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The impact of childhood cancer on parents' socio-economic situation - a systematic review

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Abstract

Objective: Taking care of children diagnosed with cancer may have considerable consequences on parents' socio-economic situation. Our systematic review aimed to evaluate and synthesize the evidence on the impact of childhood cancer on parents' socio-economic situation.

Methods: Systematic literature searches for articles published between January 2000 and January 2019 were performed in PubMed, Scopus, and PsycINFO. Findings of eligible articles were narratively synthesized and quality appraised.

Results: Our systematic review included 35 eligible articles. Childhood cancer had a substantial impact on parents' socio-economic situation across all studies. This impact varied largely by geographical region. We observed a high prevalence of disruptions in parental employment such as job quitting or job loss, particularly among mothers. The associated income losses further contributed to families' perceived financial burden in addition to increased cancer-related expenses. Adverse socio-economic consequences were most pronounced shortly after diagnosis, however, persisted into early survivorship for certain groups of parents. We identified families of children diagnosed with haematological cancers, younger age at diagnosis, and lower parental socio-economic position to be at particular risk for adverse socio-economic consequences.

Conclusions: Following the child's cancer diagnosis, parents experience a broad range of adverse socio-economic consequences. Further effort is needed to

systematically implement an assessment of financial hardship in paediatric oncology together with appropriate support services along the cancer trajectory.

Background

Childhood cancer is a devastating experience for the whole family system with few life events being as far outside a family's routine¹. This is particularly challenging for the parents who are confronted with the potential fatality of the disease and conflicting caregiving, emotional, and practical demands². The child's acute treatment requires frequent hospitalizations, invasive procedures, and depending on the cancer type, a combination of surgery, chemotherapy, and radiotherapy³. Parents are often involved by providing and monitoring treatment or managing treatment-related symptoms, particularly in the outpatient setting^{4,5}. Due to the increased risk for late effects after treatment⁶, long-term follow-up care is recommended for childhood cancer survivors⁷. Even years after treatment, many parents remain actively involved in the child's medical care^{8,9}.

The management of the child's disease alongside everyday responsibilities is highly challenging for the parents. Previous research indicates that parents of children with cancer experience substantial work and income disruptions during the child's treatment¹⁰. Moreover, many parents are confronted with medical and non-medical expenditures¹¹⁻¹⁶. Direct costs of childhood cancer have been evaluated in two reviews concluding that substantial financial toxicity may occur in paediatric oncology^{10,17}. However, a comprehensive assessment of parents' socio-economic situation also including aspects related to financial assistance is currently lacking. It further remains unclear whether the socio-economic situation of mothers and fathers is differentially affected due to different parenting roles and tasks¹⁸. Moreover, evidence on temporal

patterns after the diagnosis and socio-demographic or cancer-related determinants of adverse socio-economic consequences is lacking. There may be groups of parents that particularly struggle with their professional life during treatment or to re-establish and compensate work-related disruptions after the child's cure. Identifying parents who are at particular risk of adverse socio-economic consequences is crucial to provide targeted supportive services along the cancer trajectory to reduce these inequities from an individual and societal perspective.

The objective of this systematic review was to critically evaluate and synthesize the evidence on the impact of childhood cancer on parents' socio-economic situation.

Specifically, we aimed to address the following research questions:

- i. What are the consequences of childhood cancer for the parents' socio-economic situation regarding *employment, income, financial situation, and financial assistance*?
- ii. Are there differences in the consequences between mothers and fathers of children with cancer?
- iii. Are there temporal patterns in the consequences after the child's cancer diagnosis?
- iv. What are the main socio-demographic and cancer-related characteristics associated with adverse socio-economic consequences?

Methods

Our systematic review complies with the PRISMA statement regarding the reporting of systematic reviews and meta-analyses¹⁹. A review protocol was registered in PROSPERO (number: CRD42018096121).

Search strategy

Our literature search was conducted on 23 March 2018 and included articles published in peer-reviewed journals after 1 January 2000 that were indexed in the databases PubMed, Scopus, and PsycINFO. This time frame was chosen to account for improvements in cancer treatment protocols over time. The search was updated on 11 January 2019. Our search included four individual blocks with search terms referring to socio-economic situation, parents, childhood, and cancer (Supplementary figure 1). In PubMed we additionally performed searches using medical subject headings (MeSH). We hand-searched reference lists of included studies to identify other relevant articles.

Study selection

To select eligible articles, we hierarchically applied the following inclusion criteria: sample size >20, quantitative methodology, parents of children with cancer as main study population, child's age at cancer diagnosis <20 years, parents' socio-economic situation as primary outcome. Editorials, commentaries, conference abstracts, and original articles without English full-text were excluded. We excluded studies solely focusing on costs or expenses as the respective literature has been previously reviewed^{10,17}. Two reviewers (LM, KR) independently assessed eligibility by first screening titles and abstracts followed by the full-texts of remaining studies. Discrepancies between reviewers were resolved by consensus or consulting a third reviewer (FE).

Data extraction

We extracted first author, publication year, country, study design, sample size(s), and response rate(s). For parents of children with cancer and comparison parents (if applicable) we extracted data on sex, age at study, and other available socio-demographic characteristics. Socio-economic consequences of childhood cancer regarding *employment*, *income*, *financial situation* (financial burden, material hardship), and *financial assistance* (governmental, non-governmental) were extracted. We further extracted the following cancer-related characteristics of the child: diagnosis, treatment, diagnostic period, age at diagnosis, follow-up period, and treatment phase (categorized into *survivors* [completed treatment], *patients* [active treatment], *deceased* [death due to cancer]).

Quality assessment

Study quality was independently assessed by two reviewers (LM, FE) using the Newcastle-Ottawa Quality Assessment Scale (NOS)²⁰ as recently used in a review addressing childhood cancer survivors²¹ (Supplementary table 1). NOS evaluates the quality of non-randomised studies with a star rating system (maximum 9 stars) based on three criteria: *selection* (4 items, max. 1 star/item), *comparability* (1 item, max. 2 stars), and *outcome* (3 items, max. 1 star/item). The criterion *selection* refers to the representativeness of the study population(s) (parents of children with cancer, comparison parents) and the exposure ascertainment (childhood cancer diagnosis). According to the NOS' manual²⁰, we defined education as the most important factor to adjust for in a comparison between study populations for the criterion *comparability*. An additional star was appointed to studies controlling for sex, age, or year of outcome assessment. The criterion *outcome* refers to type of outcome assessment, length of follow-up, and adequacy of follow-up. A follow-up rate of >70% was considered unlikely to introduce bias²².

Data synthesis

Findings related to parents' socio-economic situation were narratively synthesized. A priori, we decided not to follow a meta-analytic approach due to expected heterogeneity related to study design, study period, and outcome definition between studies and differences in socio-economic context across geographical regions²³. The narrative synthesis focused on the socio-economic consequences regarding *employment, income, financial situation, and financial assistance*, differences between mothers and fathers, temporal patterns after diagnosis, and characteristics associated with adverse socio-economic consequences. We further evaluated how the quality of included studies may have affected our synthesis.

Accepted Article

Results

Literature search and study characteristics

We identified 3359 articles through literature searches and included 35 articles²⁴⁻⁵⁸, reporting on 29 individual studies (Figure 1). Thirteen (37%) studies were conducted in Europe, 16 (46%) in North America/Australia, and 6 (17%) in Asia/Africa (Table 1). Eight (23%) studies included comparison parents. The majority of studies (85%) included different cancer types. We observed large variations in study design, sample size, treatment phase, age at diagnosis, and follow-up time after diagnosis. Twenty-six (74%) studies reported on employment, 20 (57%) on income, 21 (60%) on financial situation, and 20 (57%) addressed financial assistance (Table 2).

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Employment

A high prevalence of disruptions in parental employment including job quitting, job loss, unemployment, changes in work hours or extended leaves was reported. Most studies found more profound work disruptions among mothers compared to fathers. Twelve studies reported that mothers were more likely to quit work or to be unemployed after the child's diagnosis^{24,25,28,30,31,35-38,44,46,49}. Only one study from Indonesia showed higher work loss among fathers⁵⁵. However, two studies from Australia⁴⁹ and the UK³⁶ observed that mothers were less likely to reduce work hours compared to fathers. Most work disruptions occurred shortly after diagnosis and attenuated within one year^{24,29,31,50}. However, studies from Sweden²⁸ and Switzerland³⁵ identified higher unemployment among mothers even many years after diagnosis. Diagnosis of haematological cancer^{35,38,45}, younger age of child at diagnosis^{38,43}, lower maternal education^{28,35}, and having more children^{28,31,35} were identified as the main characteristics associated with employment disruptions.

Income

The majority of studies on income reported substantial income loss after the child's diagnosis^{26,28,31,36,38-40,44,47,49-55,58}. The proportion of parents reporting income loss and the extent of these losses varied largely. Two studies from Norway²⁵ and Finland²⁴ found no effects on income and one study from New Zealand⁵² found more parents reporting income gain than loss. Evidence related to gender differences is limited with two studies showing similar effects in mothers and fathers^{25,31}, and one study each reporting higher income loss in mothers⁵³ or fathers³⁶. A population-based study from Sweden^{26,28} indicated that maternal income reductions persisted until six years after diagnosis compared to three years among fathers. Findings from longitudinal studies suggest that income losses are most pronounced in the first months after diagnosis^{24,31,39,40}, but may persist into early survivorship^{26,28}. Lower income at diagnosis^{28,40,44,47}, younger age of child at diagnosis^{25,28,38}, and diagnosis of leukaemia^{25,50} were consistently associated with income loss.

Financial situation

Parents' financial situation was affected by the child's diagnosis across all studies. The extent of the impact varied largely from 18% of parents reporting a great financial burden in Sweden³² to 83% in Kenya⁵⁸. Two thirds of parents reported debts due to the child's disease in studies from Asia and Africa^{53,55,58} and two of these studies additionally reported that parents withheld treatment due to financial reasons^{55,58}. Also in the US, a study showed that 15% of families fell below the poverty level due to cancer-related financial strains⁴⁴. Findings from three longitudinal studies^{24,39,40} suggest that the impact on the financial situation peaks about six months after diagnosis and one study from the US reports that it persisted until 2.6 years after diagnosis³⁹. The main characteristics associated with adverse consequences for parents' financial situation were rural residency or greater distance to

hospital^{37,42,45,49,51,53}, lower socio-economic position^{34,40,47,49,54}, and single parenthood^{36,49}.

Financial assistance

The different types and extent of financial assistance across studies precluded an overall synthesis. Only one Australian study emphasised that families received no assistance for most cancer-related expenses⁵¹. Two US studies reported that >50% of parents used individual fundraising as a financial coping strategy^{44,47}. In Sweden, parents of children with cancer were more likely to rely on sickness or childcare benefits than comparison parents^{26,27}. Sick leave was more often used by mothers than fathers^{26,27,31,36}. Findings from longitudinal studies suggest that the uptake of such benefits is highest in the first months after diagnosis^{24,26,27,31,38} and decreases in early survivorship^{26,27,30,31,38}. Non-governmental assistance appeared to be more often received by families with higher expenses or rural residency⁵¹, whereas the uptake of social security benefits was mainly associated with parents' education, income, and cohabitation status^{26,27}.

Study quality

The average quality rating was 5.0 (Supplementary table 1). Quality ratings were higher for studies reporting on income (mean=5.2) than for studies on employment (mean=4.7), financial situation (mean=4.6), and financial assistance (mean=4.7). We identified no conclusive patterns in the reported findings according to study quality. Quality ratings were higher for European studies (mean=6.5) compared to studies from North America/Australia (mean=4.3), and Asia/Africa (mean=4.0).

Discussion

Our systematic review of 35 articles indicates that having a child with cancer may have a considerable impact on the parents' socio-economic situation supporting conclusions from earlier reviews^{10,17}. We found a high prevalence of disruptions in parental employment, particularly among mothers. The associated income losses contributed to families' perceived financial burden. Socio-economic consequences were most pronounced shortly after diagnosis, however, persisted into early survivorship for certain groups of parents. We identified families with lower socio-economic position, parents of children diagnosed with haematological cancers and diagnosed at younger age to be at particular risk for adverse socio-economic consequences.

Disruptions in parents' socio-economic situation varied largely by geographical region. Differences in regional labour market and economic circumstances, social welfare systems including health care services, and the extent of psycho-social support provided may account for this finding. A Swiss study estimated that parents need on average 240 working days for caretaking during the child's treatment⁵⁹. Consequently, parental work disruptions are likely and the social welfare system plays a crucial role in facilitating taking care for a diseased child while maintaining employment. Such systems are widely established in the Nordic countries which may result in a more modest impact compared to countries with less extensive welfare systems²⁵. More pronounced employment disruptions among mothers may be explained by traditional parenting roles typically accrediting mothers the role of the child's primary caregiver¹⁸. Mothers could profit from more flexible work arrangements such as home office or temporary reductions that support staying in the workforce while taking care for a diseased child²⁸. Prolonged work absences may be problematic

for families' future financial stability as the competitiveness in the labour market may be compromised due to lack of skill development or lost job opportunities. Indeed, a multi-national study concluded that mothers may experience career penalties even for short absence periods such as after childbirth⁶⁰. However, an alternative explanation for prolonged changes may arise from altered priorities related to family life following the cancer experience¹². From a political or legislative point of view, policy makers and employers play a crucial role in providing the opportunity for a successful combination of work and parenting responsibilities, particularly if the child is suffering from a severe disease such as cancer.

The identification of parents at risk for adverse socio-economic consequences is essential to develop tailored support strategies along the cancer trajectory. Our review revealed that families with lower socio-economic position are particularly affected by the child's disease. An explanation may be that parents with lower education are more often engaged in less flexible working arrangements with limited options to care for the diseased child while maintaining employment^{25,28}. These families may also have less resources to cope with the cancer experience such as for organizing childcare or a smaller social support network⁶¹. The families' socio-economic position may therefore further deteriorate and predispose all family members at risk for adverse health outcomes as outlined in the literature related to health inequalities⁶². Parents of children with haematological cancers and younger age at diagnosis are more likely to experience adverse socio-economic consequences. Haematological cancers anticipate an intense treatment protocol guided by chemotherapy with a long treatment duration (up to 2.5 years for acute lymphoblastic leukaemia)⁶³. Moreover, regardless of any health condition, younger children require more parental care what more strongly interferes with the parents' professional life⁶⁴.

Study limitations

A limitation refers to the large variations in outcome definition and methodological approaches across studies which limited between-study comparisons. Our findings mainly apply to high-income countries as studies from middle- or low-income countries are underrepresented. However, a family's socio-economic situation may be of higher concern and public health relevance in such countries in regard to treatment access and health outcomes. Another limitation refers the self-reported information in many studies. This may have resulted in biased responses caused by social desirability with parents tending to present a more favourable image⁶⁵. Finally, the explanatory power of the NOS for appraising study quality is limited as sample size is not considered²¹. This aspect is critical to identify characteristics associated with parents' socio-economic situation as smaller studies may be underpowered.

However, the comprehensive literature search enabled the inclusion of studies from various countries with different socio-economic contexts. The search terms used ensured that a broad range of socio-economic consequences that parents of children with cancer may experience are captured. A major strength of our review refers to the scientifically rigorous methodological approach with searching relevant databases, performing an extensive hand search, and updating our search to include recent articles. Study selection and quality appraisal were performed independently by two researchers.

Clinical implications

Family poverty has been described as a negative prognostic indicator in paediatric oncology⁴⁰. In 2015, standards for psycho-social care of children with cancer were published⁶⁶ including a recommendation for assessing family financial hardship⁶⁷. A follow-up study from the US outlined that while most paediatric oncology programs could implement some of these standards, lack of monetary resources precludes a

comprehensive implementation⁶⁸ and only half of paediatric oncologists and psychosocial leaders agreed that their psychosocial care is state of the art⁶⁹. However, a recent study from the US evaluating the feasibility of poverty screening in paediatric oncology revealed promising results by assessing household material hardship with a short screening tool in routine care⁷⁰. From a global perspective, further efforts are needed to develop, implement and systematically evaluate cost- and time-effective screening tools for family financial hardship. Ideally, such screening tools lead to referral to targeted financial counselling and supportive services according to the families' risk profile⁶⁷. This is of particular relevance as our review revealed that a majority of parents received financial assistance. Increasing the awareness of existing support services and guidance in navigating through potential administrative barriers may reduce the parents' burden in the life-threatening context of having a child with cancer.

In conclusion, parents experience a broad range of adverse socio-economic consequences following the child's cancer diagnosis. Further effort is needed to systematically identify families at risk of financial hardship and to implement appropriate support services along the cancer trajectory to prevent future social inequities and adverse family outcomes^{5,71-73}.

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Accepted Article

Table 1. Characteristics of included studies

First author(year)	Country	Sample size [†]	Comparison group	Cancer type	Age at dx (years) [‡]	Treatment phase	Study design/data collection	Follow-up time (years) [‡]	Study quality
Europe									
Lahteenmaki(2004) ²⁴	Finland	T1:26 families 46 comparison families	parents from day care centres	mixed	median=5	patients	Longitudinal survey T1:3 months after dx T2:12 months after dx	T1-T2	6
Syse(2011) ²⁵	Norway	3263 parents 1227908 comparison parents	general population	mixed	0-4:43% 5-9:21% 10-20:36%	survivors/patients/ deceased	Cohort;registry-based	0-4 years:34% >5 years:67%	9
Hiyoshi(2018) ^{§,26}	Sweden	3626 parents 34874 comparison parents	general population	mixed	median=7	survivors/patients, deceased	Cohort;registry-based; longitudinal follow-up	Annually to 7 years after dx	9
Hjelmstedt(2017) ^{§,27}									
Norberg(2016) ^{§,28}									
Hoven(2017) ^{§,29}	Sweden	T1:277 parents	-	mixed	mean=8	survivors/patients/ deceased	Longitudinal survey T1:1 week after dx T2:2 months after dx T3:4 months after dx T4:1 week after treatment/6 months after SCT T5:3 months after treatment/9 months after SCT/death T6:1 year after treatment/18 months after SCT/death T7:5 years after treatment/SCT/death	T2-T6	4
Wikman(2016) ^{§,30}						survivors/deceased		T6-T7	
Hoven(2013) ^{§,31}						survivors/patients/ deceased		T1-T6	
Hoven(2013) ³²	Sweden	551 families	-	CNS tumour	mean=10	survivors	Cross-sectional;survey	mean=16 years	5
Enskar(2011) ³³	Sweden	320 parents	-	mixed	0-18	survivors/patients	Cross-sectional;survey	in treatment:46% after treatment:54%	5
Mader(2017) ^{§,34}	Switzerland	383 families 769 comparison families	general population	mixed	mean=3	survivors	Cross-sectional;survey	mean=9 years	8
Mader(2016) ^{§,35}		394 families 3341 comparison parents							7
Eiser(2006) ³⁶	United Kingdom	145 families	-	mixed	0-20	survivors/patients	Cross-sectional;survey	3-36 months after dx	5
North America and Australia									
Tsimicalis(2012) ³⁷	Canada	99 parents	-	mixed	mean=8	patients	Cost-of-illness;diary	2-4 months after dx	4
Limburg(2008) ³⁸	Canada	111 families	-	mixed	0-4:40% 5-9:13% 10-20:39%	survivors/deceased	Cross-sectional;survey	mean=4 years	4
Bilodeau(2018) ^{§,39}	United States	T3:52 families	-	mixed	median=6	survivors	Longitudinal survey T1:30 days after dx	T3	5

Bona(2016) ^{§,40}		T1:99 families			median=9	patients	T2:6 months after dx T3:>1 year after treatment	T1-T2	
Zamora(2016) ⁴¹	United States	366 families	-	mixed	0-25	survivors/patients	Cross-sectional;survey	<1 year:44% 1-3 years:48% 4-5 years:8%	5
Warner(2014) ⁴²	United States	254 families	-	mixed	mean=7	survivors/patients	Cross-sectional;survey	mean=2 years	5
Lau(2014) ⁴³	United States	T1:159 families	-	ALL	2-5:54% 5-10:46%	patients	Longitudinal survey T1:1 month after dx T2:6 months after dx T3:12 months after dx	T1-T3	5
Bona(2014) ⁴⁴	United States	71 families	-	mixed	mean=10	patients	Cross-sectional;survey	mean=2 years	3
Fluchel(2014) ⁴⁵	United States	354 families	-	mixed	mean=7	patients	Cross-sectional;survey	mean=2 years	5
Murphy(2008) ⁴⁶	United States	40 parents 20 comparison fathers	fathers from local schools	n.r.	n.r.	n.r.	Cross-sectional;survey	>4 months after dx	3
Dussel(2011) ⁴⁷	United States Australia	230 families	-	mixed	n.r.	deceased	Cross-sectional;survey/interview	mean=4 years after death	4
Monterosso(2009) ⁴⁸	Australia	69 families	-	mixed	mean=7	deceased	Cross-sectional;survey/interview	6-36 months after death	3
Heath(2006) ⁴⁹	Australia	56 families	parents of children with diabetes	mixed	n.r.	survivors/patients	Cross-sectional;survey	>12 months after dx	4
Goodenough(2004) ⁵⁰	Australia	104 families	-	mixed	mean=7	survivors/patients	Record review	mean=2 years	4
Cohn(2003) ⁵¹	Australia	100 families	-	mixed	mean=6	survivors/patients	Cross-sectional;survey	mean=3 years	4
Dockerty(2003) ⁵²	New Zealand	237 families	-	mixed	0-14	survivors/patients/ deceased	Cross-sectional;survey	<1 year:8% 1-2 years:59% >2 years:33%	5
Asia and Africa									
Sneha(2017) ⁵³	India	70 families	-	ALL;AML	0-18	patients	Cross-sectional;survey/interview	>3 months after dx	3
Ghatak(2016) ⁵⁴	India	50 families	-	ALL	mean=6	patients	Cost-of-illness;diary	1 month after dx	4
Mostert(2008) ⁵⁵	Indonesia	51 families	-	ALL	2-16	survivors/patients	Cross-sectional;survey/interview	in treatment:94% after treatment:6%	5
Okada(2014) ⁵⁶	Japan	62 mothers	-	mixed	mean=5	survivors	Cross-sectional;survey	mean=4 years	3
Aung(2012) ⁵⁷	Singapore	79 families	-	mixed	<5:51% 5-10:25% 10-20:24%	survivors/patients	Cross-sectional;survey	>6 months after dx	5
Njuguna(2015) ⁵⁸	Kenya	75 families	-	mixed	0-14	survivors/patients	Cross-sectional;survey/interview	at dx:5% in treatment:82% after treatment:13%	4

ALL, acute lymphoblastic leukaemia; AML, acute myeloid leukaemia; CNS, central nervous system; dx, diagnosis; n.r., not reported; SCT, stem cell transplantation; T, time point.

[†]The term *families* is used if the family was addressed as a unit.

^{*}Mean or median if reported.

[§]Articles based on the same original study/data from the respective country.

Table 2. Impact of childhood cancer on parents' socio-economic situation

First author(year)	Country	Socio-economic consequences	Differences mothers/fathers	Temporal patterns	Associations
Employment					
<i>Europe</i>					
Lahteenmaki(2004) ^{§,24}	Finland	Mothers less often employed and fewer work hours than comparison mothers Similar employment and work hours of fathers and comparison fathers	Fewer mothers employed during entire follow-up Mothers worked fewer hours during entire follow-up	Employment from 3 to 12 months after dx: Mothers: 54%(T1),65%(T2) Fathers: 95%(T1),93%(T2)	-
Syse(2011) ²⁵	Norway	Similar employment as comparison parents >90% employed at end of follow-up	Fewer mothers employed (87%vs.93%)	No association with time since dx	<u>Employment</u> [†] Bone tumour(mothers) Child death(mothers) Lower education(mothers) Being married(fathers)
Norberg(2016) ^{§,28}	Sweden	Mothers more often unemployed than comparison mothers Similar employment of fathers and comparison fathers	Mothers more often unemployed during entire follow-up	Higher unemployment in mothers than comparison mothers up to 5 years after dx No change in employment of fathers	<u>Unemployment(mothers)</u> [†] Lower education Higher population density Children at home
Hoven(2017) ^{§,29}	Sweden	Majority reported work restrictions after dx	More mothers reported work restrictions during entire follow-up	Work restrictions decreased from 2 months after dx to 1 year after treatment: 75%(T2),67%(T3),49%(T4),34%(T5),16%(T6)	<u>Work restrictions</u> [‡] Post-traumatic stress Child's symptom burden
Wikman(2016) ^{§,30}	Sweden	Majority employed during entire follow-up	Fewer mothers of survivors employed (92%vs.96%) Similar employment in bereaved parents (91%vs.90%)	Employment 1 and 5 years after treatment: Parents of survivors: 86%(T6),94%(T7) Bereaved parents :86%(T6),91%(T7)	-
Hoven(2013) ^{§,31}	Sweden	Majority stopped/reduced work after dx	Fewer mothers employed during entire follow-up	Work stop/reduction from 2 months after dx to 1 year after treatment: Mothers: 83%(T2),52%(T4),47% (T5),28%(T6) Fathers: 60%(T2),41%(T4),21%(T5),17%(T6)	<u>Unemployment</u> [†] Shorter treatment(T4) Poor prognosis(T6) ≥3 siblings(T6)
Mader(2016) ³⁵	Switzerland	Mothers more often unemployed than comparison mothers (29%vs.22%) Fathers more often full-time employed than comparison fathers (93%vs.87%)	More mothers unemployed (29%vs.3%) Fewer mothers full-time employed (9%vs.93%)	No association with time since dx	<u>Unemployment</u> [†] Lower education(mothers) >2 children(mothers) Lymphoma(mothers) Relapse(fathers)
Eiser(2006) ³⁶	United Kingdom	35% of mothers and 2% of fathers quit job 29% of mothers and 37% of fathers reduced work hours 71% of mothers and 27% of fathers took unpaid leave	More mothers quit job (35%vs.2%) Less mothers reduced work hours (29%vs.37%)	-	-
<i>North America and Australia</i>					
Tsimicalis(2012) ³⁷	Canada	65% of mothers and 63% of fathers reported work loss >50% of mothers and 5% of fathers reported unemployment	More mothers unemployed (>50%vs.5%)	-	-
Limburg(2008) ³⁸	Canada	64% of mothers and 16% of fathers took extended leave/quit job Majority returned to same job within 1 year	More mothers left work (64%vs.16%) More mothers quit job (13%vs.11%)	-	<u>Work leave</u> [‡] Leukaemia Younger age at dx

Bona(2016) ^{§,40}	United States	56% reported work disruptions 15% quit/lost job 37% took leave/reduced work hours	-	6 months after dx: 56% reported work disruptions(T2) 15% quit/lost job(T2) 37% took leave/reduced work hours(T2)	-
Zamora(2016) ⁴¹	United States	36% quit/changed job 36% missed ≥10 work days in first 6 months of treatment	-	-	-
Warner(2014) ⁴²	United States	One third quit/changed job	-	No association with time since dx	-
Lau(2014) ^{§,43}	United States	46% lost job (vs.9% in census) 18% increased work hours 68% decreased work hours 51% declined work opportunities	-	From 1 to 12 months after dx: Increase work hours: 7%(T1),13%(T2),18%(T3) Decrease work hours: 42%(T1),61%(T2),68%(T3) Decline work opportunities: 20%(T1),39%(T2),51%(T3)	Increase work hours [†] Treatment Decline work opportunities [†] Lower income Younger age at dx Treatment
Bona(2014) ⁴⁴	United States	94% reported work disruptions 42% one or both parents quit job	More mothers quit job (33%vs.6%)	-	-
Fluchel(2014) ⁴⁵	United States	36% reported quitting/changing job of ≥1 parent Mean of 14 monthly missed work days after dx	-	-	Missed work days [†] Rural residency Longer travel time to centre Quit job [†] AML
Murphy(2008) ⁴⁶	United States	40% of mothers and 100% of fathers employed Fathers worked more hours than comparison fathers (48vs.43)	Fewer mothers employed (40%vs.100%) Mothers worked fewer hours (29vs.48)	-	-
Dussel(2011) ⁴⁷	United States Australia	35% and 49% in US and Australia quit job 52% and 58% in US and Australia reduced work hours	More mothers reduced work hours in US (39%vs.14%) and Australia (24%vs.23%)	-	-
Monterosso(2009) ⁴⁸	Australia	56% full-time home carer during palliative care	-	-	-
Heath(2006) ⁴⁹	Australia	77% reported work disruptions	More mothers quit job Less mothers reduced work	-	-
Goodenough(2004) ⁵⁰	Australia	58% reported work disruptions 2% increased work hours	More mothers reported work disruptions (81%vs.35%)	Most work disruptions in first 6 weeks after dx	-
Cohn(2003) ⁵¹	Australia	49% reported work disruptions 33% quit job/reduced work hours 16% increased work hours	-	-	Increase work hours [†] Rural residency Younger age
<i>Asia and Africa</i>					
Sneha(2017) ⁵³	India	38% increased work hours	-	-	-
Ghatak(2016) ⁵⁴	India	34% of fathers lost job 16% closed shop/business 22% took unpaid leave	-	-	-
Mostert(2008) ⁵⁵	Indonesia	8% of mothers and 29% of fathers lost job	Fewer mothers lost job (8%vs.29%)	-	-
Okada(2014) ⁵⁶	Japan	31% quit job 38% took extended leave	-	-	Quit job/extended leave [†] Lower work motivation Less social support
Income					

<i>Europe</i>					
Lahteenmaki(2004) ^{§.24}	Finland	Family income similar to comparison families	-	Income loss high during first months after dx Income remains similar from 3 to 12 months after dx(T1-T2)	-
Syse(2011) ²⁵	Norway	Minor effects on income	Non-significant 4% reduction in mothers' income No reduction in fathers' income	Maternal income reductions more pronounced ≥5 years after dx	Income reduction [†] CNS tumour, germ cell tumour, leukaemia(mothers) Younger age at dx(mothers) Higher education(mothers) Not being married(fathers)
Mader(2017) ³⁴	Switzerland	Lower household income than comparison parents	-	-	-
Hiyoshi(2018) ^{§.26}	Sweden	Income decreased after dx and thereafter remained lower than comparison parents	Longer income reductions in mothers after dx	Income reductions most pronounced around dx Income of mothers reduced until 7 years after dx Income of fathers reduced until 2 years after dx	Income loss(mothers) [†] Lower education Child death Parent-couple household
Norberg(2016) ^{§.28}	Sweden	Income decreased after dx and thereafter remained lower than comparison parents	Longer income reductions in mothers after dx	Income reductions most pronounced around dx Income of mothers reduced until 7 years after dx Income of fathers reduced until 2 years after dx	Income loss [†] Lower income at dx(mothers) Lower education Younger age Unemployment at dx(mothers) Intermediate-/densely-populated area(mothers) Not born in Sweden(mothers) Children at home(mothers) Younger age at dx Partnership(fathers)
Hoven(2013) ^{§.31}	Sweden	Income reduced during treatment and similar 1 year after treatment	Income reductions similar during entire follow-up	Income reduced during treatment until 3 months after treatment(T2-T5), similar 1 year after treatment(T6)	Lower income [†] Male child
Eiser(2006) ³⁶	United Kingdom	43% reported financial impact due to income loss	Financial impact more often due to fathers' than mothers' income loss (18%vs.12%)	-	-
<i>North America and Australia</i>					
Limburg(2008) ³⁸	Canada	Decrease in income from salary	-	Income from salary increased with time since dx	Lower income from salary [†] Younger age at dx
Bilodeau(2018) ^{§.39}	United States	Income loss of 22% (36% lost >40% of annual income)	-	Income loss of 22% until >1 year after treatment(T3)	-
Bona(2016) ^{§.40}	United States	Income loss of 7% (25% lost >40% of annual income)	-	Income loss of 7% until 6 months after dx(T2)	Income loss [†] Lower income
Bona(2014) ⁴⁴	United States	Income loss of 20% (14% lost >40% of annual income)	-	-	Income loss [†] Lower income
Dussel(2011) ⁴⁷	United States Australia	60% reported income loss of >10%	-	-	Income loss [†] Lower income

Heath(2006) ⁴⁹	Australia	Great income loss in first 12 months after dx	-	-	-
Goodenough(2004) ⁵⁰	Australia	Family income loss of 53%	-	-	<u>Income loss</u> [†] Leukaemia
Cohn(2003) ⁵¹	Australia	One third reported income loss	-	-	-
Dockerty(2003) ⁵²	New Zealand	43% reported income increase 23% reported income loss	-	-	-
Asia and Africa					
Sneha(2017) ⁵³	India	Majority reported income loss	More mothers reported income loss	-	-
Ghatak(2016) ⁵⁴	India	72% reported income loss	-	-	-
Mostert(2008) ⁵⁵	Indonesia	69% reported income loss	-	-	-
Njuguna(2015) ⁵⁸	Kenya	66% reported income loss	-	-	-
Financial situation					
Europe					
Lahteenmaki(2004) ^{§24}	Finland	>40% reported significant financial impact	-	Financial impact similar 3 and 12 months after dx: 42%(T1),43%(T2)	-
Mader(2017) ³⁴	Switzerland	Higher risk-of-poverty than comparison parents	-	No association with time since dx	<u>Risk-of-poverty</u> [†] Lower education Language
Hoven(2013) ³²	Sweden	18% reported significant financial burden	-	No association with time since dx	<u>Financial burden</u> [†] Poorer health of child Unmet care needs
Enskar(2011) ³³	Sweden	Majority reported financial situation became worse	Similar reporting that financial situation became worse	Financial situation worse on compared to off treatment (mothers: 86%vs.66%; fathers: 87%vs.63%)	<u>Financial burden</u> [†] Active treatment
Eiser(2006) ³⁶	United Kingdom	55% reported cancer-related expenses 68% reported money worries	-	Cancer-related expenses highest in first 6 months after dx	<u>Expenses</u> [†] Active treatment Relapse <u>Money worries</u> [†] Single parenthood
North America and Australia					
Tsimicalis(2012) ³⁷	Canada	37% of annual income for cancer-related expenses	-	-	<u>Expenses</u> [†] Rural residency Higher income
Bilodeau(2018) ^{§39}	United States	44% reported great financial hardship 33% reported material hardship	-	Material hardship increased from dx to >1 year after treatment: 15%(T1),33%(T2),33%(T3)	-
Bona(2016) ^{§40}	United States	56% reported moderate/great financial hardship 29% reported material hardship	-	Material hardship increased from dx to 6 months after dx: 20%(T1),29%(T2)	<u>Material hardship</u> [†] Lower income
Warner(2014) ⁴²	United States	Mean financial burden 67/100	-	No association with time since dx	<u>Financial burden</u> [†] More hospitalizations Quitting/changing job Rural residency
Bona(2014) ⁴⁴	United States	28% reported great financial hardship 15% fell below poverty level 40% reported debts	-	-	-

Fluchel(2014) ⁴⁵	United States	Mean financial burden 66/100	-	-	Financial burden [†] Rural residency Longer travel time to centre
Dussel(2011) ⁴⁷	United States Australia	24% in US and 39% in Australia reported great financial hardship 16% in US and 22% in Australia dropped below poverty level	-	-	Financial hardship [†] Lower education(US) Younger age(US) Poverty Income loss
Monterosso(2009) ⁴⁸	Australia	41% reported high financial burden	-	-	-
Heath(2006) ⁴⁹	Australia	74% reported great/moderate financial hardship Majority reported cancer-related expenses	-	-	Financial hardship [†] Single parenthood Lower income Greater distance to hospital
Cohn(2003) ⁵¹	Australia	80% reported ≥5 types of cancer-related expenses	-	-	Expenses [†] Rural residency
Dockerty(2003) ⁵²	New Zealand	Mean financial burden 48/100 13% of family income for cancer-related expenses	-	-	Financial burden [†] Longer time in hospital
<i>Asia and Africa</i>					
Sneha(2017) ⁵³	India	Majority reported financial burden 68% reported debts	-	-	Financial burden [†] Rural residency
Ghatak(2016) ⁵⁴	India	Cancer-related expenses exceeded family income	-	-	Expenses [†] Lower socio-economic position
Mostert(2008) ⁵⁵	Indonesia	78% reported financial difficulties 65% reported debts 18% withhold treatment due to finances	-	-	-
Aung(2012) ⁵⁷	Singapore	Financial burden second highest family impact	-	-	Financial burden [†] Work leave
Njuguna(2015) ⁵⁸	Kenya	83% reported great financial burden 64% reported debts 28% withhold treatment due to finances	-	-	-
Financial assistance					
<i>Europe</i>					
Lahteenmaki(2004) ^{§,24}	Finland	Maternity/child care leave similar to comparison families	Maternity/child care leave similar	Maternity/child care leave increased from 3 to 12 months after dx: Mothers: 0%(T1),6%(T2) Fathers: 0%(T1),7%(T2)	-
Hiyoshi(2018) ^{§,26}	Sweden	More sickness and childcare benefits than comparison parents Less often unemployment benefits than comparison parents	More mothers received sickness, childcare or unemployment benefits	Benefit uptake most pronounced around dx More sickness and childcare benefits than comparison parents up to few years after diagnosis	Sickness benefits [†] Child death Lower education(mothers) Childcare benefits(mothers) [†] Single parenthood Unemployment benefits [†] Parent-couple household(fathers)

					Higher education(fathers) Lower education(mothers)
Hjelmstedt(2017) ^{§,27}	Sweden	More sickness benefits than comparison parents (at dx: mothers 42%vs.17%, fathers 33%vs.9%)	More mothers received sickness benefits (at dx: 42%vs.33%)	Benefit uptake most pronounced around dx More sickness benefits than comparison parents up to 4 years after dx for mothers and 3 years for fathers	<u>Sickness benefit days</u> [†] Born in Sweden Parent-couple household Higher income Higher education Child death Younger age(fathers)
Wikman(2016) ^{§,30}	Sweden	One fifth reported sick leave during follow-up	Sick leave similar in mothers and fathers of survivors (20%vs.18%) or bereaved mothers and fathers (14%vs.20%)	Sick leave 1 and 5 years after treatment: Parents of survivors: 16%(T6),19%(T7) Bereaved parents: 38%(T6),17%(T7)	-
Hoven(2013) ^{§,31}	Sweden	Highest proportion of sick leave during treatment	More mothers on sick leave during entire follow-up and for longer periods after dx	Sick leave increased from 1 week to 2 months after dx and decreased to 1 year after treatment: Mothers: 5%(T1),80%(T2),80%(T3),57%(T4),45%(T5),23%(T6) Fathers: 0%(T1),53%(T2),50%(T3),27%(T4),13%(T5),5%(T6)	<u>Sick leave</u> [†] Higher treatment intensity
Eiser(2006) ³⁶	United Kingdom	31% of mothers and 14% of fathers on sick leave 47% of mothers and 61% of fathers on compassionate leave Majority received Disability Living Allowance or other assistance	More mothers on sick leave (31%vs.14%) Fewer mothers on compassionate leave (48%vs.61%)	-	-
<i>North America and Australia</i>					
Limburg(2008) ³⁸	Canada	44% received employment insurance, social and/or other assistance at diagnosis	-	Employment insurance, social and/or other financial assistance decreased with time since dx (44% at dx vs. 20% at survey)	<u>Financial assistance</u> [†] Younger age at dx
Bona(2016) ^{§,40}	United States	34% taking leave received pay 53% took unpaid family/medical leave	-	-	-
Bona(2014) ⁴⁴	United States	51% used fundraising	-	-	-
Dussel(2011) ⁴⁷	United States Australia	52% in US and 33% in Australia used fundraising	-	-	<u>Fundraising</u> [†] Poverty(US)
Monterosso(2009) ⁴⁸	Australia	4% took paid leave 20% received disability support pension 41% received disability/carer allowance	-	-	-
Heath(2006) ⁴⁹	Australia	50% took sick leave/vacation Large variation in assistance from governmental and non-governmental sources	-	-	-
Goodenough(2004) ⁵⁰	Australia	68% received assistance for living expenses 52% received hospital-specific assistance 46% received assistance for accommodation/travel	-	-	<u>Financial assistance</u> [†] Income loss
Cohn(2003) ⁵¹	Australia	35% took annual/sick leave	-	-	<u>Financial assistance</u> [†]

		No assistance for most cancer-related expenses			Rural residency Higher expenses
Dockerty(2003) ⁵²	New Zealand	89% received assistance from governmental and non-governmental sources	-	-	-
<i>Asia and Africa</i>					
Ghatak(2016) ⁵⁴	India	12% took paid leave 78% received assistance from governmental and non-governmental sources	Fewer mothers took paid leave (2%vs.10%)	-	-
Mostert(2008) ⁵⁵	Indonesia	61% requested assistance from family	-	-	-
Okada(2014) ⁵⁶	Japan	6% took family care leave 6% took sick/child care leave	-	-	-
Aung(2012) ⁵⁷	Singapore	61% received assistance	-	-	-
Njuguna(2015) ⁵⁸	Kenya	47% received assistance from friends, 41% from relatives, 36% from community, 29% from grandparents	-	-	-

dx, diagnosis; AML, acute myeloid leukemia.

†Statistically significant in adjusted analyses.

*Statistically significant in unadjusted analyses.

§Longitudinal study design.

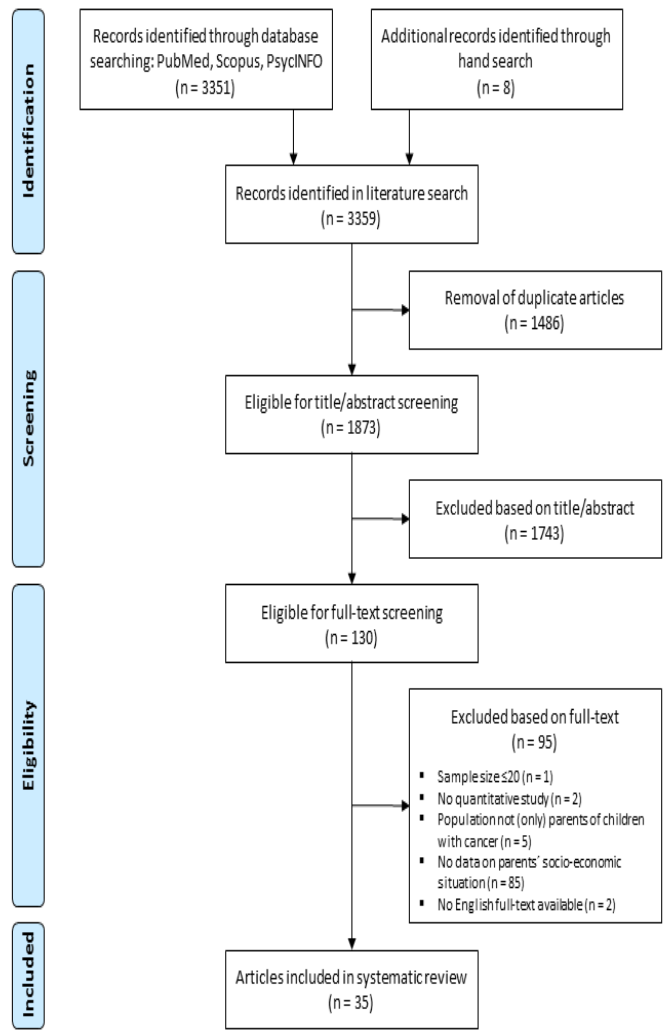


Figure 1. Flow chart of inclusion and exclusion of identified articles