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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 routine[1]. This is particularly challenging for the parents who are confronted with the potential fatality of the disease and conflicting caregiving, emotional, and practical demands[2]. The child's acute treatment requires frequent hospitalizations, invasive procedures, and depending on the cancer type, a combination of surgery, chemotherapy, and radiotherapy[3]. 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 treatment[6], long-term follow-up care is recommended for childhood cancer survivors[7]. 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 treatment[10]. Moreover, many parents are confronted with medical and non-medical expenditures[11-16]. 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 tasks[18]. 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[19]. 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 survivors[21] (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[20], 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[22].

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[23]. 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[24-58], 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 fathers[55]. However, two studies from Australia[49] and the UK[36] 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 Sweden[28] and Switzerland[35] 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 Norway[25] and Finland[24] found no effects on income and one study from New Zealand[52] 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 mothers[53] or fathers[36]. 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 Sweden[32] to 83% in Kenya[58]. 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 strains[44]. 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 diagnosis[39]. 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 expenses[51]. 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 residency[51], 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 treatment[59]. 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[25]. More pronounced employment disruptions among mothers may be explained by traditional parenting roles typically accrediting mothers the role of the child´s primary caregiver[18]. 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[28]. 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[60]. However, an alternative explanation for prolonged changes may arise from altered priorities related to family life following the cancer experience[12]. 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 network[61]. 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[62]. 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 life[64].

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[65]. Finally, the explanatory power of the NOS for appraising study quality is limited as sample size is not considered[21]. 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[40]. In 2015, standards for psycho-social care of children with cancer were published[66] including a recommendation for assessing family financial hardship[67]. 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[68] and only half of paediatric oncologists and psychosocial leaders agreed that their psychosocial care is state of the art[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[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[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[5,71-73].

References

1. Long KA, Marsland AL. Family adjustment to childhood cancer: a systematic review. Clin Child Fam Psychol Rev 2011;14(1):57-88.

2. Sulkers E, Tissing WJ, Brinksma A, Roodbol PF, Kamps WA, Stewart RE, Sanderman R, Fleer J. Providing care to a child with cancer: a longitudinal study on the course, predictors, and impact of caregiving stress during the first year after diagnosis. Psychooncology 2015;24:318-24.

3. Alderfer MA, Navsaria N, Kazak AE. Family functioning and posttraumatic stress disorder in adolescent survivors of childhood cancer. J Fam Psychol 2009;23(5):717-25.

4. James K, Keegan-Wells D, Hinds PS, Kelly KP, Bond D, Hall B, Mahan R, Moore IM, Roll L, Speckhart B. The care of my child with cancer: parents' perceptions of caregiving demands. J Pediatr Oncol Nurs 2002;19(6):218-28.

5. Klassen A, Raina P, Reineking S, Dix D, Pritchard S, O'Donnell M. Developing a literature base to understand the caregiving experience of parents of children with cancer: a systematic review of factors related to parental health and well-being. Support Care Cancer 2007;15(7):807-18.

6. Hudson MM, Armenian SH, Armstrong GT, Chow EJ, Henderson TO. Optimization of Health and Extension of Lifespan Through Childhood Cancer Survivorship Research. J Clin Oncol 2018:JCO2018790477.

7. Byrne J, Alessi D, Allodji RS, Bagnasco F, Bardi E, Bautz A, Bright CJ, Brown M, Diallo I, Feijen E, Fidler MM, Frey E, Garwicz S, Grabow D, Gudmundsdottir T, Hagberg O, Harila-Saari A, Hau EM, Haupt R, Hawkins MM, Jakab Z, Jankovic M, Kaatsch P, Kaiser M, Kremer LCM, Kuehni CE, Kuonen R, Ladenstein R, Lahteenmaki PM, Levitt G, Linge H, D LL, Michel G, Morsellino V, Mulder RL, Reulen RC, Ronckers

CM, Sacerdote C, Skinner R, Steliarova-Foucher E, van der Pal HJ, de Vathaire F, Vu Bezin G, Wesenberg F, Wiebe T, Winter DL, Falck Winther J, Witthoff E, Zadravec Zaletel L, Hjorth L. The PanCareSurFup consortium: research and guidelines to improve lives for survivors of childhood cancer. Eur J Cancer 2018;103:238-48.

8. Doshi K, Kazak AE, Hocking MC, DeRosa BW, Schwartz LA, Hobbie WL, Ginsberg JP, Deatrick J. Why mothers accompany adolescent and young adult childhood cancer survivors to follow-up clinic visits. J Pediatr Oncol Nurs 2014;31(1):51-7.

9. Vetsch J, Rueegg CS, Mader L, Bergstraesser E, Rischewski J, Kuehni CE, Michel G, Swiss Paediatric Oncology G. Follow-up care of young childhood cancer survivors: attendance and parental involvement. Support Care Cancer 2016;24(7):3127-38.

10. Santacroce SJ, Tan KR, Killela MK. A systematic scoping review of the recent literature (approximately 2011-2017) about the costs of illness to parents of children diagnosed with cancer. Eur J Oncol Nurs 2018;35:22-32.

11. Tsimicalis A, Stevens B, Ungar WJ, McKeever P, Greenberg M, Agha M, Guerriere D, Naqvi A, Barr R. A mixed method approach to describe the out-of-pocket expenses incurred by families of children with cancer. Pediatr Blood Cancer 2013;60(3):438-45.

12. Wakefield CE, McLoone JK, Evans NT, Ellis SJ, Cohn RJ. It's more than dollars and cents: the impact of childhood cancer on parents' occupational and financial health. J Psychosoc Oncol 2014;32(5):602-21.

13. Barr RD, Furlong W, Horsman JR, Feeny D, Torrance GW, Weitzman S. The monetary costs of childhood cancer to the families of patients. Int J Oncol 1996;8(5):933-40.

14. Bloom BS, Knorr RS, Evans AE. The epidemiology of disease expenses. The costs of caring for children with cancer. JAMA 1985;253(16):2393-7.

15. Lansky SB, Black JL, Cairns NU. Childhood cancer. Medical costs. Cancer 1983;52(4):762-6.

16. Lansky SB, Cairns NU, Clark GM, Lowman J, Miller L, Trueworthy R. Childhood cancer: nonmedical costs of the illness. Cancer 1979;43(1):403-8.

17. Tsimicalis A, Stevens B, Ungar WJ, McKeever P, Greenberg M. The cost of childhood cancer from the family's perspective: a critical review. Pediatr Blood Cancer 2011;56(5):707-17.

18. Clarke NE, McCarthy MC, Downie P, Ashley DM, Anderson VA. Gender differences in the psychosocial experience of parents of children with cancer: a review of the literature. Psychooncology 2009;18(9):907-15.

19. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 2009;6(7):e1000097.

20. Wells GA, Shea B, D. OC, Peterson J, Welch V, Losos M, Tugwell P. The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analyses. Ottawa, Canada: Ottawa Hospital Research Institute [last accessed 05.10.2018]. Available from: www.ohri.ca/programs/clinical_epidemiology/oxford.asp.

21. Frederiksen LE, Mader L, Feychting M, Mogensen H, Madanat-Harjuoja L, Malila N, Tolkkinen A, Hasle H, Winther JF, Erdmann F. Surviving childhood cancer: A systematic review of studies on risk and determinants of adverse socioeconomic outcomes. Int J Cancer 2018.

22. Kristman V, Manno M, Cote P. Loss to follow-up in cohort studies: how much is too much? Eur J Epidemiol 2004;19(8):751-60.

23. Mader L, Michel G, Roser K. Unemployment Following Childhood Cancer. Dtsch Arztebl Int 2017;114(47):805-12.

24. Lahteenmaki PM, Sjoblom J, Korhonen T, Salmi TT. The life situation of parents over the first year after their child's cancer diagnosis. Acta paediatrica 2004;93(12):1654-60.

25. Syse A, Larsen IK, Tretli S. Does cancer in a child affect parents' employment and earnings? A population-based study. Cancer Epidemiol 2011;35(3):298-305.

26. Hiyoshi A, Montgomery S, Bottai M, Hoven EI. Trajectories of income and social benefits for mothers and fathers of children with cancer: A national cohort study in Sweden. Cancer 2018.

27. Hjelmstedt S, Lindahl Norberg A, Montgomery S, Hed Myrberg I, Hoven E. Sick leave among parents of children with cancer - a national cohort study. Acta Oncol 2017;56(5):692-7.

28. Lindahl Norberg A, Montgomery SM, Bottai M, Heyman M, Hoven EI. Short-term and long-term effects of childhood cancer on income from employment and employment status: A national cohort study in Sweden. Cancer 2016;123:1238-48.

29. Hoven E, Gronqvist H, Poder U, von Essen L, Lindahl Norberg A. Impact of a child's cancer disease on parents' everyday life: a longitudinal study from Sweden. Acta Oncol 2017;56(1):93-100.

30. Wikman A, Hoven E, Cernvall M, Ljungman G, Ljungman L, von Essen L. Parents of children diagnosed with cancer: work situation and sick leave, a five-year post end-of-treatment or a child's death follow-up study. Acta Oncol 2016:1-6.

31. Hoven E, von Essen L, Norberg AL. A longitudinal assessment of work situation, sick leave, and household income of mothers and fathers of children with cancer in Sweden. Acta Oncol 2013;52(6):1076-85.

32. Hoven EI, Lannering B, Gustafsson G, Boman KK. Persistent impact of illness on families of adult survivors of childhood central nervous system tumors: a population-based cohort study. Psychooncology 2013;22:160-7.

33. Enskar K, Hamrin E, Carlsson M, von Essen L. Swedish mothers and fathers of children with cancer: perceptions of well-being, social life, and quality care. J Psychosoc Oncol 2011;29(1):51-66.

34. Mader L, Roser K, Baenziger J, Tinner EM, Scheinemann K, Kuehni CE, Michel G. Household income and risk-of-poverty of parents of long-term childhood cancer survivors. Pediatr Blood Cancer 2017;64(8):1-12.

35. Mader L, Rueegg CS, Vetsch J, Rischewski J, Ansari M, Kuehni CE, Michel G. Employment Situation of Parents of Long-Term Childhood Cancer Survivors. PloS one 2016;11(3):e0151966.

36. Eiser C, Upton P. Costs of caring for a child with cancer: a questionnaire survey. Child Care Health Dev 2007;33(4):455-9.

37. Tsimicalis A, Stevens B, Ungar WJ, McKeever P, Greenberg M, Agha M, Guerriere D, Barr R, Naqvi A, Moineddin R. A prospective study to determine the costs incurred by families of children newly diagnosed with cancer in Ontario. Psychooncology 2012;21(10):1113-23.

38. Limburg H, Shaw AK, McBride ML. Impact of childhood cancer on parental employment and sources of income: a Canadian pilot study. Pediatr Blood Cancer 2008;51(1):93-8.

39. Bilodeau M, Ma C, Al-Sayegh H, Wolfe J, Bona K. Household material hardship in families of children post-chemotherapy. Pediatr Blood Cancer 2018;65(1).

40. Bona K, London WB, Guo D, Frank DA, Wolfe J. Trajectory of Material Hardship and Income Poverty in Families of Children Undergoing Chemotherapy: A Prospective Cohort Study. Pediatr Blood Cancer 2016;63(1):105-11.

41. Zamora ER, Kaul S, Kirchhoff AC, Gwilliam V, Jimenez OA, Morreall DK, Montenegro RE, Kinney AY, Fluchel MN. The impact of language barriers and immigration status on the care experience for Spanish-speaking caregivers of patients with pediatric cancer. Pediatr Blood Cancer 2016;63(12):2173-80.

42. Warner EL, Kirchhoff AC, Nam GE, Fluchel M. Financial Burden of Pediatric Cancer for Patients and Their Families. J Oncol Pract 2014;11:12-8.

43. Lau S, Lu X, Balsamo L, Devidas M, Winick N, Hunger SP, Carroll W, Stork L, Maloney K, Kadan-Lottick N. Family life events in the first year of acute lymphoblastic leukemia therapy: a children's oncology group report. Pediatr Blood Cancer 2014;61(12):2277-84.

44. Bona K, Dussel V, Orellana L, Kang T, Geyer R, Feudtner C, Wolfe J. Economic impact of advanced pediatric cancer on families. J Pain Symptom Manage 2014;47(3):594-603.

45. Fluchel MN, Kirchhoff AC, Bodson J, Sweeney C, Edwards SL, Ding Q, Stoddard GJ, Kinney AY. Geography and the burden of care in pediatric cancers. Pediatr Blood Cancer 2014;61(11):1918-24.

46. Bennett Murphy LM, Flowers S, McNamara KA, Young-Saleme T. Fathers of children with cancer: involvement, coping, and adjustment. J Pediatr Health Care 2008;22(3):182-9.

47. Dussel V, Bona K, Heath JA, Hilden JM, Weeks JC, Wolfe J. Unmeasured costs of a child's death: perceived financial burden, work disruptions, and economic coping

strategies used by American and Australian families who lost children to cancer. J Clin Oncol 2011;29(8):1007-13.

48. Monterosso L, Kristjanson LJ, Phillips MB. The supportive and palliative care needs of Australian families of children who die from cancer. Palliative medicine 2009;23(6):526-36.

49. Heath JA, Lintuuran RM, Rigguto G, Tokatlian N, McCarthy M. Childhood cancer: its impact and financial costs for Australian families. Pediatr Hematol Oncol 2006;23(5):439-48.

50. Goodenough B, Foreman T, Suneson J, Cohn RJ. Change in family income as a correlate for use of social work services: An Australian study in pediatric oncology. J Psychosoc Oncol 2004;22(2):57-73.

51. Cohn RJ, Goodenough B, Foreman T, Suneson J. Hidden financial costs in treatment for childhood cancer: an Australian study of lifestyle implications for families absorbing out-of-pocket expenses. J Pediatr Hematol Oncol 2003;25(11):854-63.

52. Dockerty JD, Skegg DC, Williams SM. Economic effects of childhood cancer on families. J Paediatr Child Health 2003;39(4):254-8.

53. Sneha LM, Sai J, Sunitha Ashwini S, Ramaswamy SM, Rajan M, Scott JX. Financial burden faced by families due to out-of-pocket expenses during the treatment of their cancer children: An Indian perspective. Indian Journal of Medical and Paediatric Oncology 2017;38(1):4-9.

54. Ghatak N, Trehan A, Bansal D. Financial burden of therapy in families with a child with acute lymphoblastic leukemia: report from north India. Support Care Cancer 2016;24(1):103-8.

55. Mostert S, Sitaresmi MN, Gundy CM, Sutaryo, Veerman AJ. Parental experiences of childhood leukemia treatment in indonesia. J Pediatr Hematol Oncol 2008;30(10):738-43.

56. Okada H, Maru M, Maeda R, Iwasaki F, Nagasawa M, Takahashi M. Impact of Childhood Cancer on Maternal Employment in Japan. Cancer Nurs 2015;38:23-30.

57. Aung L, Saw SM, Chan MY, Khaing T, Quah TC, Verkooijen HM. The hidden impact of childhood cancer on the family: a multi-institutional study from Singapore. Ann Acad Med Singapore 2012;41(4):170-5.

58. Njuguna F, Mostert S, Seijffert A, Musimbi J, Langat S, van der Burgt RH, Skiles J, Sitaresmi MN, van de Ven PM, Kaspers GJ. Parental experiences of childhood cancer treatment in Kenya. Support Care Cancer 2015;23(5):1251-9.

59. Schindler M, Kuehni C. Betreuungsaufwand für Eltern von Kindern und Jugendlichen mit Krebs in der Schweiz [Caregiver burden of parents of children and adolescents with cancer in Switzerland]. Swiss Childhood Cancer Registry, Institute of Social and Preventive Medicine, University of Bern, 2014.

60. Aisenbrey S, Evertsson M, Grunow D. Is There a Career Penalty for Mothers' Time Out? A Comparison of Germany, Sweden and the United States. Soc Forces 2009;88(2):573-605.

61. Tsimicalis A, Stevens B, Ungar WJ, Greenberg M, McKeever P, Agha M, Guerriere D, Barr R, Naqvi A, Moineddin R. Determining the costs of families' support networks following a child's cancer diagnosis. Cancer Nurs 2013;36(2):E8-E19.

62. Marmot M. Social determinants of health inequalities. Lancet 2005;365(9464):1099-104.

63. Pui CH, Carroll WL, Meshinchi S, Arceci RJ. Biology, risk stratification, and therapy of pediatric acute leukemias: an update. J Clin Oncol 2011;29(5):551-65.

64. Pagano E, Baldi I, Mosso ML, di Montezemolo LC, Fagioli F, Pastore G, Merletti F. The economic burden of caregiving on families of children and adolescents with cancer: a population-based assessment. Pediatr Blood Cancer 2014;61(6):1088-93.

65. van de Mortel TF. Faking it: social desirability response bias in self-report research. Aust J Adv Nurs 2008;25(4):40-8.

66. Wiener L, Kazak AE, Noll RB, Patenaude AF, Kupst MJ. Standards for the Psychosocial Care of Children With Cancer and Their Families: An Introduction to the Special Issue. Pediatr Blood Cancer 2015;62(S5):S419-S24.

67. Pelletier W, Bona K. Assessment of Financial Burden as a Standard of Care in Pediatric Oncology. Pediatr Blood Cancer 2015;62 (Suppl 5):S619-31.

68. Scialla MA, Canter KS, Chen FF, Kolb EA, Sandler E, Wiener L, Kazak AE. Implementing the psychosocial standards in pediatric cancer: Current staffing and services available. Pediatr Blood Cancer 2017;64(11).

69. Scialla MA, Canter KS, Chen FF, Kolb EA, Sandler E, Wiener L, Kazak AE. Delivery of care consistent with the psychosocial standards in pediatric cancer: Current practices in the United States. Pediatr Blood Cancer 2018;65(3).

70. Zheng DJ, Shyr D, Ma C, Muriel AC, Wolfe J, Bona K. Feasibility of systematic poverty screening in a pediatric oncology referral center. Pediatr Blood Cancer 2018;65(12):e27380.

71. Kearney JA, Salley CG, Muriel AC. Standards of Psychosocial Care for Parents of Children With Cancer. Pediatr Blood Cancer 2015;62 (Suppl 5):S632-83.

72. Van Schoors M, Caes L, Knoble NB, Goubert L, Verhofstadt LL, Alderfer MA, Guest Editors: Cynthia A. Gerhardt CABDJW, Grayson NH. Systematic Review: Associations Between Family Functioning and Child Adjustment After Pediatric Cancer Diagnosis: A Meta-Analysis. J Pediatr Psychol 2017;42(1):6-18.

73. Alderfer MA, Long KA, Lown EA, Marsland AL, Ostrowski NL, Hock JM, Ewing LJ. Psychosocial adjustment of siblings of children with cancer: a systematic review. Psychooncology 2010;19(8):789-805.

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					
Europe					
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	Employment[†] 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	Unemployment(mothers)[†] 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)	Work restrictions[‡] 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)	Unemployment[†] 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	Unemployment[†] 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%)	-	-
North America and Australia					
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%)	-	Work leave[‡] 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
Asia and Africa					
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					

Europe					
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%)	-	-
North America and Australia					
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%	-	-	Income loss‡ 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	Risk-of-poverty† Lower education Language
Hoven(2013)[32]	Sweden	18% reported significant financial burden	-	No association with time since dx	Financial burden† 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%)	Financial burden† 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	Expenses‡ Active treatment Relapse Money worries‡ Single parenthood
North America and Australia					
Tsimicalis(2012)[37]	Canada	37% of annual income for cancer-related expenses	-	-	Expenses‡ 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)	Material hardship† Lower income
Warner(2014)[42]	United States	Mean financial burden 67/100	-	No association with time since dx	Financial burden† 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
Asia and Africa					
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					
Europe					
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	Sickness benefit days[†] 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)	Sick leave[†] 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%)	-	-
North America and Australia					
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)	Financial assistance[‡] 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	-	-	Fundraising[‡] 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	-	-	Financial assistance[‡] Income loss
Cohn(2003)[51]	Australia	35% took annual/sick leave	-	-	Financial assistance[‡]

		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	-	-	-
Asia and Africa					
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.

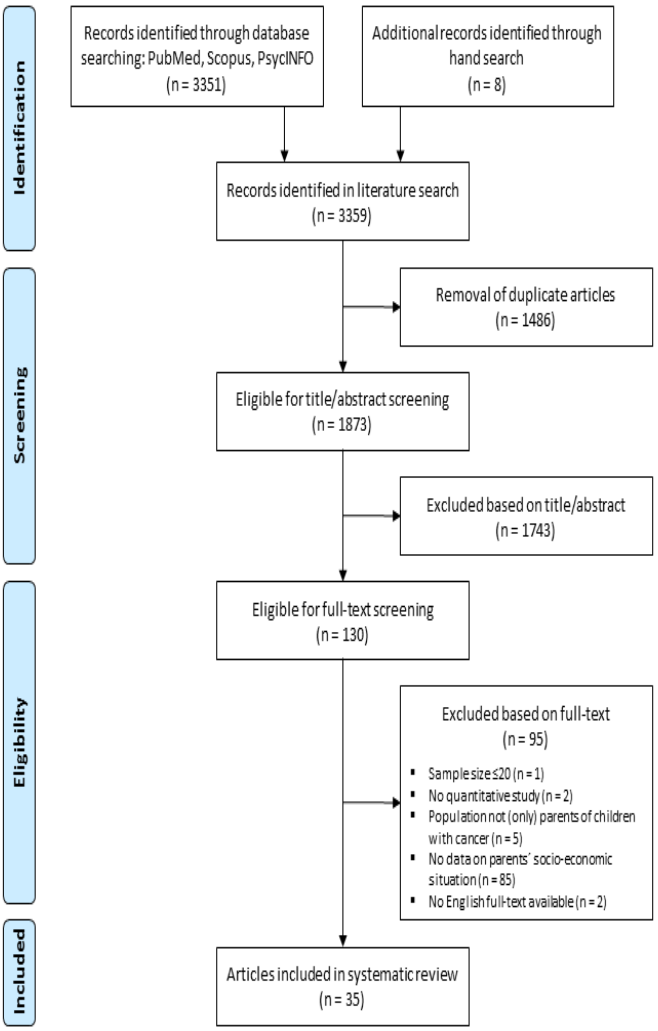

Figure 1. Flow chart of inclusion and exclusion of identified articles