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Assessment of Financial Burden as a Standard of Care in Pediatric Oncology

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Family financial hardship has emerged as a burden of pediatric cancer treatment with negative implications for family well-being. As part of an extensive project to create evidence-based standards for the psychosocial care of children with cancer, we performed a literature review of pediatric cancer-associated financial hardship utilizing six databases, and identified 24 publications for incorporation into this review. Financial hardship during childhood cancer was found to affect a significant proportion of the population and to negatively impact family well-being. Existing literature supports a strong recommendation for assessment of financial hardship as a component of comprehensive psychosocial care in pediatric oncology. Pediatr Blood Cancer 2015;62:S619–S631. © 2015 Wiley Periodicals, Inc.

Key words: pediatric oncology; psychosocial; quality of life; support care

INTRODUCTION

Family financial hardship as a consequence of childhood cancer treatment has been documented over the past three decades,[1–6] and the economic burden of caring for a child with cancer has been described as a significant source of distress for families.[3,7–9] Data suggest that financial hardship during childhood cancer treatment has implications for family economic status,[5,6,10–12] parental emotional and mental health,[3,8,13] and potentially child well-being. Efforts to identify and address family financial hardship are essential to the provision of comprehensive care for children with cancer. The primary objective of this review was to assess the existing literature on family financial burden in childhood cancer to determine whether the evidence-base supports incorporation of financial hardship assessment into pediatric cancer care, and to evaluate the quality of existing assessment tools.

METHODS

This review was performed as part of the collaborative *Standards for Psychosocial Care of Children with Cancer and Their Families* effort. For a full description of the methods used to develop each standard, refer to Wiener, Kazak, Noll, Patenaude, Kupst.[14] PubMed, Medline, CINAHL, PsychINFO, Google Scholar, OVID were searched using the terms [“economic aspects of illness” OR “cost of illness” OR “health care costs” OR “financial burden” OR “economic burden” OR “out of pocket”] AND [“neoplasms”]. Results were limited to English-language only publications from March 1, 1995 to March 1, 2015 including data on children aged less than 18 years with cancer. Due to the focus on family financial hardship, studies reporting solely on hospital costs or cost-effectiveness without consideration of family financial impact were excluded. A hand-search of the reference lists from relevant review articles and all eligible studies was additionally performed. The title and abstract of all citations obtained through the search strategy were screened, and full texts were obtained for in-depth review of potentially eligible studies.

The study team comprised a pediatric oncology social worker and pediatric oncology physician–researcher who jointly reviewed all articles. Expert opinion was elicited from additional representatives of pediatric oncology and pediatric oncology social work. Consultative reviewers indicated that the strengths and limitations of the body of evidence were clearly described and that there was an explicit link between the recommendations and the supporting evidence. Utilizing the GRADE (Grading Recommendations Assessment, Development and Evaluation) system, evidence tables were rated for the quality and strength of evidence.[15]

Psychosocial Standard of Care

Pediatric oncology families are at high risk for financial burden during cancer treatment with associated negative implications for quality of life and parental emotional health.

- Assessment of risk for financial hardship should be incorporated at time of diagnosis for all pediatric oncology families. Domains of assessment should include risk factors for financial hardship during therapy including: pre-existing low-income or financial hardship, single parent status, distance from treating center, anticipated long/intense treatment protocol, and parental employment status.
- Targeted referral for financial counseling and supportive resources (including both governmental and charitable supports) should be offered based on results of family assessment.
- Longitudinal reassessment and intervention should occur throughout the cancer treatment trajectory and into survivorship or bereavement.

Abbreviations: GRADE, grading recommendations assessment, development and evaluation

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RESULTS

Of the 42 initially identified studies, 14 failed to meet inclusion criteria based on abstract/title alone and 28 were potentially eligible. Of these 28, two were excluded because they fell outside of the acceptable publication dates, one was excluded as it was not published in a peer-reviewed journal, and one was excluded for failure to include a consideration of family financial impact.

Twenty-four studies were ultimately incorporated into this review. Of these, two articles were systematic reviews or meta analyses of controlled studies or evidence-based clinical practice guidelines, one article was a quasi-experimental study, four articles were non-experimental studies (case-control, cohort), and 17 articles were individual descriptive studies.

Supplemental Table I includes the 24 studies identified and briefly summarizes each study with regard to study design, sample characteristics, main findings related to this standard, study rigor, and level of evidence. All publications report findings of family financial burden due to childhood cancer treatment across a range of healthcare and insurance models which support the need for standardized incorporation of financial assessment into pediatric cancer care models.[4,5,12,16] Studies considered the economic and financial impact of childhood cancer on families across two primary domains: direct costs including monetary expenditures due to illness, and indirect costs including the value of lost wages or productivity.

Out-of-pocket expenses due to travel, accommodation, childcare, food, gifts, and treats were identified as significant sources of financial burden.[4,16–18] Work disruptions as a result of a child's treatment were ubiquitously reported,[4–6,12,13,19,20] including at least one parent quitting a job to provide care for their child in 30–50% of families.[5,6,12,19,20] Variations in study design—including duration of follow-up and included costs—make precise reporting of the magnitude of financial costs to families challenging. However, income loss due to work disruptions and out-of-pocket expenses were estimated at over 30% of after-tax family income in two Canadian cohorts,[10,12] and over 50% of lower income families experienced annual income losses of >40% in a U.S. cohort.[6] Two studies exploring the economic consequences of such losses reported that approximately 15% of U.S. families fell from above to below the poverty line due to treatment-related financial burden.[5,6]

Characteristics at the time of diagnosis associated with highest risk for treatment-related financial burden included baseline low-income, single-parent status, longer treatment protocols, and receipt of care far from home.[3–5,16,20,21] One population-based study identified families of younger children and those with poorer prognoses as being at risk.[22] Caregivers who experienced employment disruptions reported higher financial burden suggesting a need for ongoing reassessment of risk.[23]

A handful of studies explored the consequences of family financial burden with uniform findings of negative impact on parental and family well-being. Financial hardship during a child's cancer care was documented to result in increased emotional distress for families,[3,13] increased burden on parental relationships,[3,24] and increased risk of serious psychological distress for parents.[8,9] These findings support a recommendation for standardized efforts to evaluate family financial needs as part of comprehensive psychosocial care in children with cancer.

Numerous studies explored parental patterns of coping with financial stressors. Parents reported use of governmental supports,[4,13] community resources and foundation funds.[5,13,25] Additional coping strategies included borrowing money from family and friends, selling property or mortgaging homes, taking on loans or credit card debt and reduced spending.[5,13,17,25] Despite these efforts, parents of children with cancer report a need for more practical guidance and financial support to mitigate the financial consequences of childhood cancer treatment and facilitate their care-giving capabilities.[1,5,13,17]

Data from a handful of reviewed studies suggest that financial burden persists well beyond the initial diagnostic and treatment time period. Income losses due to work disruptions were identified in numerous studies as significant contributors to family economic hardship,[5,6,10,18] and represent a variable which cannot be assessed at the time of diagnosis. Investigations of families of children with advanced cancer[5,6,8] report that approximately 25% of families endorse experiencing great economic hardship due to their child's illness. These data support the recommendation for longitudinal reassessment of family financial burden (Table I).

There were four notable limitations to the body of literature reviewed. First, no study in our review examined the impact of family financial hardship on child outcomes or well-being. Emerging evidence suggests that that the interrelated domain of family poverty may impact child cancer outcomes. Recent publications have identified family low-income as an independent predictor of both poor adherence to oral chemotherapy[26] and decreased overall survival for children treated for cancer.[27–29] Although it is plausible that poverty or low-income resulting from financial hardship during treatment may similarly mediate child cancer outcomes, this area requires further investigation. Second, no studies in our review reported on the success of efforts by care providers to prevent or ameliorate family financial hardship in pediatric cancer. It is notable that available governmental "safety-net" programs, including examples such as Medicaid and Supplemental Nutrition Assistance Program in the United States, and child support and employment insurance benefits in Canada[13,30] vary by country and healthcare system. Evidence from general pediatrics suggests that successful enrollment in such programs is beneficial to children and families.[31–34] Third, review of the literature demonstrates significant variability in domains of hardship assessed. Fourth, the appropriate interval and duration of assessment for family financial burden has not been identified in the literature, though multiple publications identify persistent hardship during survivorship and bereavement. Alignment of financial hardship assessments with standard time-points for supportive care or late-effects evaluation is thus reasonable until further research clarifies the trajectory of financial burden.

DISCUSSION

Review of data from 24 peer-reviewed studies published over the past 20 years demonstrates that pediatric oncology families are at high risk for financial hardship during cancer treatment with associated negative implications for quality of life and parental emotional health. Studies primarily included small, cross-sectional quantitative investigations.

Lack of awareness of the scope of family financial burden in pediatric cancer by health care providers, treating institutions, governmental agencies, pediatric cancer foundations, and pediatric

TABLE I. Summary of Assessment of Financial Burden as a Standard of Care in Pediatric Oncology

Standard	Evidence summary[a]	Methodology[b]	Quality of evidence[c]	Strength of recommendation[d]
Pediatric oncology families are at high risk for financial burden during cancer treatment with associated negative implications for quality of life and parental emotional health. Assessment of risk, referral to supports, and reassessment should occur across the treatment trajectory and into bereavement or survivorship.	Research on families of children with cancer indicates that financial hardship associated with treatment increases emotional distress for families, increases the burden on parental relationships, and increases the risk of serious psychological distress for parents.	Quantitative cross-sectional, and longitudinal studies; qualitative studies; mixed-methods; systematic literature review. Majority of studies were cross-sectional retrospective survey, and in-depth interviews. Consistent replication of findings evident across all reviewed papers.	Moderate quality of evidence given methodological limitations of most studies. Consistent findings across numerous investigations and methodological approaches (qualitative, cross-sectional, systematic review) bolster the overall strength of evidence.	Strong recommendation, given the serious consequences for parents and families of financial hardship associated with pediatric cancer treatment.

[a]Based on summary of evidence; [b]Types of studies: e.g., RCT, cross-sectional, longitudinal; consensus; systematic review articles; [c]Quality of evidence: High, moderate, low, and very low; [d]Strength of recommendation: Strong or weak (based on GRADE quality criteria).[15]

cancer families represents the most significant barrier to incorporation of routine assessment during the provision of psychosocial care to pediatric cancer families. Efforts to disseminate existing evidence on the high prevalence of financial hardship during treatment could feasibly be achieved through provider educational seminars and inclusion in family educational materials. Although families already overwhelmed by a child's diagnosis and care may not be in a position to identify and advocate for their financial needs, education of patient advocacy groups and foundations aimed at supporting pediatric cancer families have the potential to facilitate family advocacy. The lack of a standardized and comprehensive instrument with which to assess financial hardship is a major barrier to incorporation into standard care.

Finally, availability of psychosocial support resources varies significantly by institution. Recommendations within this standard are achievable within a variety of clinical contexts, and can be adapted to the availability of institutional resources. Addressing financial burden represents an essential component of comprehensive psychosocial care for pediatric cancer families, thus in settings with limited social work supports routine assessment could be performed by other clinical providers, including nurses, physicians or psychologists, with subsequent referral to social work as needed. Ongoing research to develop standardized screening tools and identify evidence-based interventions is needed. In the interim, attention to this domain of family burden within pediatric cancer has the potential to significantly improve the care of patients and families.

CONCLUSION

Although evidence for this recommendation is of moderate quality secondary to the methodological limitations of reviewed studies, the robustly congruent findings of significant financial burden across numerous investigations and diverse methodological approaches strengthen the data as a whole. Taken together, existing literature supports a strong recommendation for inclusion of a formal assessment of family financial hardship as detailed in the recommended standard in the provision of comprehensive psychosocial care to pediatric oncology families.

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SUPPLEMENTARY INFORMATION

SUPPLEMENTAL TABLE I. Assessment of Financial Burden as a Standard of Care in Pediatric Oncology

Study	Design	Sample	Findings	Study Rigor	Level of Evidence
Aung L, Saw SM, Chan MY, Khaing T, Quah TC, Verkooijen HM (2012) [1]	Cross-sectional Primary aim: To assess the financial, psychological, social and emotional impact of childhood cancer in Singapore. Self-administered survey study	Parents of children (age <21 years) with cancer receiving care at a regional referral center in Singapore N = 79 Single center	Financial Burden represented the second highest weighted score (3.41) of 4 domains on the Impact on Family Scale after Familial/Social Burden When compared to caregivers who remained employed, those who were asked to quit their job, or who took voluntary leave experienced a higher financial burden ($P = 0.03$) Recipients of financial aid experienced lower Financial Burden impact	Sample size sufficient Data collection appropriate to study method Descriptive statistics appropriate to sample; statistical methods for associations poorly described Good response rate (82%) Missing data not discussed	6
Barr R, Furlong W, Horsman J Feeny D, Torrance G, Weitzman S (1996) [2]	Two-part design: Retrospective, cross-sectional survey; Prospective, longitudinal diary collection Primary aim: To describe the monetary costs borne by pediatric cancer families and determine whether these costs represent an important component of illness burden	Families of children treated for high risk leukemia, Wilm's tumor (stages 2-5), and Neuroblastoma (stages 3 and 4) at one of two major referral centers in Canada N = 40 off-treatment families N = 64 on-treatment families Multi-center	Despite universal first dollar coverage for medical care in Canada, family-borne costs during the course of these three illnesses are at least one-third of the average family's after-tax income The mean total expenses in 1986 Canadian dollars incurred by families of childhood cancer patients over the entire course of therapy were $26,000 for leukemia, $20,074 for Wilm's tumor, and $10,376 for neuroblasmoma Ongoing weekly costs amount for the largest share of expenses	Sufficient sample size Data collection appropriate to study method Analysis appropriate (descriptive) Good response rates Missing data not well described	6

(*Continued*)

SUPPLEMENTAL TABLE I (*Continued*)

Study	Design	Sample	Findings	Study Rigor	Level of Evidence
Bona K, Dussel V, Kang T, Geyer JR, Feudtner C, Wolfe J (2014) [3]	Cross-sectional Primary aim: To describe parent-perceived financial hardship, work disruptions and income losses in families of children with advanced cancer via self-administered survey	Parents of children at least 2 years of age with progressive recurrent or non-responsive cancer treated at three pediatric U.S. referral centers N = 71 Multi-center	Parental work disruptions were prevalent across all income levels with 94% of families reporting some disruption due to child's illness. At least one parent quit a job because of the child's illness in 42% of families Income losses because of work disruption were substantial for all families; families at or below 200% Federal Poverty Level (FPL), were disproportionately affected 50% of the poorest families lost more than 40% of their annual income as compared with 5% of the wealthiest families ($P = 0.006$). 15% of previously non-poor families fell from above to below 200% FPL due to work related income losses 27% of families described their child's illness as a great economic hardship	Sufficient sample size Data collection appropriate to study method Analysis appropriate (descriptive statistics and univariate analyses) Underrepresentation of racial/ethnic minorities and non-English speaking families may underestimate results Cross-sectional nature does not allow for analysis of financial hardship over time Minimal missing data	6
Close P, Burkey E, Kazak A, Danz P, Lange B (1995) [4]	Pre-post-test without control group Primary aim: To compare billed medical charges, out-of-pocket expenses and quality of life for a course of IV chemotherapy administered in-hospital versus at home	Children with cancer receiving treatment at a major U.S. referral center. N = 14 Single-center	Daily charges for chemotherapy, out-of-pocket costs, and loss of income were less for home chemotherapy administration compared to hospital chemotherapy administration Administration of selected chemotherapy at home results in lower billed charges, reduced expenses, reduced loss of income for parents, and a more satisfying lifestyle for patients and parents	Sufficient sample size Data collection appropriate to study method Analysis appropriate (t-test) Selective patient population, unable to control for impact of time Missing data not described	3
Cohn RJ, Goodenough B, Foreman T, Suneson J (2003) [5]	Cross-sectional Primary aim: To document parent-perceived impact of out-of-pocket expenses on life-style utilizing self-administered survey	Parents of children with cancer in Australia N = 100 Single-center	80% reported a minimum of five different out-of- pocket expenses (total mean value = \$9,723 US or \$19,064 AUS) The most common out-of-pocket expenses included: travel, accommodation, communication costs, use of work-related entitlements, and changes in paid employment Out-of-pocket expenses had the greatest impact on the social domain (such as cancelling vacations and giving up recreational pleasures)	Sufficient sample size Data collection appropriate to study method Appropriate analysis Low response rate (47%), limited methods description, unclear recall period utilized for analysis Missing data not described	6

(*Continued*)

SUPPLEMENTAL TABLE I (*Continued*)

Study	Design	Sample	Findings	Study Rigor	Level of Evidence
Creswell PD, Wisk LE, Litzelman K, Allchin A, Witt WP (2014) [6]	Cross-sectional case-control Primary aim: To determine if caring for a child with cancer was related to clinically relevant depressive symptoms among parents, if financial difficulties mediate parental depressive symptoms, and if financial difficulties are independently associated with symptoms of parental depression. Interviewer-assisted surveys	Parents of children ages 2-18 years with cancer (cases) N = 75 Parents of healthy children recruited through research registries (controls) N = 140	Parents of children with cancer were more likely to experience depression (OR = 4.93; 95% CI 1.97-12.3). Negative financial events did not mediate this relationship However, among parents of children with cancer, negative financial events were independently associated with symptoms of parental depression (OR = 4.89; 95% CI 1.26-18.96)	Sufficient sample size Data collection appropriate to study method Analysis appropriate (multivariate logistic regression models) Cross-sectional nature does not allow for control of pre-diagnosis income as a confounding factor in analyses Power calculations not included, and null finding with regard to finances mediating link between child's cancer and parental depression may be due to sample size Minimal missing data, all well-described	4
Dockerty JD, Skegg DC, Williams SM (2003) [7]	Cross-sectional Primary aim: To assess financial impact of childhood cancer on families. Parents completed self-administered questionnaires	Parents of children with cancer in New Zealand. Cohort drawn from National Registry Parents N = 237 Children N = 192 (81%) living; N = 45 (19%) deceased Population-based	Average extra amount of money spent due to child's illness in the 30 days prior to study participation was 13% of a family's income after tax Expenditure was greater for those children who spent more time in hospital ($P = 0.003$) There was no significant association between the total cost and the distance travelled to the treatment center 37% of families reported that they needed to borrow money because of the financial effects of the child's illness Bereaved parents spent $3, 065 NZ on funeral expenses	Sufficient sample size Data collection appropriate to study method Appropriate analysis (descriptive) Good response rates, representative population Missing data not well-described	6
Dussel V, Bona K, Heath JA, Hilden JM, Weeks JC, Wolfe J (2011) [8]	Cross-sectional Primary aim: To describe bereaved parents' perceptions of the degree of economic hardship and work disruptions experienced due to their child's cancer and the economic coping strategies used to deal with such burdens. To explore child and family characteristics associated with financial hardship. Families completed self-administered retrospective survey	Bereaved American and Australian parents of children with cancer who died between 1990-1999 and 1996-2004 respectively N =230 Multi-center	24% of families from US centers and 39% of families from the Australia center reported a great deal of financial hardship resulting from their child's illness Work disruptions were substantial (84% in the US and 88% on Australia) 60% of families lost more than 10% of their annual income as a result of work disruptions. Poor families experienced the greatest income loss After accounting for income loss due to child's illness, 16% of US and 22% of Australian families dropped below the poverty line Fundraising was the most common coping strategy (52% in the US and 33% in Australia) followed by reduced spending	Sufficient sample size Data collection appropriate to study method Analysis appropriate (descriptive statistics and univariate analyses) Reasonable response rate (63%) Cross-sectional nature does not allow for analysis of financial hardship over time Minimal missing data	6

(*Continued*)

SUPPLEMENTAL TABLE I (*Continued*)

Study	Design	Sample	Findings	Study Rigor	Level of Evidence
Eiser C, Upton P (2007) [9]	Cross-sectional Primary aim: To estimate the costs of caring for a child with cancer in the UK including impact on parental income and contribution of government benefits and charities via self-administered survey	Parents of children with any cancer diagnosed prior to age 16 years and treated at one of 3 UK centers N = 145 Multi-center	Family expenditure was highest in the first 6 months of treatment Expenses were not related to diagnosis Money worries increased for 68.3% of families from time of diagnosis, and single parents were more likely to report increased money worries Following diagnosis, 34.7% of working mothers gave up all paid employment and 28.7% cut their working hours; 1.7% of fathers gave up paid employment and 37.3% reduced their working hours A majority of families applied for and successfully received governmental assistance	Sufficient sample size Data collection appropriate to study method Analysis appropriate (descriptive statistics, univariate analyses) Excellent response rate (97%) Results difficult to extrapolate beyond UK political/healthcare system Minimal missing data	6
Fletcher PC (2010) [10]	Qualitative study Retrospective, cross-sectional Primary aim: To examine the various costs (financial and non-financial) associated with caring for a child with cancer in an exploratory fashion	Mothers of children with cancer (including bereaved and non-bereaved) N = 9 Single-center	Pertinent themes developed: 1. Financial and work issues 2. Altered work schedules 3. Unpaid leaves 4. Loss of employment 5. Tenuous financial situations	Research question stated without explicit clarity Qualitative approach clearly justified Study context clearly described Sampling strategy appropriate for research question (purposeful sampling) Data analysis clearly described (Heuristic inquiry phenomenology approach; supplemented by NVivo) and appropriate for research question Recruitment process (posters/announcements to pediatric cancer support groups) likely resulted in biased sample	6
Fluchel MN, Kirchhoff AC, Bodson J, Sweeney C, Edwards SL, Ding Q, Stoddard GJ, Kinney AY (2014) [11]	Cross-sectional Primary aim: To evaluate the impact of residence and travel time on the burden of care for pediatric cancer patients (including employment and finances) via survey	Caregivers of pediatric cancer patients ages 0-18 years at least 3 months from diagnosis treated at a U.S. referral center N = 354 Single-center	36% of parents reported at least one caregiver quit or changed jobs as a direct result of their child's cancer diagnosis Rural and remote (>1 hour travel time) caregivers missed more days of work during the first month after diagnosis than did urban and local caregivers. However, these differences did not persist over the first 6 months of therapy Rural respondents had greater out-of-pocket travel expenses and reported a significantly greater perceived financial burden	Sufficient sample size Data collection appropriate to study method Analysis appropriate (Descriptive statistics, multivariable regression models) Good response rate (79%) Minimal missing data	6

(*Continued*)

SUPPLEMENTAL TABLE I (*Continued*)

Study	Design	Sample	Findings	Study Rigor	Level of Evidence
Guy Jr GP, Yabroff KR Ekwueme DU, Smith AW, Dowling EC, Rechis R, Nutt S, Richardson LC (2014) [12]	Case-control Primary aim: To estimate economic burden among adolescent and young adult (AYA) cancer survivors compared to people without history of cancer	Adolescent and young adult (AYA) cancer survivors first diagnosed between 15-39 years (cases) N = 1,464 Adults without a history of cancer (controls) N = 86,865 Sample derived from nationally representative Medical Expenditure Panel Survey (2008-2011) Population-based	AYA survivors have lower income, are less likely to be employed, and have higher annual per person medical expenditures than adults without a history of cancer Economic burden among AYA survivors is substantial including lost productivity, decreased employment and decreased income	Sufficient sample size Data collection appropriate to study method Analysis appropriate Nationally representative population Minimal missing data	4
Heath JA, Lintuuran RM, Rigguto G, Tikotlian N, McCarthy M (2006) [13]	Cross-sectional Primary aim: To evaluate the psychosocial impact and economic burden of childhood cancer on families	Parents of children newly diagnosed with cancer in Australia in 2002 N = 56 Single-center	74% of parents reported experiencing a great or moderate degree of economic hardship in the 12 months following cancer diagnosis Economic hardship caused: Great additional emotional stress for >90% of families. Moderate to great additional burden on relationship in 60% of partnered parents Univariate factors associated with economic hardship included: Lower household income, greater distance from hospital 100% of single parents (N = 6) reported great/moderate hardship, though not significant Despite a socialized healthcare system and additional government assistance, many families struggle to meet the extra financial demands	Insufficient sample size Data collection appropriate to study design Appropriate analysis (univariate testing, underpowered for multivariate testing) Low response rate (58%) Missing data not described	6
Limburg H, Shaw AK, McBride ML (2008) [14]	Cross-sectional Primary aim: Pilot study to assess the impact of childhood cancer on the employment and income sources of parents and families. Parents completed retrospective mailed survey	Parents of children with cancer diagnosed at least 2 years prior to survey completion in British Columbia from 1990-1996 Sample derived from regional British Columbia Cancer Registry N = 111 Population-based	Among full or part-time employed parents, 64% of mothers and 16% of fathers left their job after their child's diagnosis (a majority took extended leave) A majority of parents who left their jobs were away for less than 1 year (65% of mothers; 78% of fathers); and nearly all were able to return to their same job if they chose to do so (80% of mothers; 89% of fathers) Parents with children <10 years at diagnosis and those with leukemia were most likely to take leave from their jobs Most families were able to return to stable income and employment within 5 years after diagnosis	Sufficient sample size Data collection appropriate to study method Analysis appropriate (descriptive statistics, univariate analyses, stratified analyses) Low response rate (41%). Use of regional cancer registry to draw sample allows for good representation of Canadian pediatric cancer patients Results difficult to extrapolate beyond Canadian political/healthcare system Minimal missing data	6

(*Continued*)

SUPPLEMENTAL TABLE I (*Continued*)

Study	Design	Sample	Findings	Study Rigor	Level of Evidence
Miedema B, Easley J, Fortin P, Hamilton R, Matthews M (2008) [15]	Qualitative Cross-sectional study Primary aim: To examine the economic impact on families of caring for a child with cancer	Families of children <19 years old with cancer in New Brunswick, Newfoundland and Labrador Canada N = 28 Sample recruited through summer camps for children with cancer, and childhood cancer support foundations	Themes related to economic effects: 1. Travel expenses for treatment and follow-up care 2. Loss of income because of a reduction or termination of parental employment 3. Out-of-pocket expenses for treatment and 4. An inability to draw on programs for assistance or income supplements Government programs are inadequate to support families with catastrophic illnesses Debts accrued over the course of treatment and follow-up Mother most common care-giver who reduced or terminated employment regardless of earning power	Research question clearly stated Qualitative approach clearly justified Study context clearly described Role of researcher clearly described Sampling strategy appropriate for research question Method of data collection clearly described (semi-structured interviews) Method of data collection described; analysis appropriate for research question (thematic analysis)	6
Pagano E, Baldi I, Mosso ML, Di Montezemolo LC, Fagioli F, Pastore G, Merletti F (2014) [16]	Population-based Childhood Cancer Registry linked to administrative data set analysis Primary aim: To analyze the opportunity cost of caregiving for children with cancer during treatment episodes in the first 3-years following diagnosis using administrative data	Children and adolescents (ages 0-19 years) with newly diagnosed cancer 2000-2005 in Piedmont Region of Italy N = 917 Population-based	Median estimated economic burden of caregiving by one parent was $7954, approximately 7% of annual per person GDP in the Piedmont Region The economic burden of caregiving was increased by: 1. Receipt of care at the Regional Referral Center 2. High treatment complexity 3. Younger age of child at diagnosis 4. Diagnosis of leukemia	Sufficient sample size Data collection appropriate to study method Strengths: Use of administrative/Cancer registry linked data allow extrapolation to population, limit response bias Weakness: Costs estimated utilizing administrative data and estimates without measurement of actual family expenditures Appropriate analysis Reporting comprehensive, clearly described No significant issues with missing data and clearly described	4
Rosenberg AR, Dussel V, Kang T, Geyer JR, Gerhardt CA, Feudtner C, Wolfe J (2013) [17]	Cross-sectional Primary aim: To describe the prevalence and factors of psychological distress (as measured by the Kessler-6 Psychological Distress Scale) among parents of children with advanced cancer. Survey embedded in RCT	Parents of children (at least 2 years of age) with advanced cancer at 3 U.S. referral centers. N = 81 Multi-center	50% of parents scored as having psychological distress, and 16% of parents met criteria for serious psychological distress (K6 of >13) In multivariate analysis parent psychological distress scores were higher among parents who reported great economic hardship due to their child's cancer and those who believed their child was suffering highly Parents who reported great economic hardship due to their child's cancer were more likely to have serious psychological distress	Sample size sufficient Data collection appropriate to study method Appropriate analysis (univariate and multivariate regression; descriptive statistics) Comprehensive reporting, good response rate (83%) No missing data	6

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SUPPLEMENTAL TABLE I (*Continued*)

Study	Design	Sample	Findings	Study Rigor	Level of Evidence
Rosenberg-Yunger ZR, Granek L, Sung L, Klassen R, Dix D, Cairney J, Klassen AF (2013) [18]	Qualitative Cross-sectional semi-structured interviews Primary aim: To identify factors that helped Canadian single-parent caregivers cope with the strains of caring for a child with cancer, including their knowledge and use of various supports and resources available	Single parents of children with cancer at 4 Canadian pediatric oncology centers at least 6 months post-diagnosis N = 29 Multi-center	Parents identified a range of social-emotional, practical and financial resources and supports they received from a range of sources (healthcare providers, family/friends, community, charitable organizations, and public aid programs A majority of parents were not working during their child's treatment, and most of these parents received some form of Canadian-specific public aid assistance including: child support, employment insurance benefits, housing programs, and social assistance Parents who did not apply, were ineligible for, or had exhausted public aid benefits used financial savings or credit, loans from family members, or continued to work	Research question clearly stated Qualitative approach clearly justified Study context clearly described Sampling strategy appropriate for research question Data analysis clearly described (Constructive grounded theory approach; supplemented by NVivo) and appropriate for research question Results applicable to Canadian political/insurance system only	6
Tsimicalis A, Stevens B, Ungar WJ, McKeever P, Greenberg M, Agha M, Guerriere D, Naqvi A, Barr R (2013) [19]	Mixed methods 1. Prospective, longitudinal cohort study (diary completion at three time-points) 2. Repeated qualitative, face-to-face, in-depth interviews Primary aim: To disaggregate parent-reported direct costs of childhood cancer treatment, and to provide contextual portrayal of family costs	Families of children 0-18 years with new diagnosis of cancer receiving chemotherapy at one of two Canadian hospitals N = 99 Multi-center	Parents completed diary of resource utilization for 1 week per month for 3 consecutive months. Monthly structured interviews supplemented diary collection. Final completion structured interview Wide-range of costs incurred: parents reported costs in 16 cost categories and 74 cost items. This exceeds types of resources utilized by other families of chronically ill children 3/4 of reported costs were attributed to travel (56%) and food 18%)	Sufficient sample size Data collection appropriate to study method Analysis appropriate (Descriptive statistics; content analysis with NVivo utilized) Good response rate (76%) and retention rate (91%) completed all diaries and 72% completed all interviews) Mixed methodology strengthens value of data Extrapolation to populations without universal health coverage may be limited Minimal missing data well-described and appropriately handled	6

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SUPPLEMENTAL TABLE I (*Continued*)

Study	Design	Sample	Findings	Study Rigor	Level of Evidence
Tsimicalis A, Stevens B, Ungar WJ, McKeever P, Greenberg M, Agha M, Guerriere D, Barr R, Naqvi A, Moineddin R (2012) [20]	Prospective, longitudinal cohort study Primary aim: To identify the direct (out-of-pocket) expenses and time costs incurred by families of children diagnosed with cancer during the first 3-months post-diagnosis and to determine independent predictors of these costs. Families completed diaries at three time-points	Families of children 0-18 years with new diagnosis of cancer from 2006-2008 receiving chemotherapy at one of two tertiary care pediatric Canadian hospitals N = 99 Multi-center	Parents recorded the resources consumed and costs incurred during 1 week per month for 3 consecutive months. Information supplemented by face-to-face and telephone interviews for micro-costing approach Mean total cost over 3-months was $CAD28,475 (SD $CAD12,670) Overall median proportion of annual after-tax income spent by families on direct and time costs over the 3-months was 37% There were no significant differences in median direct and time costs between low, medium and high income families Over 50% of mothers reported unemployment following child's diagnosis, while 95% of fathers remained employed regardless of income There were no statistically significant predictors of direct costs	Sufficient sample size Data collection appropriate to study method Analysis appropriate (Descriptive statistics) Good response rate (76%) Extrapolation to populations without universal health coverage may be limited Minimal missing data well-described and appropriately handled (imputed national wage data)	6
Tsimicalis A, Stevens B, Ungar WJ, McKeever P, Greenberg M (2011) [21]	Systematic Literature review Primary objective: To systematically review the literature on the costs incurred by the families of children with cancer, and identify research and clinical implications	Families of children with cancer 13 publications included	All studies were critiqued with attention to three domains of cost: direct, indirect, and psychosocial Families incur significant variable costs throughout treatment Problems with the published studies related to various Pediatric Quality Appraisal Questionnaire (PQAQ) domains (eg. time horizon, sensitivity analysis) rendered the magnitude of families' childhood cancer costs somewhat uncertain, derived cost estimates may not appropriately reflect the magnitude of families' true costs; many studies published over 20 years ago may no longer be valid due to changing healthcare systems and treatment modalities Recommend future studies fill gaps through attention to: Conceptual framework for cost of illness. Use of validated costing instruments to measure direct and indirect costs. Establishing a threshold as an indication of unfair burden of costs incurred by families	Appropriate inclusion/exclusion criteria Important, relevant studies included Appropriately assessed for quality of studies Reasonable to combine results in this way Important outcomes considered	1

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SUPPLEMENTAL TABLE I (*Continued*)

Study	Design	Sample	Findings	Study Rigor	Level of Evidence
Wakefield CE, McLoone JK, Evans NT, Ellis SJ, Cohn RJ (2014) [22]	Qualitative pilot study Retrospective semi-structured interviews Primary aim: To explore factors affecting parents' return to work after their child's cancer treatment; to describe parents' perceived impact of cancer on their financial and occupational status	Parents of childhood cancer survivors diagnosed in the preceding 5 years treated at tertiary referral center in Australia N = 78 Single-center	Parents reported familial, psychological, and practical factors affecting their ability to return to work Prioritizing family, reinstituting career progression, and negative workplace attitudes were particularly challenging	Research question clearly stated Qualitative approach clearly justified Study context clearly described Sampling strategy (total population sample) appropriate for research question Data analysis clearly described (thematic analysis; coding supplemented by NVivo) and appropriate for research question Low response rate (34%) raises concerns for sample participant bias	6
Warner EL, Kirchhoff AC, Bodson J, Sweeney C, Edwards SL, Ding Q, Stoddard GJ, Kinney AY (2015) [23]	Cross-sectional Primary aim: To understand the economic impact of pediatric cancer on families in the first 5 years after diagnosis utilizing self-administered surveys	Primary caretakers of childhood cancer patients ages 0-21 years treated at a single U.S. center from 2010-2012 N = 254 Single-center	1/3 of caregivers reported a parent quitting or changing work due to child's cancer diagnosis, and this was associated in multivariate analysis with increased financial burden more than 1 year from diagnosis, though not in the first year from diagnosis More than 5 unexpected hospitalizations associated with greater perceived financial stress	Sample size sufficient Data collection appropriate to study method Analysis appropriate (multivariate regression models) Good response rate (77%), non-validated measures of financial burden make interpretation challenging Minimal missing data, all well-described	6
Williams PD, Williams KA, Williams AR (2014) [24]	Literature review Primary aim: To describe the nursing literature regarding impact of a pediatric cancer diagnosis on parental caregiving and the family system, and on economic burden	Families of children with cancer, nursing publications only 19 publications included	Two of 19 reviewed studies reported on economic strain: • Parents often reported economic losses • Economic issues provoked anxiety in parents and added to the difficulty in caring for a child with cancer	Choice of inclusion/exclusion criteria poorly justified (limited to studies of pediatric cancer impact conducted by a nurse or published in a nursing journal for unclear reasons) Appropriately assessed for quality of studies Unclear what questions answered by literature review Poor generalizability of findings given limitations of inclusion/exclusion criteria	1

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