect of the disease variable are shown, but all covariates from table1 were included. In the analysis of earnings, work status 1990 was substituted by earnings in 1990. <sup>b</sup>Number of cancer cases in the respective categories. <sup>c</sup>Odds Ratio. <sup>d</sup>Confidence interval. <sup>e</sup>Change in percent. <sup>f</sup> Not otherwise specified. For these cancers, a statistically significant 59.8% reduction in earnings was observed. <sup>g</sup> Primarily Wilm's tumor. <sup>h</sup>Primarily thyroid cancer. <sup>i</sup>Primarily retinoblastoma.

Table 2. Parents' employment probability and earnings by the child's cancer type, vital status, time from diagnosis and age at diagnosis.

3.1.2.3 The importance of cancer severity and prognosis

Length and severity of treatment regimens may influence parents’ care burden and thus their ability to work regular hours. Analyses based on standardized treatment protocols for common childhood cancers did not, however, reveal significant differences. There were also no differences in employment and/or earnings for the different cancer stages at diagnosis.

A significantly elevated employment probability was seen for mothers who lost a child to cancer (OR 1.70). Child death was not associated with inclines or declines in earnings, but a 10% reduction in earnings was observed for those with living children, and the reductions became more pronounced with the time elapsed from diagnosis. Fathers’ employment and earnings were not statistically significantly affected by their child’s status.

3.1.2.4 Children’s age at diagnosis

Children’s age at diagnosis may be hypothesized to influence parents’ work ability. Among mothers, children’s age at diagnosis was not significantly associated with the probability of being employed. A young age at diagnosis (<10 years old) did, however, adversely affect

mothers' earnings by around 9%. The effect was most pronounced for those with children 5-9 years old. Children's age did not affect fathers' overall employment or earnings.

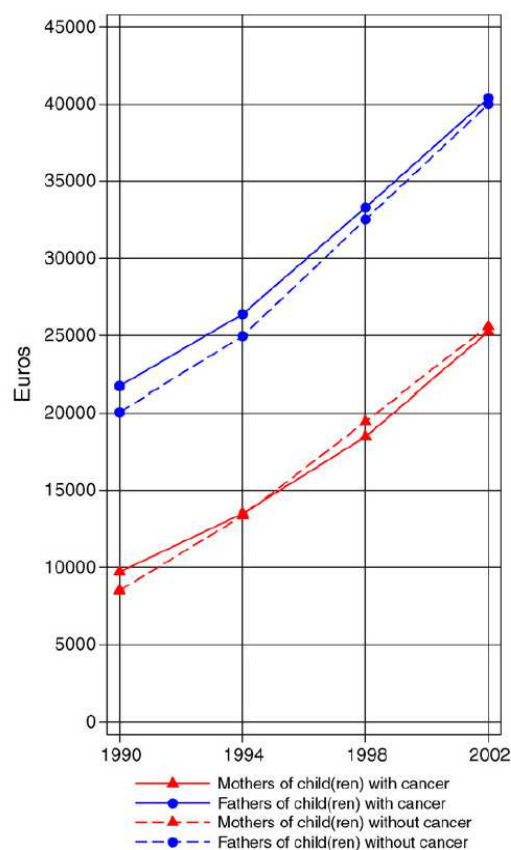


Fig. 1. Median gross labor earnings

### 3.1.2.5 Impact of siblings, marital status, and household level effects

The presence of healthy siblings was hypothesized to further increase parental strain and stress, imposing a division of parental care between the sick child and its healthy siblings, perhaps impacting negatively on parents' work ability. No difference was, however, observed in employment or earnings for persons with and without also healthy children ( $p_{\text{interaction}}$  0.12 for mothers and 0.11 for fathers). There was also no difference in cancer's effect on employment or earnings in married versus unmarried persons overall ( $p_{\text{interaction}}$  0.87 for mothers and 0.89 for fathers). Subanalyses did, however, reveal that the married fathers were more likely to remain employed and to maintain their earnings compared to the not married fathers. The effect was particularly pronounced for fathers with children 10 years and older at time of diagnosis and for fathers who lost a child to cancer ( $p_{\text{interaction}}$  0.001 and 0.01).

Among married couples with a child with cancer there was an increased probability of either spouse working, as the OR for household employment was 2.30 (95% confidence interval (CI) 1.32-4.00). It was particularly pronounced the first five years after diagnosis (OR 4.91, CI 1.44-16.72) and after child death (OR 3.40, CI 1.00-12.38). There was no significant difference in the employment probabilities for the different cancer forms. Household earnings were not reduced overall among the married couples after child cancer, but the household earnings were reduced around 7% for those with children age 5-9 ( $p$  0.05).



3.1.2.6 Effects of parents’ education

Educational level did not affect fathers’ employment or earnings differently ( $p_{\text{interaction}} 0.81$ ). As shown in Table 3, however, mothers with a lower education were less likely to stop working when experiencing cancer in their child (OR 1.31), and the probability of employment was further increased five years after diagnosis (OR 1.47). Employment was most likely after leukemia (OR 1.54) and after child death (OR 1.94). The earnings of mothers with a lower education were not affected more adversely than the earnings of mothers with a higher education. Mothers with a higher education did not experience any significant changes in their employment, but their earnings were reduced 6% overall provided their child did not die. A highly significant 26% reduction was observed after germinal cell cancer.

	Low education <sup>b</sup>				High education <sup>c</sup>			
	Employment		Earnings		Employment		Earnings	
Cancer status	OR <sup>d</sup>	95 % CI <sup>e</sup>	% change <sup>f</sup>	95 % CI	OR	95 % CI	% change	95 % CI
No cancer	1.00	(ref)	NA	(ref)	1.00	(ref)	NA	(ref)
Any cancer, any time	1.31	1.07-1.60	-2.9	-10.0,3.8	1.00	0.73-1.37	-4.5	-10.1,0.9
<b>Cancer form</b>								
Any leukemia	1.54	1.02-2.34	1.2	-12.8,13.5	0.73	0.44-1.23	-4.8	-15.4,4.8
Acute lymphoblastic leukemia	1.34	0.85-2.11	4.9	-10.8,18.6	0.68	0.39-1.17	-7.0	-19.1,3.8
Acute myelogenous leukemia	3.71	0.86-16.10	5.8	-28.6,31.3	1.03	0.24-4.33	7.7	-17.5,27.8
CNS tumor	1.08	0.75-1.57	-9.6	-24.9,3.8	1.62	0.80-3.31	-8.7	-19.9,1.5
Lymphomas	1.51	0.82-2.76	6.2	-14.4,23.2	1.35	0.42-4.29	-7.0	-26.4,9.3
Germinal cell cancer	0.80	0.39-1.63	-10.0	-50.0,18.5	3.14	0.43-22.98	-26.2	-57.3,-3.6
Neuroblastoma	0.84	0.40-1.78	16.4	-11.3,38.1	0.49	0.19-1.26	-2.0	-28.3,18.7
Bone cancer	13.32	1.79-98.94	9.6	-18.2,31.4	1.60	0.22-11.80	-3.0	-33.9,20.1
Renal cancer <sup>g</sup>	0.93	0.31-2.79	-12.2	-60.0,20.0	1.12	0.26-4.78	10.4	-16.0,31.4
<b>Child status</b>								
Child with cancer, alive	1.18	0.94-1.48	-4.5	-12.9,3.2	0.93	0.67-1.30	-6.4	-12.8,-0.4
Child with cancer, dead	1.94	1.20-3.14	2.4	-12.2,15.2	1.44	0.63-3.28	3.6	-8.9,14.7
<b>Time since diagnosis</b>								
Cancer 0-4 yrs prior	1.05	0.76-1.46	2.1	-10.6,13.4	0.99	0.59-1.68	-2.3	-11.9,6.4
Cancer >= 5 yrs prior	1.47	1.14-1.90	-5.1	-14.0,3.0	1.01	0.69-1.48	-5.6	-12.7,1.0
<b>Age at diagnosis</b>								
Child 0-4 yrs	1.31	0.94-1.84	-6.1	-18.5,5.1	0.85	0.57-1.29	-2.0	-10.0,5.5
Child 5-9 yrs	1.40	0.88-2.23	-15.4	-34.1,0.4	0.81	0.44-1.50	-10.4	-23.7,1.4
Child 10-14 yrs	1.14	0.76-1.70	7.3	-7.5,20.1	1.64	0.60-4.47	-9.4	-24.7,3.9
Child >= 15 yrs	1.42	0.90-2.22	3.5	-11.6,16.6	2.13	0.67-6.76	1.4	-13.8,14.5

<sup>a</sup>Only the effect of the disease variable are shown, but all covariates from table 2 exept mother's education were included. Prior work status was included in analyses of employment whereas prior earnings was included in analyses of earnings. <sup>b</sup>Unknown/low, elementary or high school education, accounting for 279192 (45%) of the cohort, of which 791 encountered child cancer. <sup>c</sup>College education or above, accounting for 343891 persons in total, of which 853 encountered child cancer. The percentage employed in the respective groups were 78% and 95%, respectively. <sup>d</sup>Odds Ratio. <sup>e</sup>Confidence interval. <sup>f</sup>Change in perecent. <sup>g</sup>Primarily Wilm's tumor.

Table 3. Mother's employment probability and changes in earnings by cancer in a child and educational level<sup>a</sup>

3.1.3 Summary of main findings

Parents’ employment is not adversely affected by a child's cancer in Norway. Earnings are reduced in certain instances, but the overall effects are minor. In line with traditional caregiving responsibilities, reductions in earnings were most pronounced for mothers.

### **3.2 Parents' risk of divorce after cancer in a child**

#### **3.2.1 Material and methods**

Data on the entire Norwegian married population aged 17-69 with children under the age of 20 in 1974-2001 (N=1.04 million couples) was retrieved from national registers. The divorce rates for 4590 couples with a child (age <20 years) with cancer were compared to the divorce rate of otherwise similar couples not affected by childhood cancer by means of discrete-time hazard regression models. Couples were followed for an average of 12 years, and the total number of divorces was 168 110. Of these, 535 divorces occurred among couples with a child with cancer. Expected outcomes and the length and severity of treatments may influence parents' relationships, and effects of time elapsed, common childhood cancer types, spread, and death were thus explored. The child's age at diagnosis, the number of siblings, parents' age, earnings and educational level, the duration of marriage, and calendar period, were all included as covariates (Table 4). Additional stratified models and models including interaction terms were also set up to explore potential modifying effects of covariates.

#### **3.2.2 Results**

Cancer in a child was not associated with an increased risk of parental divorce rate overall, or for any of the more common cancer forms among children. A tendency towards an increased divorce risk (OR 1.34, CI 1.00-1.81) was observed for parents' of children with renal cancers (primarily Wilms tumor). Neither age, time from diagnosis, nor prognosis influenced the estimates adversely. The death of a child with cancer did not influence the divorce rates significantly in either direction. The couples in which the mothers' education was above high school level did, however, display significantly increased divorce rates (OR 1.19, CI 1.05-1.36). The risk was particularly high shortly after diagnosis. Other risk factors for these couples were CNS cancers, age 5-9 years, and death of the child.

##### **3.2.2.1 Overall effects and site-specific effects**

Parents of a child with a cancer of any form, diagnosed at any time, had a divorce rate similar to that of parents of children without cancer (OR 1.04, CI 0.95-1.13). As is shown in Table 5, only renal cancer was statistically significantly associated with an increased risk of parental divorce. The point estimates varied somewhat across cancer sites, and tendencies of both increased and reduced rates were observed. CNS, renal, and endocrine cancer yielded OR estimates above 1.00, whereas malignant melanomas, bone, and hepatic cancers resulted in OR estimates below 1.00. Lymphoma, leukemia, retinoblastoma, soft-tissue, and germinal cell cancer yielded OR estimates close to 1.00. No significant difference in the effect of AML and ALL was observed.

##### **3.2.2.2 The importance of prognosis and cancer stage**

No significant differences were observed between cancers with and without spread at time of diagnosis. The point estimate was highest for metastatic cancer (1.16), but statistical significance was not achieved. Likewise, almost identical estimates were obtained for parents with a child who died and for parents with children who remained alive.

	Divorces/pyrs <sup>a</sup>	OR <sup>b</sup>	95 % CI <sup>c</sup>
No cancer	192722/17.94 mill	1.00	(ref)
Child with cancer (any time)	624/64829	1.05	0.97-1.14
<b>Time from diagnosis</b>			
Cancer 0-5 yrs prior	248/17542	1.11	0.98-1.26
Cancer > 5 yrs prior	376/47287	1.01	0.91-1.12
<b>Age group</b>			
17-19 years	328/10918	1.42	1.27-1.59
20-24 years	10653/393128	1.00	(ref)
25-29 years	29994/1.50 mill	0.61	0.60-0.62
30-34 years	39896/2.35 mill	0.46	0.45-0.47
35-39 years	38921/2.52 mill	0.39	0.38-0.40
40-44 years	31700/2.43 mill	0.32	0.31-0.33
45-49 years	21471/2.31 mill	0.22	0.21-0.23
50-54 years	11752/2.23 mill	0.13	0.12-0.13
55-59 years	5499/1.86 mill	0.07	0.06-0.07
60-64 years	2214/1.39 mill	0.03	0.03-0.04
65-69 years	918/987625	0.02	0.02-0.02
<b>Educational level</b>			
Low or unknown	1510/74657	1.51	1.43-1.59
Elementary school	43068/5.45 mill	1.00	(ref)
High school	104984/9.03 mill	0.92	0.90-0.93
College education	39207/3.13 mill	0.86	0.85-0.87
Master degree	4577/325929	0.92	0.89-0.95
<b>Duration of marriage</b>			
0-2 years	10090/1.04 mill	0.64	0.62-0.65
3-4 years	14183/1.00 mill	1.00	(ref)
5-6 years	29179/1.91 mill	1.25	1.22-1.27
7-8 years	25075/1.78 mill	1.36	1.34-1.39
9 years or more	114819/12.27 mill	1.39	1.36-1.42
<b>Calendar period</b>			
1974-1980	30802/3.74 mill	0.96	0.94-0.97
1981-1985	33233/3.28 mill	1.00	(ref)
1986-1990	36707/3.42 mill	1.25	1.23-1.27
1991-1995	39861/3.28 mill	1.57	1.54-1.59
1996-2001	52743/4.28 mill	1.75	1.72-1.78
<b>Number of children</b>			
One child only	43248/3.23 mill	1.30	1.28-1.31
Two children	91496/7.76 mill	1.00	(ref)
Three or more children	58602/7.01 mill	0.90	0.89-0.91
<b>Married in 1974</b>			
	58602		
Yes	102058/5.35 mill	1.00	0.99-1.02
No	91288/12.65 mill	1.00	(ref)
<b>Remarried</b>			
Yes	7275/248514	3.10	3.02-3.18
No	186071/17.75 mill	1.00	(ref)

<sup>a</sup>Number of divorces per person-year. <sup>b</sup>Odds Ratio. <sup>c</sup>Confidence interval.

Table 4. Fully adjusted model of the effect of a child's cancer illness on a parents' divorce probability

Cancer type	Divorces/pyrs <sup>b</sup>	OR <sup>c</sup>	95 % CI <sup>d</sup>
No cancer	192722/19.94 mill	1.00	(ref)
Any leukemia	181/17239	1.02	0.88-1.18
<i>Leukemia, nos</i> <sup>e</sup>	14/1273	1.26	0.74-2.13
<i>Acute lymphoblastic leukemia</i>	139/12983	0.99	0.84-1.17
<i>Acute myelogenous leukemia</i>	28/2983	1.07	0.74-1.56
CNS tumor	162/15523	1.11	0.95-1.29
Lymphomas	57/6460	1.12	0.86-1.45
Germinal cell cancer	38/4303	1.24	0.90-1.70
Bone cancer	23/3733	0.78	0.52-1.18
Renal cancer <sup>f</sup>	44/3297	1.34	1.00-1.81
Eye cancer <sup>g</sup>	24/2599	0.91	0.61-1.37
Soft tissue cancer	23/2548	1.01	0.67-1.52
Malignant melanoma	15/2536	0.82	0.49-1.36
Endocrine cancer <sup>h</sup>	8/1004	1.20	0.60-2.41
Hepatic cancer	7/920	0.75	0.36-1.59
Other or unknown	42/4667	0.97	0.71-1.31
Local cancer <sup>i</sup>	520/53748	1.04	0.97-1.15
Regional cancer	82/9798	1.03	0.83-1.28
Metastatic cancer	22/1283	1.14	0.75-1.74
Stage unknown	62/7448	1.01	0.78-1.29
Child with cancer, alive	365/34688	1.05	0.95-1.17
Child with cancer, dead	259/30141	1.04	0.92-1.18
Child 0-4 yrs at diagnosis	300/25315	1.04	0.92-1.16
Child 5-9 yrs at diagnosis	133/12595	1.08	0.91-1.28
Child 10-14 yrs at diagnosis	86/10734	1.03	0.83-1.28
Child >= 15 yrs at diagnosis	105/16185	1.07	0.88-1.30

<sup>a</sup>Only the effect of the disease variable are shown, but all covariates from table 4 were included in the model. <sup>b</sup>Number of divorcing per person-year. <sup>c</sup>Odds Ratio. <sup>d</sup>Confidence interval. <sup>e</sup>Not otherwise specified. <sup>f</sup>Primarily Wilm's tumor. <sup>g</sup>Primarily retinoblastoma. <sup>h</sup>Primarily thyroid cancer. <sup>i</sup>Including blood, lymph, and brain tumors for which no stage is recorded.

Table 5. Devorce probability by children's type, stage, vital status and age<sup>a</sup>

3.2.2.3 Effects of time from diagnosis

Duration of disease did not influence parental divorce risk significantly. Parents of children with a relatively recent cancer diagnosis (0-5 years earlier) had a slightly higher divorce rates than those with children with a cancer diagnosed further back in time (>5 years), but the estimates were not significantly different from those of parents with children without cancer, or from each other (OR 1.10, CI 0.97-1.25 v OR 0.98, CI 0.88-1.10).

3.2.2.4 Effects of age at diagnosis

Cancer in a child 0-9 years old yielded an OR of 1.05 (CI 0.95-1.15), whereas the corresponding estimate for an older child was 1.00 (CI 0.84-1.19). A further subdivision of this age span did not reveal significant differences between parents of younger versus older children.

3.2.2.5 Presence of sibling

No difference was observed between divorce rates for couples with and without also healthy children (OR 1.04, CI 0.96-1.13 v 0.90, 0.63-1.26).

3.2.2.6 Effects of parents’ education

The inclusion of an interaction term between cancer and mothers’ educational level in the original model suggested a differential effect of cancer depending on the mother’s educational level ( $p_{\text{interaction}} < 0.01$ ). Stratified analyses confirmed that couples in which the mothers had an education beyond high school displayed a 16% higher divorce rate overall compared to couples with mothers with a lower education, as is shown in Table 6. The risk was particularly high the first five years after diagnosis (OR 1.23, CI 1.02-1.50), due to a 35% increase in the divorce rate the first few years after diagnosis. A significantly elevated rate was also observed for young children (OR 1.20, CI 1.03-1.41), and for CNS cancer (32%), Wilms tumor (64%), and child death (31%). A similar inclusion of an interaction term between cancer and father’s educational level did not suggest a differential effect of cancer ( $p_{\text{interaction}} 0.25$ ), and further stratified analyses were thus not undertaken.

Cancer status	High education <sup>b</sup>		Low education <sup>c</sup>	
	OR <sup>d</sup>	95 % CI <sup>e</sup>	OR	95 % CI
No cancer	1.00	(ref)	1.00	(ref)
Any cancer, any time	1.19	1.05-1.36	0.97	0.87-1.07
Cancer 0-2 yrs prior	1.32	1.01-1.76	0.91	0.70-1.19
Cancer 3-5 yrs prior	1.21	0.93-1.57	1.08	0.87-1.33
Cancer 6-7 yrs prior	1.10	0.81-1.50	0.81	0.62-1.05
Cancer 8-10 yrs prior	1.23	0.81-1.86	1.11	0.83-1.50
Cancer > 10 yrs prior	1.14	0.90-1.45	0.96	0.82-1.14
Child 0-4 yrs at diagnosis	1.17	0.98-1.40	0.93	0.80-1.08
Child 5-9 yrs at diagnosis	1.32	1.01-1.74	0.95	0.76-1.19
Child 10-14 yrs at diagnosis	1.04	0.72-1.73	1.02	0.78-1.32
Child >= 15 yrs at diagnosis	1.22	0.86-1.73	1.05	0.83-1.32
Child with cancer, alive	1.11	0.94-1.31	1.01	0.88-1.15
Child with cancer, dead	1.35	1.10-1.65	0.92	0.79-1.07
Acute lymphoblastic leukemia	1.18	0.91-1.53	0.88	0.71-1.10
Acute myelogenous leukemia	1.03	0.54-2.00	1.09	0.69-1.72
CNS tumor	1.35	1.04-1.73	0.99	0.81-1.20
Lymphomas	1.15	0.75-1.75	1.09	0.78-1.52
Germinal cell cancer	1.45	0.87-2.41	1.09	0.72-1.65
Renal cancer <sup>f</sup>	1.52	0.95-2.42	1.21	0.82-1.79
Eye cancer <sup>g</sup>	0.93	0.48-1.80	0.85	0.51-1.41
Local cancer	1.16	0.99-1.35	0.99	0.88-1.11
Regional cancer	1.19	0.82-1.73	0.97	0.74-1.26
Metastatic cancer	1.19	0.61-2.29	1.04	0.60-1.80

<sup>a</sup>Only the effects of the disease variable are shown, but all covariates from table 6 were included in the model. <sup>b</sup>High school education or above. <sup>c</sup>Elementary education only. <sup>d</sup>Odds Ratio. <sup>e</sup>Confidence interval. <sup>f</sup>Primarily Wilm's tumor. <sup>g</sup>Primarily retinoblastoma.

Table 6. Divorce probability by cancer in children and mother's educational level<sup>a</sup>

3.2.3 Summary of main findings

Parents’ divorce rates are not generally adversely affected by a child's cancer in Norway. Possible negative long term effects on the parents may be balanced by strengthened parental



bonds. An exception exists for couples with a child with highly educated mothers, and further studies are warranted to understand the background for this increase in divorce risk.

#### **4. Discussion of findings from empirical studies on economic consequences and divorce in families after cancer in a child**

This large registry-based study has shown that contrary to existing myths, cancer in a child is not associated with substantive reductions in parental employment or earnings, nor in an increase in parental divorce rates.

##### **4.1 Expected outcomes and extent of treatments provided**

It was perhaps surprising that employment rates were increased for mothers who lost their child, as other studies have shown that bereavement may interfere with parents' work ability (53;54). Caregiving tasks associated with cancer illness in children eventually subside in cases of child death, and bereavement as an exposure may thus not be a relevant proxy for the cancer form, stage, or treatment endured. Cancer death in children has been shown to be unrelated to parents' social class (15;17), and mothers who experience child death are likely to have endured pronounced, long-term care burdens in the past (12;26), which in turn may have impacted negatively on their working abilities. As the mothers' care burdens are eliminated, they may find opportunities to rejoin the work force. Similarly, mothers' earnings were negatively affected by cancer in their child only when the child remained alive, and their earnings actually appeared to increase beyond that of the comparison group after child death. As the data recordings for employment and earnings come in yearly intervals, it is primarily longer-term effects that are assessed here. Short-term consequences may be different and highly relevant for families in different settings. It was also surprising that divorce was no more or less likely for parents who lost their child (53).

In general, no cancer form reduced the overall employment probability for either parent, and neither overall nor specific childhood cancer forms impacted on fathers' earnings overall.

CNS cancer during childhood may be quite debilitating and alter physical, psychological, and social functioning dramatically (55;56). This could be predicted to increase the care load for parents and have lifelong consequences for the family, including reductions in parental employment and earnings as well as elevated divorce rates. In line with this, a modest but statistically significant reduction in mothers' earnings was observed. Similarly, higher divorce rates were expected after CNS cancer, but this was not observed. Along the same lines, AML was expected to affect employment, earnings and divorce rates more strongly than ALL due to differences in treatment intensities and expected outcomes. This was not observed, but unspecified leukemia was associated with a significant reduction in mothers' earnings.

In line with what has been reported previously, couples with a child with cancer have similar divorce rates as couples with children without cancer (36). An increased risk of divorce was observed only after renal cancer. This may be a chance finding due to the large number of tests performed, and further explorations with a clearly stated *a priori* hypothesis are needed. Parental divorce risk thus appears unrelated to cancer form, stage, and prognosis in Norway.

## 4.2 Family orientation, obligations and gender

Encountering and 'conquering' cancer illness in a child has been suggested to increase parents' family orientation (6;26). This may affect work force participation, as parents (and mothers in particular) may choose to work less. In addition, parents' abilities to undertake their usual chores and obligations in family and working life may also be affected, temporarily or permanently. In practical terms, one person may need to stay for prolonged periods in hospitals with the sick child, and either spouse may thus experience a 'role overload' (12), which could affect employment or earnings adversely. In addition, the quality of the marital interactions may be enhanced. A child's illness is often considered by the couple as a common experience, and may thus result in a strengthening of existing bonds between them, perhaps especially if the relationship was good at the outset (8;57). Also their values may change in such a way that divorce becomes less likely: Persons encountering a serious disease in a family member may become more conscious about whatever quality there is in the relationship (58;59), and later marital conflicts may tend to be seen as small compared to what have been endured previously (36). It is also possible that cancer may affect the quality of the relationship adversely. Poor health in a child may lead to parental behavioral and mood changes, and thus yield smaller emotional rewards from the relationship.(36) Spouses' abilities to undertake their usual chores and obligations in marital relationships may be affected (12;41;60). This could pertain in particular to highly educated mothers. Studies have shown that mothers in general take on the greatest parental care burden in case of illness in a child (26), and that fathers thus may be less involved. Remaining engaged in working life and/or upholding a social life may thus be more difficult for mothers than fathers. The relevance of these mechanisms may depend on the age of the child at diagnosis, time elapsed since diagnosis, cancer site and stage, and the type and extent of necessary treatment. Many treatment regimens have become less aggressive over the last few decades, both as a result of technological innovations and an increased awareness and recognition of childhood cancer survivors' overall functioning, possibly accounting for the effects of the earlier time periods.

A meta-analysis on the influence of pediatric cancer on parent and family functioning demonstrated that mothers in particular report a significant increased level of family strain and stress compared to healthy controls (12), whereas other studies show that this is most markedly seen among families who were vulnerable at the outset (8). Reductions in work hours may be a way to decrease stress, and this could be what is picked up here in terms of tendencies towards reduced incomes for mothers in particular. Studies have shown that mothers in general take on the greatest parental care burden in case of illness in a child (26), and remaining engaged in working life may thus be more difficult for mothers than fathers. The gender difference observed corresponds well with the general perceptions of gendered parental caregiving roles and parental care for sick children to a larger extent being undertaken by women, and are in line with what has been observed previously (33;34). To compensate for declines in mothers' work hours, fathers may need or choose to work more to uphold the household's overall income.

Marital status per se did not modify the overall effect of a child's cancer on employment or earnings. Fathers with children with cancer were, however, particularly likely to remain employed after child death and when they were parenting older children. This may reflect compensations at a household level to maintain previous income levels. The likelihood of

either spouse experiencing unemployment was, however, greatly reduced among married couples, and these couples may be in a better situation than for instance single parents in case of cancer illness in a child.

#### **4.3 The importance of education**

Analyses stratified on parents' educational level showed that mothers with a low education remained employed and/or increased their employment relative to other mothers. This was contrary to what was expected, as occupations only requiring a low education in general are believed to be less flexible. On the other hand, these mothers may "need" to work for economic reasons, and they may thus not have the choice to dedicate themselves to caregiving. At a national level, single Norwegian mothers hold on average a lower education than married and/or cohabitant mothers, and this issue thus needs further exploration. No modifying effect was seen for the fathers' educational level. Cancer may also affect employment and earnings differently across different baseline educational levels and incomes, but the cancer estimates remained nearly identical with and without the inclusion of these factors.

Independent of education, neither husbands nor wives' earnings did influence divorce rates in this study. Elevated divorce rates were, however, observed for couples in which the wives had an above average educational level. No modifying effect was seen for the husband's education. In case of parental divorce, shared parental responsibility is more common among Norwegian couples in which the mother has a high education, but whether this can account for the elevated divorce rate among these couples has not been established.

#### **4.4 Generalisability and implications of results**

Cancer incidence in children is very hard to predict, and few well known risk factors have been established (26). Cancer in children thus affects persons randomly across social strata (15), and a cancer diagnosis in a child is therefore not associated with the same stigma as illnesses more obviously resulting from families' life-styles or lack of socioeconomic resources. Possible observed effects are thus likely consequences of cancer.

Norway is a welfare state with public health care available to all citizens, free of charge. The direct parental costs associated with cancer in children, i.e. diagnostic work-up and treatment, are thus minimal, in contrast to what is observed in other countries (33;35). In addition, leaves-of-absence and various economic welfare benefits are commonly yielded parents with chronically ill children. As previously stated, some of the compensatory measures cannot be assessed as they are included in the earnings variable. The existing welfare system, compensating for losses in ordinary labor market incomes and providing health services free of charge, may result in families' financial situations being only modestly affected in Norway compared to countries with less extensive welfare systems. I therefore consider it likely that the observed findings apply to countries with similar health and welfare options, employment rates, and earnings, as for instance Canada and the other Nordic and Western European countries. The relevance of these findings for other populations remains largely unexplored.

#### **4.5 Summary of discussion**

This large, methodologically rigorous registry-based study has shown that cancer in children is not associated with reductions in parents' employment probabilities, and that cancer in

children is associated with only minor reductions in parents' earnings overall. The latter finding may be due to the extensive welfare options in the Nordic countries in case of illness in children. Contrary to what has been reported previously, parents' employment is not found to be generally adversely affected by cancer in children in this study. Earnings of certain subgroups of parents are, on the other hand, negatively affected, and this is in line with what has been reported previously (10;28;31;33;35). The magnitude overall is, however, minor. Reductions in earnings are mainly seen for mothers who have a high(er) education level, for mothers with living children, and for mothers with children diagnosed at young ages.

Exceptions exist for employed mothers with children with CNS cancers, germinal cell cancers, and unspecified leukemia, for whom significant reductions in earnings were observed. Reductions were particularly pronounced for mothers with young and living children, and became more pronounced with time elapsed from diagnosis. Additional studies are warranted to understand the background for these observed findings, as well as to identify possible interventions to reduce the adverse financial impact on these households. In line with traditional caregiving responsibilities, the adverse effects observed on earnings were most pronounced for mothers. Single mothers' earnings may be particularly affected, and research targeting this specific subgroup is necessary.

Contrary to existing myths, cancer in a child is not associated with an increase in parental divorce rates. Possible negative long term effects on the parents are perhaps balanced by strengthened parental bonds. Couples with highly educated mothers are exempted, and further studies are warranted to understand the background for their increased divorce risk.

A child's cancer illness was expected to increase divorce rates through an increased parental care burden and an increase in the psychological stress experienced by parents. However, except for couples with highly educated mothers, it seems that the divorce-reducing effects dominate or at least balance the opposite contributions, or that both types of effects are weak. Increased parental stress has, however, been documented in other studies, particularly for families who were vulnerable at the outset (8;57), and more research on the relationship between parental stress and divorce is needed.

## **5. The impact of family resources on childhood cancer**

The general inverse association between childhood mortality and socioeconomic status is well established (61). As previously mentioned, the Norwegian public health care system offers all residents free cancer diagnosis and treatment. Private health services that exist typically handle less critical conditions and provide neither primary nor follow-up treatment for cancer. Further, because of highly standardized procedures conducted within centralized designated pediatric hospital departments (62), children supposedly receive the same initial and subsequent treatment regardless of where in the country they live and independent of their parents' resources and personal initiatives vis a vis health personnel. Thus, if there were no other determinants of the survival from these cancers, one would expect to see small differentials in survival by, for example, parents' education or other socio-demographic characteristics.

However, reality may be more complex. Treatments may perhaps be less standardized than widely assumed, and there may be socio-demographic variations in families' abilities to comply with the recommendations for follow-up assessments and treatment, in developed



countries as well as in poorer settings (18;63). This might be of particular relevance in out-patient hospital settings or community-based primary care settings, where patients in general have to take on more responsibility to achieve appropriate care. Cancer may also be diagnosed earlier in some social groups than others, which may be important for survival. In addition, some children may have poorer health than others at time of diagnosis, with consequences for survival prospects, or they may develop diseases after diagnosis that are unrelated to the malignancy but increase the chance of dying from it. These so-called 'host factors' are probably influenced by, for example, families' socio-economic resources, as is all-cause mortality in this age group (61).

There is also limited knowledge about the importance of parents' socioeconomic resources from other countries, where effects also may be expected to be dissimilar because of inherent differences in the health care and welfare systems. One study from New Zealand showed that cancer survival was significantly reduced if a parent did not have a registered occupation or if a parent was unemployed, and an adverse effect of low education was also weakly indicated, while single parenthood had no impact (14). Similarly, ethnicity did not play a role (16). A relatively small, older study from the Netherlands concluded that parents' educational level only had a minor impact on childhood leukemia survival in the period 1973-79 (17). A Korean study from 2009 found that parental resources played a minor role (15), whereas a more recent study by the same authors found a clear inverse relationship between childhood cancer mortality and parental socioeconomic position (19). In developing countries, parental resources have been documented to have a significant beneficial effect (18;64).

Survival rates have improved substantially over the last decades for most childhood cancers (3). Childhood cancers represent, however, diverse diseases treated differently and with dissimilar risks for poor outcomes (3;22-24). The burden associated with modern pediatric oncology treatment thus varies considerably, as certain cancers are treated by one modality for a short period of time while others involve active multi-modal treatments for many years often associated with potential life-threatening complications (65). The latter treatments also require prolonged and more frequent hospitalizations in which one of the parents generally accompanies the child, and socio-demographic variation in survival might be expected to be more pronounced.

## **6. Findings from an empirical study on the impact of family resources on childhood cancer**

Diagnostic and treatment protocols for childhood cancer are generally standardized, and survival ought therefore be fairly equal across social strata in societies with free public health care readily available. This study explores whether there nevertheless are disparities in mortality after childhood cancer in Norway depending on parents' socioeconomic status. As shown above, limited knowledge on mortality differentials exist from earlier analyses. Effects of the mother's age, education, and marital status, the mother's and father's combined annual labor earnings, and whether they have additional children, were therefore assessed.

### **6.1 Material and methods**

Data on all Norwegian children diagnosed with cancer at age 0-19 from 1974 through 2007 (N=6280) and their parents were extracted from national registers. Cancer data at time of



diagnosis was obtained from the Cancer Registry of Norway, but information on initial and subsequent courses of treatment was not available (52).

Discrete-time hazard regression models for all-cause mortality the first ten years following diagnosis were estimated. For each child, a series of one-month observations were created, starting at time of diagnosis and ending at time of death or emigration, when a second cancer was diagnosed, after ten years had passed since diagnosis, or on December 31<sup>st</sup> 2007. Each observation included various characteristics of the child, its disease, and its parents. The outcome variable was whether the child died within the month or not. Almost all deaths (i.e. >95%) were registered as due to cancer. In total, there were 1619 deaths within 500 837 person-months of observation. On average, each child contributed 6.7 observation years.

All models included time from diagnosis, child's age at diagnosis, calendar year, whether the parents were married to each other at time of diagnosis, number of siblings, mother's age when the child was born, her education at time of diagnosis, and average combined earnings of mothers and fathers during the last three years prior to diagnosis. Father's educational level could not be included in addition to that of the mother, because of a high degree of educational homogamy in Norway (66). Substituting mothers' education with those of fathers yielded fairly similar estimates. For the same reason, only mothers' age was included.

Some cancer types are more aggressive than others. In case these also occur more frequently in some groups than others, cancer type was controlled for in all models. It turned out, however, that this adjustment was unnecessary, i.e. the distribution of the cancer cases is fairly random. Stage at diagnosis was included in one model to assess its importance as a causally intermediate factor. Lastly, models were estimated separately for mothers with a high versus a low education, for children with and without siblings at diagnosis, for cancer forms anticipated to create long-lasting care burdens versus the remaining, and for an early (<1990) versus later (≥1990) diagnostic period. The cancer forms anticipated to involve long-term care burdens were CNS tumors, leukemias (AML excluded), neuroblastomas, and bone cancers (65).

## 6.2 Results

### 6.2.1 Descriptive statistics

Tables 7 show descriptive characteristics of children with cancer and their families. The most common cancer forms among children were CNS tumors, leukemias, lymphomas, germ cell cancers and neuroblastomas. Around 45% of the cancers were diagnosed at a localized stage, and only 6% had metastases at time of diagnosis. Cancer was most common among children older than 15 (36%) and younger than 5 (29%). The annual number of childhood cancer cases has been quite stable (67).

### 6.2.2 Mortality differentials after childhood cancer

Mortality increases from the first to the second half year after diagnosis (from OR 1.24 CI 1.04-1.49 to OR 1.42 CI 1.18-1.70) and then declines gradually to 0.13 (CI 0.10-0.16). As expected, the estimates also showed that there has been a substantial improvement in survival over time (OR 2.55 CI 2.03-3.19 in 1974-79 and OR 0.60 CI 0.50-0.74 in 2000-07). The lowest mortality was seen for children diagnosed before age 15 (a 22% advantage compared

to the oldest children), those with no siblings (a 20% advantage), and those having mothers with a tertiary education (a 17% advantage). Parents’ marital status did not affect survival, and neither did mother’s age nor the parents’ earnings. Mortality was highest for leukemia, bone cancer, hepatic cancer, soft-tissue cancer, neuroblastoma and CNS tumors. As expected, the outcome after localized cancer was clearly superior to that of more advanced cancer (OR 3.59 CI 2.88-4.49 and 6.59 CI 5.09-8.53 for regional and metastatic cancers, respectively). When stage was included in the model, the effects of number of siblings and mother’s education remained virtually unchanged (OR 0.80 v 0.82 and 0.83 v 0.86, respectively).

Children				Parents			
Child categories	N <sup>b</sup>	% <sup>c</sup>	Deaths/pmo <sup>d</sup>	Parental categories	N	%	Deaths/pmo
<b>Cancer form</b>				<b>Mothers' age at birth<sup>i</sup></b>			
CNS tumor	1524	24.3 %	434/115541	< 20 years old <sup>j</sup>	830	13.2 %	226/69280
Any leukemia	1520	24.2 %	474/115675	20-24 years old	2757	43.9 %	775/221698
Acute lymphoblastic leukemia (ALL)	940	15.0 %	281/85342	25-29 years old	1965	31.3 %	467/157315
Acute myelogenous leukemia (AML)	210	3.3 %	124/12118	30-34 years old	579	9.2 %	118/44792
Leukemias, nos <sup>e</sup>	370	5.9 %	69/18215	> 34 years old	149	2.4 %	33/11198
Lymphomas	742	11.8 %	130/62166	<b>Mothers' education</b>			
Germinal cell cancer	509	8.1 %	61/47449	High school or below <sup>j</sup>	4614	73.5 %	1317/376515
Neuroblastoma	360	5.7 %	104/27822	College education or above	1666	26.5 %	302/127768
Bone cancer	352	5.6 %	151/23928	<b>Parents' marital status</b>			
Soft tissue cancer	256	4.1 %	74/20094	Married	4296	68.4 %	1120/352229
Malignant melanoma	246	3.9 %	28/25232	Not married <sup>j</sup>	1984	31.6 %	499/152054
Renal cancer <sup>f</sup>	219	3.5 %	28/20616	<b>Number of siblings</b>			
Endocrine cancer <sup>g</sup>	118	1.9 %	2/12198	0 <sup>j</sup>	991	15.8 %	222/81367
Hepatic cancer	86	1.4 %	33/5544	1	2514	40.0 %	647/203095
Other or unknown	348	5.5 %	100/28018	>=2	2775	44.2 %	750/219821
<b>Cancer stage at diagnosis</b>				<b>Parents' earnings<sup>k</sup></b>			
Local cancer	2822	44.9 %	630/243078	< \$10 000 <sup>f</sup>	992	15.8 %	381/75510
Regional cancer	670	10.7 %	202/48911	\$10 000-\$19 999	837	13.3 %	304/69029
Metastatic cancer	350	5.6 %	124/22827	\$20 000-\$39 999	1415	22.5 %	380/127093
Unknown <sup>h</sup>	2438	38.8 %	663/189467	\$40 000-\$59 999	1054	16.8 %	236/93447
<b>Age at diagnosis</b>				\$60 000-\$79 999	821	13.1 %	151/67797
Child 0-4 yrs	1791	28.5 %	448/145376	\$80 000-\$99 999	520	8.3 %	79/35778
Child 5-9 yrs	1165	18.6 %	321/92103	>= \$100 000	641	10.2 %	88/35629
Child 10-14 yrs	1088	17.3 %	307/85511				
Child >= 15 yrs	2236	35.6 %	543/181293				

<sup>a</sup>Only the time invariant characteristics are shown here. <sup>b</sup>Number of children or parents in the respective categories. <sup>c</sup>Percentage of children or parents in the respective categories. <sup>d</sup>Number of child deaths per person-month. <sup>e</sup>Not otherwise specified. <sup>f</sup>Primarily Wilm's tumor. <sup>g</sup>Primarily thyroid cancer. <sup>h</sup>Including CNS tumors and around 60% of the lymphomas for which no stage is recorded. <sup>i</sup>Age at birth of child later diagnosed with cancer. <sup>j</sup>Including also those with missing values. <sup>k</sup>Three-year average of parents' combined gross annual labor earning prior to diagnosis. Excluding parents with missing earnings gave a median combined earningsat diagnosis of \$47 000.

Table 7. Characteristics of children with cancer and their families at time of diagnosis is and deaths per person - month<sup>a</sup>

Results from stratified analyses are portrayed in Table 8. Stratifying the children by their mothers' educational level (high, i.e. above high school level, versus low, i.e. high school level or below) resulted in a statistically significant advantage of 22% of being an only child

for children with mothers with a low educational level. This was, however, not observed for children with mothers with a high education. A non-significant protective effect was also suggested for children with married mothers with a high education.

When stratifying the children by having sibling(s) versus being an only child, similar results were obtained. The mother's educational level was unimportant for children with cancer without siblings. Children with cancer with sibling(s) at time of diagnosis had, however, a 21% lower death probability if their mothers had a high education.

For children with cancers that require long-term treatments, having no siblings or better-educated mothers was associated with a statistically significant mortality advantage of around 18-19%. This relationship was present but not significant for those with other cancers. A mortality disadvantage of 42% was observed for the oldest children with chronic cancers, whereas an advantage was seen for other cancers in this age group.

	Mothers' educational level				Only child or siblings at diagnosis				Chronic or resolving disease			
	Low education <sup>b</sup>		High education <sup>c</sup>		No siblings <sup>d</sup>		Siblings <sup>e</sup>		Chronic <sup>f</sup>		Resolving <sup>g</sup>	
	OR <sup>h</sup>	95 % CI <sup>i</sup>	OR	95 % CI	OR	95 % CI	OR	95 % CI	OR <sup>d</sup>	95 % CI	OR	95 % CI
<b>Current calendar period</b>												
1974-1979	<b>2.26</b>	1.78-2.88	<b>2.34</b>	1.21-4.50	1.69	0.90-3.19	<b>2.42</b>	1.90-3.08	<b>2.02</b>	1.53-2.66	<b>3.26</b>	2.22-4.77
1980-1984	<b>1.56</b>	1.25-1.94	<b>2.22</b>	1.31-3.75	1.37	0.78-2.41	<b>1.70</b>	1.36-2.11	<b>1.47</b>	1.14-1.89	<b>2.29</b>	1.63-3.22
1985-1989	<b>1.24</b>	1.01-1.52	1.44	0.88-2.37	1.26	0.75-2.13	<b>1.27</b>	1.04-1.56	1.19	0.95-1.51	<b>1.51</b>	1.09-2.08
1990-1994	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	ref
1995-1999	0.83	0.66-1.03	1.21	0.76-1.91	1.02	0.60-1.70	0.87	0.70-1.07	0.92	0.72-1.16	0.84	0.60-1.19
2000-2007	<b>0.61</b>	0.49-0.77	0.95	0.60-1.52	0.61	0.36-1.03	<b>0.69</b>	0.56-0.86	<b>0.62</b>	0.48-0.79	0.84	0.60-1.17
<b>Age at diagnosis</b>												
Child 0-4 yrs	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	ref
Child 5-9 yrs	1.11	0.94-1.31	0.97	0.68-1.38	0.91	0.60-1.38	1.10	0.93-1.30	1.12	0.95-1.33	0.82	0.61-1.11
Child 10-14 yrs	1.09	0.91-1.31	1.21	0.84-1.74	1.11	0.66-1.87	1.11	0.94-1.32	1.13	0.94-1.37	0.98	0.74-1.28
Child >= 15 yrs	<b>1.19</b>	1.01-1.41	1.42	0.98-2.04	1.47	0.91-2.37	<b>1.22</b>	1.04-1.44	<b>1.42</b>	1.19-1.69	<b>0.68</b>	0.54-0.86
<b>Parents' marital status<sup>j</sup></b>												
Married	1.04	0.91-1.19	0.86	0.65-1.14	1.16	0.85-1.59	0.99	0.87-1.13	0.96	0.83-1.11	1.03	0.84-1.26
Not married <sup>k</sup>	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	ref
<b>Number of siblings<sup>l</sup></b>												
0 siblings	<b>0.78</b>	0.64-0.94	0.93	0.65-1.33	N/A	N/A	N/A	N/A	<b>0.81</b>	0.66-0.99	0.83	0.61-1.13
1 sibling	1.00	ref	1.00	ref	N/A	N/A	N/A	N/A	1.00	ref	1.00	ref
2 or more siblings	0.98	0.87-1.11	0.86	0.66-1.11	N/A	N/A	N/A	N/A	0.91	0.79-1.05	1.11	0.92-1.33
<b>Mothers' educational level<sup>j</sup></b>												
High school or less <sup>k</sup>	N/A	N/A	N/A	N/A	1.00	ref	1.00	ref	1.00	ref	1.00	ref
College and above	N/A	N/A	N/A	N/A	1.03	0.71-1.50	<b>0.79</b>	0.68-0.93	<b>0.82</b>	0.69-0.98	0.81	0.64-1.03

<sup>a</sup>All covariates were included in the respective models, cancer form exempted (chronic/resolving cancers, time since diagnosis, parents' earnings and mother age not shown). <sup>b</sup>Low education at or below high school level and includes missing. <sup>c</sup>High education refers to any education beyond high school level. <sup>d</sup>No siblings at time of diagnosis. <sup>e</sup>One or more siblings at time of diagnosis. <sup>f</sup>Includes CNS tumors, leukemias (AML excluded), neuroblastoma and bone cancers. <sup>g</sup>Includes the remaining cancer forms. <sup>h</sup>Odds Ratio. <sup>i</sup>Confidence interval. <sup>j</sup>Refers to the situation at time of diagnosis. <sup>k</sup>Including those with missing values.

Table 8. A child;s death probability stratified according to mother's educational level, number of siblings, and the expected chronicity of treatment and adverse long-term effects<sup>a</sup>

6.2.3 Summary of main findings

This large registry-based study shows that survival after childhood cancer depends on the family’s resources: Mortality was reduced by about 15-20% for children without siblings and

children whose mother has tertiary education. Stratified analyses suggest, however, that these effects are restricted to cancers that involve long-term treatment. The parents' earnings seem to have no effect above and beyond education, and there is also no or minor impact of parents' age or marital status.

### **6.3 Discussion**

Survival after childhood cancer in Norway depends on the family's resources. Similar studies, based on smaller data sets for other countries, have not shown such a clear relationship between parental education and survival from childhood cancer (14;17;18;68), but the results are in line with those from a recent, large Korean study (19). No earlier investigation has addressed the possible importance of siblings. The lack of effect of marital status accords well with the literature. Income effects have been reported by some authors (14;15), but comparison to studies from different countries is complicated due to dissimilar health care and welfare systems.

#### **6.3.1 Effects of being an only child at time of diagnosis**

Stage at time of diagnosis turned out to be relatively unimportant, and in principle two main channels remain for the various socio-demographic factors to operate through in affecting cancer survival: Treatment (the primary and follow-up treatment that is offered and the family's ability to make good use of it), and 'host factors' (the child's health at the time of diagnosis and later health problems unrelated to the malignancy). The presence of siblings may have the consequence that the parents can devote less time to assisting the sick child, which could have effect through both pathways (69). While it may well be the case that every child in Norway is offered the same cancer treatment, regardless of any personal initiatives from eager parents vis a vis the health personnel, mothers and fathers with additional family obligations might be less likely to comply with the recommended procedures for follow-up and less attentive to any unforeseen problems that they ideally should seek help for. When there are more children, there is also less to spend on each (70), given the family income, but the lack of effect of parents' earnings suggests that such economic factors are generally unimportant. It is also possible that having more siblings that compete for parents' time increases the chance of comorbidities before or after diagnosis, though there is little evidence for such effects in developed countries. The above arguments are particularly relevant for cancers that require long-term treatment and thus develop into rather chronic health conditions. It is thus reasonable that I see the sharpest effects of the number of siblings in these instances.

#### **6.3.2 Effects of parents' education**

The better survival among children with a better-educated mother, and thus also usually a better-educated father, may partly be the result of these parents having a higher level of health literacy, i.e. being better able to communicate and interact with health care personnel and navigate the health care system. Further, parents who have high education generally hold more flexible jobs that make it easier to spend time in hospitals with their children. All this may increase the chance of the child receiving adequate follow-up treatment. For similar reasons, children of better-educated parents may also have better health at diagnosis and

thus avoid later comorbidities. It thus appears reasonable that the observed effects are sharpest for the cancers that require long-term treatment.

### 6.3.3 The lack of effect of parents' earnings and marital status

It would not be unreasonable to expect an effect of the parents' income, even within a public health care setting. Couples with higher incomes might, for instance, find it easier to reduce their working hours to provide extra care for their child, with implications for the child's follow-up treatment as well as the chance of avoiding comorbidities. Children from richer families may also have better health at time of diagnosis. However, the lack of effect suggests that these mechanisms on the whole are of little importance in Norway. The effect of parents' marital status, net of the other variables included in the model, might be expected to affect the survival largely through time constraints: To the extent that a child with non-married parents lives with only one parent, there may be less time available to help and care for the child, in particular if the other parent is less involved and/or supportive. This might seem to be an important factor in light of the previously discussed sibling-effect. No effect is, however, observed of parents' marital status, and the reason may be that most of the non-married parents are cohabitants, or that also the non-resident parent contributes in case of a child's cancer illness.

### 6.3.4 Summary of discussion

This large, registry-based study suggests that parents' time constraints and various non-economic rewards from their education impact on childhood cancer survival. It may be that children with resourceful parents are healthier at the outset and/or more likely to avoid later health problems that are unrelated to the malignancy but that weaken the survival prospects. It may also be that children of well-informed and strongly involved parents actually may be *offered* better initial and/or subsequent treatment, even within a universal health care setting with limited private alternatives and supposedly highly standardized treatment protocols in place (18). Alternatively, such parents may be better able to *make use of* what is offered, for instance by adhering more closely to recommendations for out-patient follow-up care (71). The possibility of such differentials in offered and actual treatment should be addressed in future research.

## 7. Conclusions from Norway in a comparative perspective

### 7.1 Employment and earnings

Parents' employment is not adversely affected by a child's cancer in Norway. Earnings are reduced in certain instances, but the overall effects are minor. Generous welfare options and flexible labor markets typical for Nordic welfare states may account for this. In line with traditional caregiving responsibilities, mothers' reductions in earnings were most pronounced.

Few studies from other countries on parents' work force participation exist, and no reviews on parental employment and/or earnings after cancer or other chronic illness in children could be identified. The existing studies are relatively small and are likely to reflect policies and labor markets in particular geographic areas (10;28-35), and only a few utilizes a



comparison group (29-31). Overall, the results from Norway are more positive and suggest lesser declines in earnings than what has been reported previously (10;28;31;33;35), perhaps due to Norway's extensive welfare system. The negative impact on mothers' employment and earnings are, however, similar in Norway and other countries (33;34). In conclusion, existing knowledge indicate that there may be country-specific or regional differences with regard to work opportunities and also that the various features of children's cancer may influence family employment and earnings differentially.

### **7.2 Divorce**

Parents' divorce rates are not adversely affected by a child's cancer in general in Norway. Possible negative long term effects on the parents may be balanced by strengthening of parental bonds. An exception exists for couples with highly educated mothers, and further studies are warranted to understand the background for this increase in divorce risk.

The overall finding of no effect of cancer in a child on parents' divorce risk is in line with results from earlier studies (46-48). To my knowledge, earlier studies have not been large enough to account for differential effects of mothers' educational level, and this finding needs to be confirmed in future studies. Regional differences in health and welfare systems may also play a role, and studies from diverse settings are warranted.

### **7.3 Survival**

Mortality was reduced by about 15-20% for children with highly educated mothers and children without siblings. These effects were most pronounced for cancers predicted to encompass intense, long-lasting treatments resulting in chronic health problems. Neither parents' earnings nor their marital status affected children's survival.

There is limited knowledge about the importance of parents' socioeconomic resources from other countries, where effects also may be expected to be dissimilar because of inherent differences in the health care and welfare systems. A study from New Zealand showed that cancer survival was significantly reduced if a parent did not have a registered occupation or if a parent was unemployed, and an adverse effect of low education was also weakly indicated, while single parenthood had no impact (14). A relatively small, older study from the Netherlands concluded that parents' educational level only had a minor impact on childhood leukemia survival (17). Likewise, a Korean study from 2009 also found that parental resources played a minor role (15). The Norwegian findings are, however, in line with a more recent Korean study where a clear inverse relationship between childhood cancer mortality and parental socioeconomic position was seen (19). In developing countries, parental resources have been documented to have a significant beneficial effect (18;64), but more research from developed countries is clearly needed.

## **8. Current state of the knowledge and future directions**

Empirical findings from Norway show that cancer in a child adversely affects women's earnings, but that it does not, in general increase divorce rates. Although research shows that parenting a child diagnosed with cancer is burdensome, it does not appear to impact strongly on parental incomes or divorce rates in welfare states. Findings may be different in

countries with less extensive welfare systems, be it health care or compensatory benefits to parents in case of illness of children. More research is thus needed to establish how valid these results are for persons in different cultures and societies, as there is conflicting evidence on how cancer in a child affects family life in the published literature.

Further, childhood cancer mortality in Norway varies with parents' education and family size. Low education, especially among mothers, and a larger family size are both associated with increased mortality. There is much evidence from developing countries on that mortality is dependent upon parental socioeconomic status. I find that this is the case also in modern welfare states, and suggest that the situation will be even worse in less extensive welfare states, like for instance the US. Given the widely accepted idea that the health care system should reach well out to everyone and the suspicion that this perhaps is not quite the case after all, a careful analysis of possible treatment differentials utilizing longitudinal directly measured treatment data should be welcome in future studies. While a key concern would be that everyone is offered the same treatment, attention should also be given to the degree of compliance, as it might be argued that this is not solely an individual responsibility but resides within the domain of public policy. Should no such differences in treatment be revealed in future studies, the observed effects must be due to differences in general health (behavior), which would indicate the need for health policy initiatives of a different type. It is obviously challenging to generalize to other settings, and in particular with respect to the effects of economic resources. They could, presumably, be expected to be even more pronounced in most other countries with less generous health and welfare systems.

To summarize, cross-national research on treatment decisions, health care delivery, and utilization across social groups to further comprehend discrepancies in outcomes for both families and children after childhood cancer appears warranted. Larger samples sizes and more studies utilizing control groups are also clearly needed. Lastly, longitudinal designs to assess family dynamics and consequences in a longer-term perspective would be welcome. The great advances in childhood cancer survival over the last decades are positive, but may also have some negative implications that are beginning to surface and needs to be considered.

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