

# Socioeconomic consequences of parenting a child with cancer for fathers and mothers in Sweden: A population-based difference-in-difference study

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## Abstract

Parents are the primary source of support for children with cancer. To inform clinical practice and health policies, the socioeconomic consequences of childhood cancer for fathers and mothers in Sweden were investigated. A total of 3865 mothers and 3865 fathers of 3865 children diagnosed with cancer in Sweden when 0 to 18 years were followed for 5 years before and 10 years after diagnosis. Socioeconomic consequences of the cancer diagnosis on earnings and employment, and mental health (number of inpatient diagnoses), were investigated exploiting variation in timing of cancer diagnosis. Data were obtained from the Swedish Childhood Cancer Registry, Intergenerational Registry and Inpatient Registry. Childhood cancer has a negative short-term effect on fathers' and mothers' earnings; a negative long-term effect on fathers' earnings; a positive long-term effect on mothers' earnings; negative short- and long-term effects on fathers' and mothers' employment; and no effect on the number of inpatient diagnosis of mental and behavioral disorders for fathers or mothers. Taken together, findings show that in Sweden childhood cancer has negative effects on parents' employment, a more negative impact on fathers' than mothers' earnings and no effect on inpatient diagnosis of mental and behavioral disorders. Future research should explore mechanisms possibly explaining, for example, mental health, social support and priorities regarding work and private life potentially resulting in changes from full-time to part-time work or vice versa. The novel findings should change clinical practice and help inform health policies for parents of children with cancer in Sweden and countries with a similar health and welfare system.

## KEYWORDS

childhood cancer, parents, socioeconomic consequences

## 1 | INTRODUCTION

**Abbreviations:** €, Euro; EUR, Euro; ICD, International Classification of Diseases; PTSD, posttraumatic stress disorder; PTSS, symptoms of posttraumatic stress; SEK, Swedish krona.

Every year, approximately 215 000 children 0-14 years and 85 000 15-19 years are diagnosed with cancer worldwide.<sup>1</sup> Treatment has

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seen significant progress; however, cancer remains a leading cause of death for children around the world.<sup>2</sup> Most often parents are the primary source of support for children with cancer.

Parents of children with cancer report a higher prevalence of anxiety, depression and posttraumatic stress disorder (PTSD) than population controls and a subgroup report symptoms of posttraumatic stress (PTSS) after the end of the child's treatment.<sup>3-5</sup> Twenty to 40% report PTSS at least 5 years after the diagnosis and/or 2 years after the end of treatment.<sup>4</sup> Distress declines over time with a greater impact on mothers than fathers.<sup>3-5</sup> However, the great majority of the literature is based on cross-sectional research hampering the understanding of the development of distress and fathers are usually underrepresented in study samples.<sup>3</sup> With a longitudinal design, we have shown that fathers and mothers of children diagnosed with cancer in Sweden report different needs and distress trajectories, highlighting a need to understand fathers' and mothers' unique responses to caregiving.<sup>6-8</sup>

Both during and after treatment, parents experience work disruptions, for example, because of accompanying the child to the hospital, providing medications, managing equipment and caring for the child's health problems. However, there is only a small body of literature examining the socioeconomic consequences of parenting a child with cancer. A recent systematic review of 35 articles (29 studies) investigated the impact of childhood cancer on parents' socioeconomic situation.<sup>9</sup> Thirteen (37%) were from Europe, 16 (46%) from North America/Australia and 6 (17%) from Asia/Africa; 8 (23%) included comparison parents; the majority (85%) included different cancer types. Large variations in study design, sample size, treatment phase, age at diagnosis and follow-up time after diagnosis were observed. Twenty-six (74%) reported on employment, 20 (57%) on income, 21 (60%) on financial situation and 20 (57%) addressed financial assistance.<sup>9</sup> Findings showed a high prevalence of disruptions in parental employment such as job quitting or job loss, particularly among mothers. Adverse socioeconomic consequences were most pronounced shortly after diagnosis, however, persisted into early survivorship for certain groups of parents. Only one study, from Indonesia, showed higher work loss among fathers than mothers.<sup>10</sup> Two studies, one from Australia<sup>11</sup> and one from the United Kingdom<sup>12</sup> showed that mothers were less likely to reduce work hours compared to fathers. Most work disruptions occurred shortly after diagnosis and attenuated within 1 year.

Some research has been done in Norway and Sweden where conditions on the labor market and the welfare system are relatively similar. A study from Norway investigating the impact of childhood cancer on parents' work opportunities concluded that the overall effects were minor.<sup>13</sup> Reductions in earnings were most pronounced for mothers. An investigation in Sweden of the short- and long-term effects of childhood cancer on fathers' and mothers' income and employment status demonstrated that parents' income decreased after the child's diagnosis.<sup>14</sup> The effect was most pronounced for mothers, whose income was reduced for 6 years, whereas fathers' income was similar to that of control fathers' 3 years after diagnosis.<sup>14</sup> Our longitudinal research on socioeconomic consequences of childhood cancer for fathers and mothers in Sweden show that 1 year after the end of treatment, the proportion of working fathers was lower compared to 1 week after

## What's new?

Parents of children with cancer experience work disruptions both during and after treatment. However, few studies have examined the socioeconomic consequences for these parents. This study shows that, in Sweden, childhood cancer has negative short-term effects on fathers' and mothers' earnings, with negative effects for fathers but positive effects for mothers in the long term. Negative effects were found on fathers' and mothers' employment, with stronger effects for mothers in the short term. The novel findings could help inform health policies for parents of children with cancer in Sweden and other countries with a similarly supportive health and welfare system.

diagnosis, while there was no difference for mothers.<sup>15</sup> Further, findings indicated delayed negative consequences regarding fathers' sick leave.<sup>16</sup> Thus, in contrast to other research conducted in Norway<sup>13</sup> and Sweden<sup>14</sup> our previous research<sup>15,16</sup> indicates that the work situation for fathers of children diagnosed with cancer gets worse over time.

In order to fill a gap in the literature, our study investigated the socioeconomic consequences of childhood cancer for fathers and mothers. The objectives were to investigate the annual inflation-adjusted earnings and employment rate for fathers and mothers and the number of fathers and mothers receiving an inpatient diagnosis in the area of behavioral, emotional and/or mental disorders.

## 2 | MATERIALS AND METHODS

### 2.1 | Design

A difference-in-difference design was used to investigate the objectives.<sup>17</sup> The strategy relies on that, with few exceptions, childhood cancer is an exogenous event.<sup>18</sup> We follow fathers and mothers of a child (0-18 years), who, at some point of time, receive a cancer diagnosis between 1995 and 2006 in Sweden for 5 years before to 10 years after the diagnosis. Effects are estimated exploiting the variation in timing of the diagnosis. The estimating equation use two-way fixed effects (individual and calendar time) where the effects are estimated using relative time in years from diagnosis:

$$Y_{it} = \sum_{T=-4}^{\geq 9} \gamma_T D_{it}^T + \delta_i + \lambda_t + X_{it} + \varepsilon_{it}$$

where  $Y$  is the measured outcome.  $D$  are dummy variables on relative time in years from diagnosis ( $T = -4, \dots, \geq 9$ ), where  $\geq 9$  groups the ninth and tenth year to avoid multicollinearity and secure that there is always a control group. Four years before the diagnosis were included to test the assumption of no effects before treatment.  $\delta$  is individual fixed effects and  $\lambda$  is calendar time fixed effects ( $t = 1990, \dots, 2016$ ).  $X$  is a

vector of control variables. The year before diagnosis is omitted in the regression. Standard errors are clustered on individual level.

The empirical strategy is chosen to mimic a randomized controlled experiment. The randomization in an experiment creates balance in characteristics between the treatment and control group, ensuring that causal effects can be estimated. As randomization is not possible using registry data, a common strategy in observational studies is to control for observable characteristics. Controlling for observable characteristics does, however, not solve the problem with imbalance in *unobserved* characteristics, which may bias the estimates. In the context of our study, we want to ensure that we use a population where the pretreatment trends are parallel in both observable and unobservable characteristics, where “treatment” refers to the diagnosis of the child.

The regression model used aims to solve the problem with unobservable characteristics. The control group for parents whose child is diagnosed with cancer consists of the parents whose child is *not yet* diagnosed. Thus, any unobserved characteristics common for parents whose child is eventually diagnosed with cancer is effectively controlled for as well as characteristics constant for an individual.

## 2.2 | Data

Data on children's (0-18 years) year of birth, gender, diagnosis and date for diagnosis was retrieved from the Swedish Childhood Cancer Registry. In all, 4590 children were diagnosed with cancer between 1995 and 2006 in Sweden. Eighteen children were excluded because they were not the first child in the family diagnosed with cancer. Due to missing data for one or both parents, 705 children were excluded. Two children were excluded due to the parents being extreme outliers concerning earnings for a single year (more than 10 times the mean earnings in the panel). Data for 3865 fathers and 3865 mothers to 3865 children diagnosed with cancer were analyzed. The five most common diagnoses (International Classification of Diseases [ICD] 10) were: Acute Lymphoblastic Leukemia, C910 (18.9%); malignant tumor in the cerebellum, C716 (5.2%); unspecified localization of malignant tumor in the brain, C719 (5.0%); Hodgkin's lymphoma (classic) with nodular sclerosis, C811 (3.5%); and malignant tumor of kidney with the exception of the renal pelvis, C640 (3.3%). The mean age of the children when diagnosed with cancer was 9.0 (SD: 6.0). During the follow-up period, 739 children died.

Data on parents' year of birth, gender, civil status, education level, earnings, employment status and number of children between 1990 and 2016 were retrieved from Statistics Sweden. Using the Inter-generational Registry, Statistics Sweden linked children to parents. Data on parents' inpatient diagnoses were retrieved from the Inpatient Registry, the National Board of Health and Welfare. The data identified by Statistics Sweden and the National Board of Health and Welfare were delivered with anonymized identification numbers which we used to link the registers. Stata/MP 16.1 (StataCorp. 2019. *Stata Statistical Software: Release 16*. College Station, TX: StataCorp LLC.) was used for data management and statistical analyses.

The following covariates were used in the regressions (data correspond to the year of the child's diagnosis): college education (31.2%

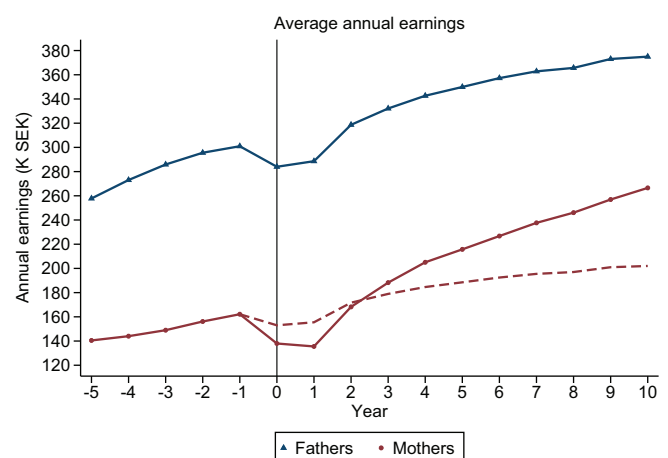
fathers, 34.6% mothers), number of children at home (mean: 1.9 for fathers, SD: 1.2; mean: 2.2 for mothers, SD: 1.0) and marital status (61.9% of fathers and 60.7% of mothers married). Mean age for fathers at the year of diagnosis was 41.2 (SD: 7.8) and for mothers was 38.5 (SD: 7.3).

Earnings was investigated in terms of annual inflation-adjusted earnings (base year 2018) and employment status in November each year (employed or not employed). One Swedish krona (SEK) was worth about 0.1 Euro (EUR) January 1, 2018. Inpatient diagnoses in the following ICD10 groups were investigated: Mental and behavioral disorders due to psychoactive substance use (F01-19); mood affective disorders (F30-39); anxiety, dissociative, stress-related, somatoform and other nonpsychotic mental disorders (F40-48); behavioral syndromes associated with physiological disturbances and physical factors (F50-59); disorders of adult personality and behavior (F60-69); behavioral and emotional disorders with onset usually occurring in childhood and adolescence (F90-98); unspecified mental disorder (F99) and for the years 1990-1996 the corresponding ICD9 codes. A dummy variable which takes the value 1 if the individual has received such an inpatient diagnosis during the respective year was constructed.

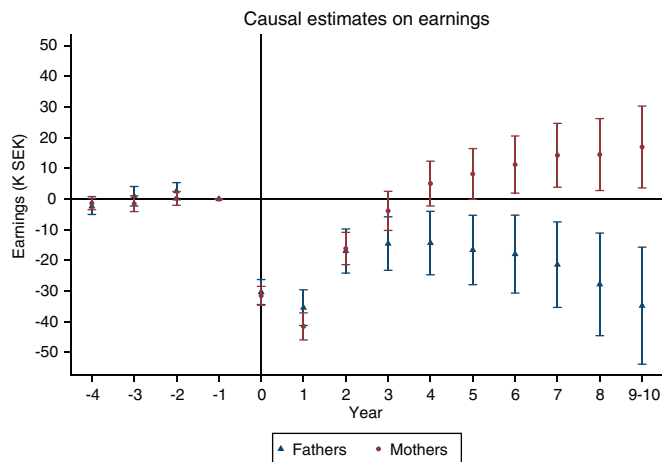
The research was approved by the independent regional review body Etikprövningsnämnden in Uppsala (Dnr 2018-169 B and 2018-169-1 B) and the corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication. Informed consent was not collected given no data beyond that routinely collected in the registries are used and there is no direct contact with study participants.<sup>19</sup>

## 2.3 | Role of the funding sources

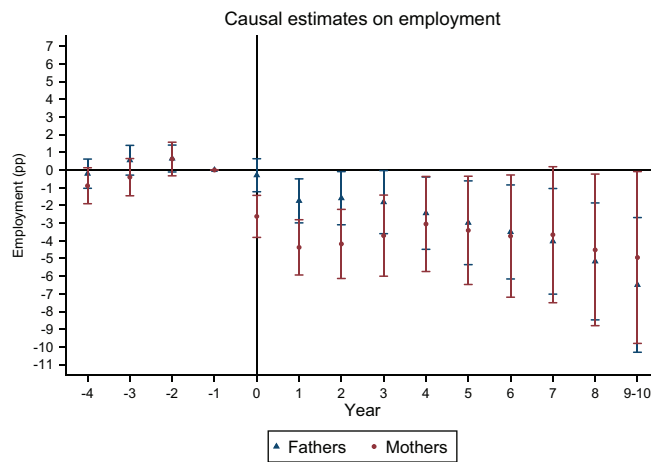
The funding sources have not been involved in the study design, data collection and analysis, decision to publish or preparation of the article. The funding sources do not bear any responsibility for the analyses or interpretations presented here.



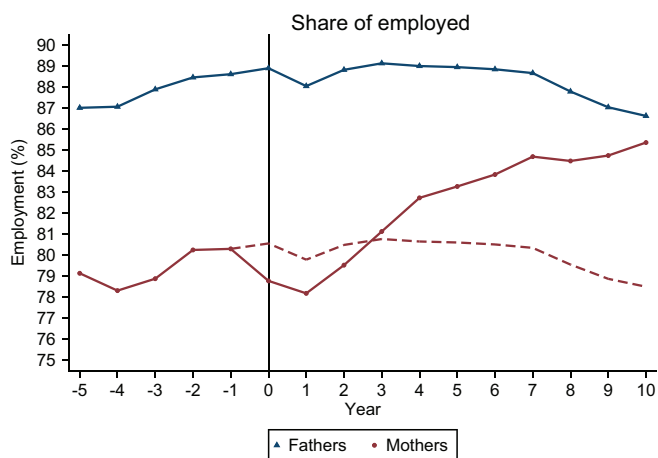
**FIGURE 1** Fathers' and mothers' average annual earnings (SEK, inflation-adjusted, base = 2018). Year 0 is the year of the child's cancer diagnosis. The dashed line illustrates mothers' trajectory if it had followed the fathers' in percentual change. 1 SEK = 0.10 €



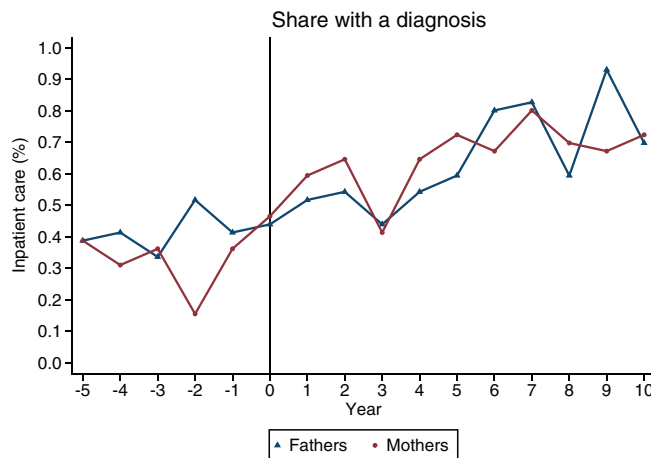
**FIGURE 2** Causal estimates (95% CI) of child cancer diagnosis (Year 0) on earnings. 1 SEK = 0.10 €



**FIGURE 4** Causal estimates (95% CI) of child cancer diagnosis (Year 0) on employment



**FIGURE 3** Share of employed fathers and mothers. Year 0 is the year of the child's cancer diagnosis. The dashed line illustrates mothers' trajectory if it had followed the fathers' in percentual change



**FIGURE 5** Share of fathers and mothers with an F01-19, F30-69 or F90-99 diagnoses. Year 0 is the year of the child's cancer diagnosis

### 3 | RESULTS

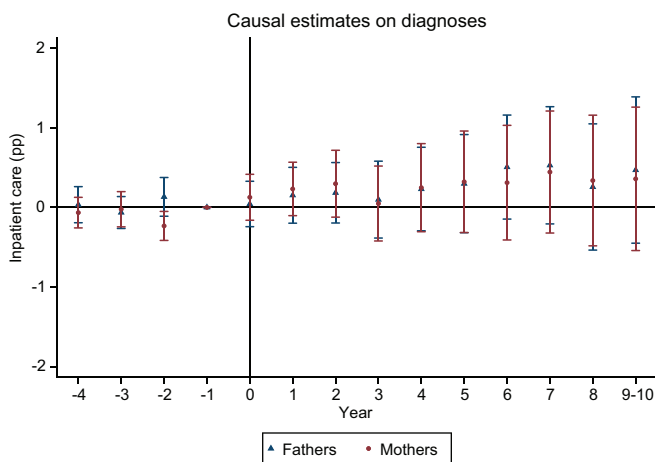
#### 3.1 | Earnings

Fathers' and mothers' average annual earnings are shown in Figure 1. Before the child's diagnosis, both fathers' and mothers' earnings increase with 3% to 4% per year. The year of diagnosis fathers' earnings decrease by 7% and mothers by 15%. Two years after the diagnosis, mothers' earnings increase. The dashed line illustrates mothers' trajectory if it had followed the fathers'. Figure 2 presents causal estimates using the equation presented above. In the year of diagnosis, fathers' earnings decrease by 30 000 SEK (about 3000 EUR) and in the year after diagnosis by 35 000 SEK (about 3500 EUR). In the year of diagnosis, mothers' earnings decrease by 31 000 SEK (about 3100 EUR) and in the year after by 41 000 SEK (about 4100 EUR). Fathers have a negative whereas mothers have a positive long-term earning trajectory.

#### 3.2 | Employment

Fathers' and mothers' employment rate trajectories are shown in Figure 3. Before the child's diagnosis, both fathers' and mothers' trajectory are positive. The year of diagnosis fathers' trajectory remains positive, but their employment rate decreases by 1% the year after diagnosis. Fathers' trajectory is negative for the remaining period. Mothers' employment rate decreases the year of diagnosis by about 1.5% and by 0.5% the year after diagnosis. Mothers' employment rate trajectory is positive 2 years after diagnosis and remains positive for the rest of the period. The dashed line illustrates mothers' employment rate trajectory if it had followed the fathers'.

Figure 4 presents causal estimates using the equation presented above. There is no effect on fathers' employment the year of diagnosis, but a decrease by 1% 1 year after diagnosis. There is a decrease of 2.5% on mothers' employment in the year of diagnosis, and a decrease of 4.5% the following year. The long-term effects are negative for fathers and mothers.



**FIGURE 6** Causal estimates (95% CI) of child cancer diagnosis (Year 0) on F01-19, F30-69 or F90-99 diagnoses

### 3.3 | Inpatient diagnoses

The percentage of fathers and mothers who received at least one inpatient diagnosis from the investigated ICD10 categories (and corresponding ICD9) are shown in Figure 5. The share of fathers receiving a diagnosis increases by 0.05% the year of the child's cancer diagnosis and continue to increase the following 2 years. The share of mothers receiving a diagnosis increases with about 0.1% the year of the diagnosis and continue to increase the following 2 years. Each year during the 16-year period, less than 1% of fathers and mothers receive a diagnosis. Figure 6 presents causal estimates using the equation presented above. There is no effect on the rate of diagnoses for neither fathers nor mothers.

## 4 | DISCUSSION

### 4.1 | Summary of findings and potential explanations

This is the very first study to investigate the socioeconomic consequences of childhood cancer for fathers and mothers using an empirical strategy that allows for casual interpretation. The richness of the Swedish population-wide registry data provides a unique possibility to contribute to the literature.

The findings show that in Sweden childhood cancer has negative short-term effects on fathers' and mothers' earnings. The long-term effects on earnings are negative for fathers, and positive for mothers. Negative short-term effects on employment were found for fathers and strong negative short-term effects for mothers. The long-term effects on employment are negative for both fathers and mothers. Findings do not show an effect of childhood cancer on the number of inpatient diagnosis in the area of mental and behavioral disorders.

The findings should be understood in light of the social security system in Sweden that guarantees generous benefit levels for its residents when absent from paid work due to own ill health or care of a sick child. Certain welfare state policies including job security legislations, for

example, the Employment Protection Act enables individuals to be absent from work without having to give up their employment thus facilitating return to work after periods of absence. The generalizability of findings from the present study must therefore be limited to Sweden and countries with a similar health and welfare system.

Despite the Swedish equality model, parental responsibilities are unequally distributed, with mothers more likely to assume the primary caregiving role for a sick child.<sup>20</sup> The role includes spending time in hospital, administering medication and providing care for health difficulties.<sup>21</sup> This may explain the differences in earnings between mothers and fathers during the year of diagnosis, with mothers' earnings more negatively affected. Evidence related to gender differences in earnings is very limited with two studies showing similar effects for fathers and mothers<sup>13,15</sup> and one study reporting higher income loss in mothers<sup>22</sup> or fathers.<sup>12</sup> Interestingly, however, the longer term findings showing a positive earning trajectory for mothers differ from general findings from Sweden as well as Germany and the United States showing that absence from work to care for a sick child has a negative impact on mothers' future career trajectories.<sup>23</sup> One potential explanation for gender differences in earnings is that assuming the role of primary caregiver of a child with cancer may also result in increased support from family, friends and health-care staff which may function as a protective factor in the long-term. For example, mothers of children with cancer have been found to be more likely to use coping strategies such as actively seeking social support and information.<sup>24</sup> Further, some mothers of children with cancer report post-traumatic growth, including an increased appreciation of life, personal strength and new opportunities that may account for gender differences in earnings.<sup>25</sup> The positive earning trajectory for mothers could also be explained by more mothers working full-time after the child's cancer diagnosis than before the diagnosis. However, unfortunately the data available in Swedish registries do not allow this kind of investigation.

A further explanation for gender differences in earnings may be that mothers learn to cope with challenges associated with diagnosis and treatment given they are to a greater extent exposed to these.<sup>26</sup> Conversely, fathers are more likely to take responsibility for maintaining the household, looking after siblings and meeting employment responsibilities.<sup>27</sup> Fathers report being socially isolated and alienated from some aspects of the cancer experience.<sup>28</sup> Further, men are more likely than woman to use avoidance coping strategies, have an increased risk of misusing alcohol and substances and are less likely to seek help for mental health difficulties.<sup>29-31</sup> This is of particular importance given emotional avoidance and low levels of emotional expression are associated with depression severity and symptoms of PTSD.<sup>32</sup> If fathers are more likely to experience mental health difficulties, these are associated with lost income which may explain the more blunted earning trajectory for fathers. Indeed, our previous research showed that more fathers of children with cancer were on sick leave at 5 years than at 1 year after the end of cancer treatment/or a child's death.<sup>16</sup> Although this increase was not statistically significant, it indicates that fathers are more vulnerable to late consequences (eg, impacts on career, salary and pension development) as captured in the present study. Notably, we have previously observed a delayed effect in a subgroup of fathers of children with cancer in the development of PTSD.<sup>7</sup>

Further potential explanations for fathers having a negative whereas mothers a positive long-term earning trajectory, may pertain to symptoms of burnout that affect long-term work ability.<sup>15</sup> Fathers of children with cancer report that they find it difficult to continue to meet workplace demands, a decrease in workplace productivity, increased stress and exhaustion juggling both workplace and family responsibilities, and a lack of flexibility from employers to help manage these responsibilities.<sup>27</sup> Potentially, these impacts in the workplace result in both a short and longer-term negative impact on earning trajectories. Indeed, research suggests more generally, men who take extended parental leave beyond the standard or assume more caregiving responsibilities receive more negative evaluations of competence and experience more workplace harassment and mistreatment.<sup>33</sup> However, research is required in the Swedish context to examine whether fathers of children with cancer experience negative treatment in the workplace. Lastly, it can be speculated that parents reevaluate their priorities and private life/work balance resulting in a larger share of employed mothers chose to work full-time after the child's diagnosis, while a larger share of employed fathers chose to work part-time.

## 4.2 | Limitations

There is a negative link between prolonged stress and negative physical health outcomes in parents of children with chronic health conditions (eg, cardiovascular, gastrointestinal and immune).<sup>34,35</sup> However, within our study, only health outcomes relating to inpatient diagnoses in the area of mental and behavioral disorders were examined. While this decision was justified on the basis of research consistently indicating increased symptoms related to psychological distress in the population, future studies should seek to include diagnoses of physical health conditions commonly associated with increased stress and psychological distress. Future research should also seek to include data from visits to outpatient care for mental health reasons. This kind of data would probably give a more accurate picture of the mental health consequences of childhood cancer for fathers and mothers. Unfortunately, Swedish registries do not include outpatient mental health care data. Prescription data could also be used to complement the information on the mental health consequences of parenting a child diagnosed with cancer. Another important limitation of the data is that it does not include information on full-time vs part-time employment. This kind of information could have helped interpreting the positive earning trajectory for mothers and negative earning trajectory for fathers. Importantly, future research should attempt to explore which mechanisms may explain the different earning trajectories for fathers and mothers, for example, via self-reports of mental health and social support or prescribed drugs related to mental health and changed priorities regarding work and private life.

## 5 | CONCLUSION

Taken together, the findings show that in Sweden childhood cancer has negative effects on parents' employment, a more negative impact

on fathers' than mothers' earnings and no effect on inpatient diagnosis in the area of mental and behavioral disorders. The research can change clinical practice and help inform health policies for parents of children struck by cancer in Sweden and countries with a similar health and welfare system.

## Implications

Sweden guarantees a certain economic basic security for its citizens, including, for example, sickness benefit and parental benefit for the care of children. However, these compensations cover only part of the income loss and are temporary. To the best of our knowledge, there has been little empirical investigation regarding how government support programs compensate the consequences of parenting a child in active cancer treatment and into survivorship or after bereavement. The findings of our study can help inform health policies for parents of children struck by cancer in Sweden and countries with similar health and welfare systems. Policy guidelines with a greater focus on fathers, and the positive side of being close to a sick child. For example, reducing parental work hours to facilitate spending more time with their sick child and family, and the provision of psychosocial support throughout the disease trajectory.

## ACKNOWLEDGMENT

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## CONFLICT OF INTEREST

The authors declared no potential conflicts of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. Data derives from public Swedish records and can be accessed under national law, Public Access to Information and Secrecy Act (SFS 2009:400).

## ETHICS STATEMENT

The study was approved by the Regional Ethics Board in Uppsala (2018-169 B and 2018-169-1 B). Informed consent was not collected given no data beyond that routinely collected in the registries is used and there is no direct contact with study participants.<sup>19</sup>

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