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

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Impact of childhood cancer on parents’ socio-economic situation

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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 routine. This is particularly challenging for the parents who are confronted with the potential fatality of the disease and conflicting caregiving, emotional, and practical demands. The child’s acute treatment requires frequent hospitalizations, invasive procedures, and depending on the cancer type, a combination of surgery, chemotherapy, and radiotherapy. Parents are often involved by providing and monitoring treatment or managing treatment-related symptoms, particularly in the outpatient setting. Due to the increased risk for late effects after treatment, long-term follow-up care is recommended for childhood cancer survivors. Even years after treatment, many parents remain actively involved in the child’s medical care.

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 treatment. Moreover, many parents are confronted with medical and non-medical expenditures. Direct costs of childhood cancer have been evaluated in two reviews concluding that substantial financial toxicity may occur in paediatric oncology. 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 tasks. 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-analyses. 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. 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) as recently used in a review addressing childhood cancer survivors (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´ manual 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 bias. 
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 regions. 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.
Results

Literature search and study characteristics

We identified 3359 articles through literature searches and included 35 articles, 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. Only one study from Indonesia showed higher work loss among fathers. However, two studies from Australia and the UK 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. However, studies from Sweden and Switzerland identified higher unemployment among mothers even many years after diagnosis. Diagnosis of haematological cancer, younger age of child at diagnosis, lower maternal education, and having more children 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. The proportion of parents reporting income loss and the extent of these losses varied largely. Two studies from Norway and Finland found no effects on income and one study from New Zealand 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 and one study each reporting higher income loss in mothers or fathers. A population-based study from Sweden 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 but may persist into early survivorship. Lower income at diagnosis, younger age of child at diagnosis, and diagnosis of leukaemia 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 Sweden to 83% in Kenya. Two thirds of parents reported debts due to the child’s disease in studies from Asia and Africa and two of these studies additionally reported that parents withheld treatment due to financial reasons. Also in the US, a study showed that 15% of families fell below the poverty level due to cancer-related financial strains. Findings from three longitudinal studies 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 diagnosis. The main characteristics associated with adverse consequences for parents’ financial situation were rural residency or greater distance to
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 expenses. Two US studies reported that >50% of parents used individual fundraising as a financial coping strategy. In Sweden, parents of children with cancer were more likely to rely on sickness or childcare benefits than comparison parents. Sick leave was more often used by mothers than fathers. Findings from longitudinal studies suggest that the uptake of such benefits is highest in the first months after diagnosis and decreases in early survivorship. Non-governmental assistance appeared to be more often received by families with higher expenses or rural residency, whereas the uptake of social security benefits was mainly associated with parents’ education, income, and cohabitation status.

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. 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 treatment. 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 systems. More pronounced employment disruptions among mothers may be explained by traditional parenting roles typically accrediting mothers the role of the child’s primary caregiver. 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 child. 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 childbirth. However, an alternative explanation for prolonged changes may arise from altered priorities related to family life following the cancer experience. 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. These families may also have less resources to cope with the cancer experience such as for organizing childcare or a smaller social support network. 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 inequalities. 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). Moreover, regardless of any health condition, younger children require more parental care what more strongly interferes with the parents’ professional life.
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 image. Finally, the explanatory power of the NOS for appraising study quality is limited as sample size is not considered. 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 oncology. In 2015, standards for psycho-social care of children with cancer were published including a recommendation for assessing family financial hardship. 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 implementation\textsuperscript{65} and only half of paediatric oncologists and psychosocial leaders agreed that their psychosocial care is state of the art\textsuperscript{69}. 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 care\textsuperscript{70}. 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 the families’ risk profile\textsuperscript{67}. 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\textsuperscript{5,71-73}. 
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| 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) | 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)       | 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)    | 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) |               |             |                  |             |                  |                |                               |                       |               |
| Norberg (2016)    |               |             |                  |             |                  |                |                               |                       |               |
| Hovén (2017)      | Sweden        | T1:277 parents | - | mixed | mean=8 | survivors/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 | T1-T6 | 4 |
| Wikman (2016)     | Sweden        | T1:26 families | - | mixed | mean=7 | survivors/patients/deceased | Cross-sectional;survey | mean=16 years | 5 |
| Hovén (2013)      | Sweden        | 551 families | - | CNS tumour | mean=10 | survivors/patients | Cross-sectional;survey | in treatment:46% after treatment:54% | 5 |
| Enskar (2011)     | Sweden        | 320 parents | - | mixed | 0-18 | survivors | Cross-sectional;survey | mean=9 years | 8 |
| Mader (2017)      | Switzerland   | 383 families 769 comparison families | general population | mixed | mean=3 | survivors | Cross-sectional;survey | mean=9 years | 7 |
| Mader (2016)      |              | 394 families 3341 comparison parents | general population | mixed | mean=3 | survivors | Cross-sectional;survey | mean=9 years | 7 |
| Eiser (2006)      | United Kingdom | 145 families | - | mixed | 0-20 | survivors/patients | Cross-sectional;survey | 3-36 months after dx | 5 |
| North America and Australia | | | | | | | | | |
| Tsimicalis (2012) | Canada        | 99 parents | - | mixed | mean=8 | patients | Cost-of-illness;diary | 2-4 months after dx | 4 |
| Limburg (2008)    | Canada        | 111 families | - | mixed | 0-4:40% 5-9:13% 10-20:39% | survivors/deceased | Cross-sectional;survey | mean=4 years | 4 |
| Bilodeau (2018)   | United States | T3:52 families | - | mixed | median=6 | survivors | Longitudinal survey T1:30 days after dx | T3 | 5 |
| Study (Year) | Location | Sample Size | Type | Follow-up | Design | Outcome | Time Points | Notes |
|-------------|----------|-------------|------|-----------|--------|---------|-------------|-------|
| Bona (2016) | United States | 366 families | - | mixed | median=9 | patients | T1:99 families | T1-T2 |
| Zamora (2016) | United States | 254 families | - | mixed | mean=7 | patients | T1:6 months after dx | T2:6 months after dx |
| Lau (2014) | United States | T1:159 families | - | ALL | 2-5/54% | patients | Longitudinal survey | T1:1 month after dx |
| Warner (2014) | United States | 254 families | - | mixed | mean=10 | patients | Cross-sectional; survey | T1:1 month after dx |
| Murphy (2008) | United States | 354 families | - | mixed | mean=7 | patients | Cross-sectional; survey | T1:1 month after dx |
| Dussel (2011) | United States | 230 families | - | mixed | n.r. | deceased | Cross-sectional; survey | T1:6-36 months after death |
| Monroesso (2009) | Australia | 69 families | - | mixed | mean=7 | deceased | Cross-sectional; survey | T1:6-36 months after death |
| Heath (2006) | Australia | 56 families | - | mixed | n.r. | survivors/patients | Cross-sectional; survey | T1:12 months after dx |
| Goodenugh (2004) | Australia | 104 families | - | mixed | mean=7 | survivors/patients | Record review | T1:mean=12 years after dx |
| Cohn (2003) | Australia | 100 families | - | mixed | mean=6 | survivors/patients | Cross-sectional; survey | T1:mean=3 years after dx |
| Dockerty (2003) | New Zealand | 237 families | - | mixed | 0-14 | survivors/patients/deceased | Cross-sectional; survey | T1:<1 year:3% |
| Asia and Africa | | | | | | | | |
| Sneha (2017) | India | 70 families | - | ALL; AML | 0-18 | patients | Cross-sectional; survey | T1:3 months after dx |
| Ghatata (2016) | India | 50 families | - | ALL | mean=6 | patients | Cost-of-illness; diary | T1:1 month after dx |
| Mostert (2008) | Indonesia | 51 families | - | ALL | 2-16 | survivors/patients | Cross-sectional; survey | T1:94% in treatment;6% after treatment |
| Okada (2014) | Japa | 62 mothers | - | mixed | mean=5 | survivors/patients | Cross-sectional; survey | T1:mean=4 years after dx |
| Aung (2012) | Singapore | 79 families | - | mixed | <5.51% | survivors/patients | Cross-sectional; survey | T1:6 months after dx |
| Njuguna (2019) | Kenya | 75 families | - | mixed | 0-14 | survivors/patients | Cross-sectional; survey | T1:5% in treatment;82% after treatment |

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**     |               |                                                                                                |                                                                                           |                                                                                  |                                                                               |
| Europe             |               |                                                                                                |                                                                                           |                                                                                  |                                                                               |
| Lahteenmaki(2004)  | Finland       | Mothers less often employed and fewer work hours than comparison mothers                        | Fewer mothers employed during entire follow-up                                            | Employment from 3 to 12 months after dx: Mothers: 54%(T1),65%(T2) Fathers: 95%(T1),93%(T2) | -                                                                            |
|                    |               | Similar employment and work hours of fathers and comparison fathers                           | Mothers worked fewer hours during entire follow-up                                         |                                                                                  |                                                                               |
| Syse(2011)         | 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                                                 | Employment† Bone tumour(mothers) Child death(mothers) Lower education(mothers) Being married(fathers) |
| Norberg(2016)      | Sweden        | Mothers more often unemployed than comparison mothers                                         | Mothers more often unemployed during entire follow-up                                     | Higher unemployment in mothers than comparison mothers up to 5 years after dx     | Employment† Lower education Higher education† Children at home               |
|                    |               | Similar employment of fathers and comparison fathers                                           |                                                                                           | No change in employment of fathers                                                 |                                                                               |
| Hoven(2017)        | 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:     | Work restrictions† Post-traumatic stress Child’s symptom burden              |
|                    |               |                                                                                                |                                                                                           | Parents: 75%(T2),67%(T3),49%(T4),34%(T5),16%(T6) Bereaved parents: 86%(T6),91%(T7) |                                                                               |
| Wikman(2016)       | Sweden        | Majority employed during entire follow-up                                                   | Fewer mothers of survivors employed (92%vs.96%) Similar employment in bereaved parents   | Employment 1 and 5 years after treatment: Parents of survivors: 86%(T6),94%(T7) | Unemployment† Poor prognosis(T6) ≥3 siblings(T6)                              |
|                    |               |                                                                                                | (91%vs.90%)                                                                               | Bereaved parents: 86%(T6),91%(T7)                                                 |                                                                               |
| Hoven(2013)        | 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) | Unemployment† Poor prognosis(T6) ≥3 siblings(T6)                              |
|                    |               |                                                                                                |                                                                                           | Fathers: 60%(T2),41%(T4),21%(T5),17%(T6)                                           |                                                                               |
| Mader(2016)        | Switzerland   | Mothers more often unemployed than comparison mothers (29%vs.22%) Fathers more often full-time employed than comparison fathers (95%vs.87%) | More mothers unemployed (29%vs.3%) Fewer mothers full-time employed (9%vs.93%)            | No association with time since dx                                                  | Unemployment† Lower education(mothers) Lymphoma(mothers) Relapse(fathers)    |
| Eiser(2006)        | 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                                          |                                                                                           |                                                                                  |                                                                               |
| North America and Australia | | |                                                                                           |                                                                                  |                                                                               |
| Tsimicalis(2012)   | 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)      | Canada        | 64% of mothers and 16% of fathers took extended leave/quit job                                | More mothers left work (64%vs.16%) More mothers quit job (13%vs.11%)                      |                                                                                  | Work leave‡ Leukaemia Younger age at dx                                       |
| Authors       | Year | Country     | Work Disruptions                                                                 | Quit/Change Job | Missed Work Days | Full-time Care | Work Motivation | Social Support | Lower Income | Younger Age | Rural Residency | AML | Income |
|--------------|------|-------------|---------------------------------------------------------------------------------|-----------------|-----------------|---------------|-----------------|---------------|-------------|-------------|----------------|------|--------|
| Bona(2016)   | 2016 | United States | 56% reported work disruptions 15% quit/lost job 37% took leave/reduced work hours | -               | -               | -             |                |               |             |             |                |      |        |
| Zamora(2016) | 2016 | United States | 36% quit/changed job 36% missed ≥10 work days in first 6 months of treatment | -               | -               | -             |                |               |             |             |                |      |        |
| Warner(2014) | 2014 | United States | One third quit/changed job                                                     | -               | -               | -             |                |               |             |             |                |      |        |
| Lau(2014)    | 2014 | United States | 46% lost job (vs.9% in census) 18% increased work hours 68% decreased work hours 51% declined work opportunities | -               | -               | -             |                |               |             |             | Missed work days† | Rural residency |        |
| Bona(2014)   | 2014 | United States | 94% reported work disruptions 42% one or both parents quit job | More mothers quit job (33% vs. 6%) | -               | -             |                |               |             |             |                |      |        |
| Fluchel(2014) | 2014 | United States | 36% reported quitting/changing job of ≥1 parent Mean of 14 monthly missed work days after dx | -               | -               | -             |                | Missed work days† | Rural residency |                |                |        |
| Murphy(2008) | 2008 | United States | 40% of mothers and 100% of fathers employed Fathers worked more hours than comparison fathers (48 vs. 43) | Fewer mothers employed (40% vs. 100%) Mothers worked fewer hours (29 vs. 48) | -               | -             |                |                |             |             |                |      |        |
| Dussel(2011) | 2011 | United States | 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) | 2009 | Australia     | 56% full-time home care during palliative care | -               | -               | -             |                |                |             |             |                |      |        |
| Heath(2006)  | 2006 | Australia     | 77% reported work disruptions More mothers quit job Less mothers reduced work | -               | -               | -             |                |                |             |             |                |      |        |
| Goodenough(2004) | 2004 | 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)   | 2003 | Australia     | 49% reported work disruptions 46% quit/reduced work hours 16% increased work hours | -               | -               | -             | Increase work hours‡ | Rural residency |                |                |                |      |        |
| Asia and Africa |     |              |                                                                 |                |                |               |                |                |             |             |                |      |        |
| Sneh(2017)   | 2017 | India         | 38% increased work hours                                                        | -               | -               | -             |                |                |             |             |                |      |        |
| Ghatak(2016) | 2016 | India         | 34% of fathers lost job 16% closed shop/business 22% took unpaid leave           | -               | -               | -             |                |                |             |             |                |      |        |
| Mostert(2008) | 2008 | Indonesia     | 8% of mothers and 29% of fathers lost job                                    | Fewer mothers lost job (8% vs. 29%) | -               | -             |                |                |             |             |                |      |        |
| Okada(2014)  | 2014 | Japan         | 31% quit job 38% took extended leave                                          | -               | -               | -             | Quit job/extended leave‡ | Lower work motivation Less social support |                | |
| Country        | 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) | Income Reduction† | CNS Tumour, Germ Cell Tumour, Leukaemia(Mothers) | Younger Age at Dx(Mothers) | Higher Education(Mothers) | Not Being Married(Fathers) |
|---------------|------------------------------------------|-----------------------------------------------|-------------------------------------------------------|-------------------|-----------------------------------------------|--------------------------|----------------------------|--------------------------|
| Finland       | Family income similar to comparison families | -                                             | Income remains similar from 3 to 12 months after dx(T1-T2) | -                 | Income reduction† | CNS tumour, germ cell tumour, leukaemia (mothers) | Younger age at dx (mothers) | Higher education (mothers) | Not being married (fathers) |
| Norway        | Minor effects on income                  | Non-significant 4% reduction in mothers’ income | Maternal income reductions more pronounced ≥5 years after dx | Maternal income reductions more pronounced ≥5 years after dx | Maternal income reductions more pronounced ≥5 years after dx | Maternal income reductions more pronounced ≥5 years after dx | Maternal income reductions more pronounced ≥5 years after dx | Maternal income reductions more pronounced ≥5 years after dx |
| Switzerland   | Lower household income than comparison parents | -                                             | -                                                      | -                 | -                                             | -                         | -                          | -                         |
| Norway        | Income decreased after dx and thereafter remained lower than comparison parents | Longer income reductions in mothers after dx | Income of mothers reduced until 7 years after dx | Income of mothers reduced until 7 years after dx | Income of mothers reduced until 7 years after dx | Income of mothers reduced until 7 years after dx | Income of mothers reduced until 7 years after dx | Income of mothers reduced until 7 years after dx |
| Switzerland   | Income decreased after dx and thereafter remained lower than comparison parents | Longer income reductions in mothers after dx | Income of mothers reduced until 2 years after dx | Income of mothers reduced until 2 years after dx | Income of mothers reduced until 2 years after dx | Income of mothers reduced until 2 years after dx | Income of mothers reduced until 2 years after dx | Income of mothers reduced until 2 years after dx |
| Sweden        | Income decreased after dx and thereafter remained lower than comparison parents | Longer income reductions in mothers after dx | Income of mothers reduced until 2 years after dx | Income of mothers reduced until 2 years after dx | Income of mothers reduced until 2 years after dx | Income of mothers reduced until 2 years after dx | Income of mothers reduced until 2 years after dx | Income of mothers reduced until 2 years after dx |
| United Kingdom| 43% reported financial impact due to income loss | Financial impact more often due to fathers’ income loss (18% vs. 12%) | -                                                      | -                 | Lower income† | Male child | -                         | -                         |

North America and Australia

| Country        | Decrease in income from salary | Income from salary increased with time since dx | Lower income from salary† | Younger age at dx |
|---------------|-------------------------------|------------------------------------------------|---------------------------|------------------|
| Canada        | Decrease in income from salary | -                                             | Lower income from salary† | Younger age at dx |
| United States | Income loss of 22% (36% lost >40% of annual income) | Income loss of 22% until >1 year after treatment(T3) | -                         | -                |
| United States | Income loss of 7% (25% lost >40% of annual income) | Income loss of 7% until 6 months after dx(T2) | -                         | -                |
| United States | Income loss of 20% (14% lost >40% of annual income) | -                                             | -                         | -                |
| United States | 60% reported income loss of >10% | -                                             | -                         | -                |
| Reference | Country     | Description                                                                 | Financial situation                                                                 |
|-----------|-------------|-----------------------------------------------------------------------------|------------------------------------------------------------------------------------|
| Heath (2006) | Australia   | Great income loss in first 12 months after dx                               | -                                                                                 |
| Goodenough (2004) | Australia | Family income loss of 53%                                                  | Income loss†                                                                        |
| Cohn (2003) | Australia   | One third reported income loss                                              | Leukaemia                                                                          |
| Dockerty (2003) | New Zealand | 43% reported income increase                                                 | 23% reported income loss                                                           |
| Asia and Africa |            |                                                                             |                                     |
| Sneha (2017) | India       | Majority reported income loss                                               | More mothers reported income loss                                                  |
| Ghatak (2016) | India       | 72% reported income loss                                                    |                                     |
| Mostert (2008) | Indonesia | 69% reported income loss                                                    |                                     |
| Njuguna (2015) | Kenya       | 66% reported income loss                                                    |                                     |
| Europe     |             |                                                                             |                                     |
| Lähteenmäki (2004) | Finland | >40% reported significant financial impact                                  | Financial impact similar 3 and 12 months after dx: 42%(T1), 43%(T2)                 |
| Mader (2017) | Switzerland | Higher risk-of-poverty than comparison parents                              | No association with time since dx                                                  |
| Hoven (2019) | Sweden      | 18% reported significant financial burden                                   | No association with time since dx                                                  |
| Enskar (2011) | Sweden      | Majority reported financial situation became worse                          | Financial situation worse on compared to off treatment (mothers: 86% vs. 66%; fathers: 87% vs. 63%) |
| Eiser (2006) | United Kingdom | 55% reported cancer-related expenses                                        | Cancer-related expenses highest in first 6 months after dx                          |
| North America and Australia |            |                                                                             |                                     |
| Tsimicalis (2012) | Canada | 37% of annual income for cancer-related expenses                            | Expenses†                                                                          |
| Bilodeau (2018) | United States | 44% reported great financial hardship                                        | Rural residency                                                                     |
| Bona (2016) | United States | 56% reported moderate/great financial hardship                             | Higher income                                                                       |
| Warner (2014) | United States | Mean financial burden 67/100                                               | No association with time since dx                                                  |
| Bona (2014) | United States | 28% reported great financial hardship                                        | Financial burden‡                                                                   |

† Income loss
‡ Financial impact
§ Risk-of-poverty
†† Language
‡‡ Lower education
¶ Health of child
††† Unmet care needs
§§ Financial burden
¶¶ Active treatment
¶¶¶ Expenses
†††† Single parenthood
¶¶¶¶ Active treatment
¶¶¶¶¶ Relapse
¶¶¶¶¶¶ Money worries
††††† Rural residency
‡‡‡‡ Higher income
‡‡‡‡‡ More hospitalizations
‡‡‡‡‡‡ Quitting/changing job
¶¶¶¶¶¶¶ Rural residency
| Study | Country | Financial impact | Rural residency | Longer travel time to centre | Financial hardship | Lower education(US) | Younger age(US) | Poverty | Income loss |
|-------|---------|-----------------|----------------|-----------------------------|------------------|--------------------|-----------------|--------|-------------|
| Fluchel(2014)<sup>14</sup> | United States | Mean financial burden 66/100 | - | - | - | - | - | - | - |
| Dussel(2011)<sup>11</sup> | United States | 24% in US and 39% in Australia reported great financial hardship | - | - | - | - | - | - | - |
| Monterosso(2009)<sup>10</sup> | Australia | 41% reported high financial burden | - | - | - | - | - | - | - |
| Heath(2006)<sup>9</sup> | Australia | 74% reported great/moderate financial hardship | - | - | - | - | - | - | - |
| Cohn(2003)<sup>8</sup> | Australia | 80% reported ≥5 types of cancer-related expenses | - | - | - | - | - | - | - |
| Dockerty(2003)<sup>7</sup> | New Zealand | Mean financial burden 48/100 | - | - | - | - | - | - | - |
| Asia and Africa | | | | | | | | | |
| Sneha(2017)<sup>6</sup> | India | Majority reported financial burden 68% reported debts | - | - | - | - | - | - | - |
| Ghatak(2016)<sup>5</sup> | India | Cancer-related expenses exceeded family income | - | - | - | - | - | - | - |
| Mostert(2008)<sup>4</sup> | Indonesia | 78% reported financial difficulties 65% reported debts 18% withhold treatment due to finances | - | - | - | - | - | - | - |
| Aung(2012)<sup>3</sup> | Singapore | Financial burden second highest family impact | - | - | - | - | - | - | - |
| Njuguna(2015)<sup>2</sup> | Kenya | 83% reported great financial burden 64% reported debts 28% withhold treatment due to finances | - | - | - | - | - | - | - |
| Financial assistance | | | | | | | | | |
| Europe | | | | | | | | | |
| Lahteenmaki(2004)<sup>1</sup> | 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)<sup>1</sup> | 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<sup>†</sup> Child death Lower education(mothers) Childcare Benefits(mothers)<sup>†</sup> Single parenthood Unemployment benefits<sup>†</sup> Parent-couple household(fathers) | - | - | - | - | - |

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| Study (Year) | Region | Main Finding | Comment |
|-------------|--------|--------------|---------|
| Hjelmstedt (2017) | Sweden | More sickness benefits than comparison parents (at dx: mothers 42% vs. 17%, fathers 33% vs. 9%) | 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. |
| Wikman (2016) | 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%). |
| Hoven (2013) | Sweden | Highest proportion of sick leave during treatment | 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). |
| Eiser (2006) | 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. |
| North America and Australia | | | |
| Limburg (2008) | 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). |
| Bona (2016) | United States | 34% taking leave received pay | - |
| Bona (2014) | United States | 51% used fundraising | - |
| Dussel (2011) | United States/Australia | 52% in US and 33% in Australia used fundraising | - |
| Monterosso (2009) | Australia | 4% took paid leave | Financial assistance² Younger age at dx. |
| Heath (2006) | Australia | 50% took sick leave/vacation | Large variation in assistance from governmental and non-governmental sources. |
| Goodenough (2004) | Australia | 68% received assistance for living expenses | - |
| Cohn (2003) | Australia | 35% took annual/sick leave | Financial assistance². |
| Country         | Region | Year | Assistance | Paid Leave | Family Care Leave | Sick/Child Care Leave | Expenses | Rural Residency |
|----------------|--------|------|------------|------------|-------------------|-----------------------|----------|-----------------|
| New Zealand    |        | 2003 | No assistance for most cancer-related expenses | -          | -                | -                 | -        |                 |
| India          | Asia and Africa | 2016 | 89% received assistance from governmental and non-governmental sources | 12% took paid leave | 78% received assistance from governmental and non-governmental sources | - | -   |
| Indonesia      | Asia and Africa | 2008 | 61% requested assistance from family | - | - | - | - |
| Japan          | Asia and Africa | 2014 | Fewer mothers took paid leave (2% vs. 10%) | 6% took family care leave | 6% took sick/child care leave | - | - |
| Singapore      | Asia and Africa | 2012 | 61% received assistance | - | - | - | - |
| Kenya          | Asia and Africa | 2015 | 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